ECONOMIC BURDEN OF BREAST CANCER ON HOUSEHOLDS IN KERALA

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By

ESTA MARTIN

Under the supervision of

Dr. Sanathanan Velluva
(Research Guide)
Associate Professor and Head (Retd)

&

Dr. Shiby M. Thomas
(Co-guide)
Associate Professor

PG and Research Department of Economics
St. Joseph's College (Autonomous)
Devagiri, Kozhikode, Kerala, India
2024

DECLARATION

I, **ESTA MARTIN,** hereby declare that the work presented in the thesis entitled **"ECONOMIC BURDEN OF BREAST CANCER ON HOUSEHOLDS IN KERALA"** is based on the original work done by me under the guidance of **Dr. Sanathanan Velluva, Former HoD and Associate Professor (Retd),** and Co-Guidance of **Dr. Shiby M Thomas, Associate Professor, PG and Research Department of Economics, St. Joseph's College (Autonomous) Devagiri, Calicut.** It has not been included in any other thesis submitted previously for the award of any degree. The contents of the thesis have undergone a plagiarism check using iThenticate software at C.H. M.K Library, University of Calicut and the similarity index is within the permissible limit. I also declare that the thesis is free from AI-generated content.

Devagiri

Esta Martin
Research Scholar
Department of Economics
St. Joseph's College (Autonomous)
Devagiri, Calicut-673008

Dr. Sanathanan Velluva
Associate Professor and HOD (Retd)
PG and Research Department of Economics
St. Joseph's College (Autonomous)
Devagiri, Calicut, 673008

CERTIFICATE

This is to certify that the dissertation titled **“ECONOMIC BURDEN OF BREAST CANCER ON HOUSEHOLDS IN KERALA”** is the record of the original work done by **Ms. Esta Martin** under my guidance and supervision. The results of the research presented in this thesis have not previously formed the basis for the award of any degree, diploma, or certificate of this institute or any other institute or university.

Devagiri

Dr. Sanathanan Velluva
Associate Professor and HOD (Retd)
PG and Research Department of Economics
St. Joseph’s College (Autonomous)
Devagiri, Calicut, 673008

CERTIFICATE

This is to certify that the document herein, the thesis entitled “**ECONOMIC BURDEN OF BREAST CANCER ON HOUSEHOLDS IN KERALA”** , submitted by **Ms. Esta Martin** to the University of Calicut under my guidance. No corrections or modifications have been recommended by the adjudicators in the thesis. Further certified that the contents in the thesis and the soft copy are one and the same.

Devagiri
Date:

Dr. Sanathanan Velluva,
Associate Professor and HOD (Retd)
PG and Research Department of Economics
St. Joseph’s College (Autonomous)
Devagiri, Calicut, 673008

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Devagiri

Dr. Shiby M Thomas
Associate Professor
PG and Research Department of Economics
St. Joseph's College (Autonomous)
Devagiri, Calicut, 673008

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CHAPTER I

ECONOMIC BURDEN OF BREAST CANCER

1.1 Introduction

Health is an important asset for all human beings, significantly determining the overall success of an individual's life. It is essential for the success of all other activities. Individuals are considered producers of their health, influenced by factors such as age, lifestyle, and the utilisation of medical services. Grossman and Becker, in their theories, modelled health as a part of human capital. Over the years, the incidence of cancer has been increasing globally. It has become one of the leading causes of death worldwide. In 2020, the global incidence of cancer rose to 19.3 million cases, with 10 million cancer-related deaths (David, 1965). Breast cancer alone represents one in four cancers among women globally. The impact of cancer extends beyond physical health, significantly affecting individuals economically as well.

Cancer is a disease where the cost of treatment often creates significant financial stress for patients and their families. Upon diagnosis, a patient typically worries about two primary concerns: survival and funding the treatment. The exhaustive treatment procedures take a toll on a patient’s physical and mental health, leading to a deterioration in their quality of life and affecting their motivation to live. Cancer care requires expensive treatments and medications. The out-of-pocket costs can consume a substantial part of a family's income and budget. Cancer care can lead to significant financial distress for households living on a tight budget. These households often need to allocate a considerable portion of their financial assets toward treatment, resulting in the forgoing of essential goods as a coping mechanism.

Previous attempts have been made to describe national and state-level patterns of cancer burden and epidemiology in different parts of India. However, a systematic and comprehensive understanding of the costs associated with cancer is still lacking. Though the government have placed cancer treatment as an important item on the public health agenda, there cannot be much progress in the effectiveness of policy unless there is a understanding of the socioeconomic patterns in treatment-seeking behaviour and financing. Considering this, the present study aims to analyse the economic burden of breast cancer on households in Kerala. The research results will be valuable to individual patients, their family caregivers, healthcare providers, and policymakers.

1.2 Breast Cancer: A Global Perspective

The World Health Organisation (2018) reported that non-communicable diseases are the primary cause of death worldwide, with cancer projected to become the leading cause in the near future. Ferlay et al. (2008) predicted that the global burden of cancer will increase to 20.3 million new cases and 13.2 million cancer-related deaths by 2030. Even though substantial progress has been made with regard to screening, prevention, and treatment of cancer, cancer incidence and mortality are growing rapidly worldwide. The main factors for high cancer incidence are increasing growth and ageing of the population, lifestyle choices, and socioeconomic development of the countries. Cancer is a global problem, but it is not a uniform one due to the heterogeneity of underlying risk factors.

The global incidence of breast cancer surpassed lung cancer in 2020, now representing 11.7% of all cancer cases (GLOBOCAN,2020). In 159 out of 185 countries, the leading type of cancer is breast cancer. Women in transitioned countries have an 88% higher incidence rate than in transitioning countries, but the mortality rate in transitioning countries is 17 per cent higher when compared to transitioned countries. Female breast cancer is the only type of cancer that is common in all regions, irrespective of the level of HDI in countries (Bray et al.,2012).

There are several risk factors that are responsible for the elevated incidence of breast cancer in high HDI countries. The risk factors can be broadly classified into reproductive and hormonal factors, including early menarche, late menopause, older age at first childbirth, fewer children, limited breastfeeding, and the use of menopausal hormone therapy or oral contraceptives. Additionally, lifestyle factors such as alcohol consumption, excess body weight, and physical inactivity also contribute to increased risk. The presence of highly mutating genes like BRCA1 and BRCA2 among women of Ashkenazi Jewish heritage has led to an increased incidence in Israel and other European subcontinents (Metcalfe et al., 2010; Brinton et al., 2018).

Early detection and breast cancer prevention programmes are still a challenge in many countries. Awareness programmes regarding the risk factors, like excessive weight, physical inactivity and alcohol consumption, can be effective. Population-based screening programmes and effective treatments will help in reducing breast cancer mortality.

1.3 Healthcare Expenditures in India

Cancer and its treatment can have a financial impact on the patient and their families. This financial burden is determined by a multitude of factors like household income, socio-economic status, extent of disease and insurance status. It has been observed that out-of-pocket related expenses are higher among patients with cancer than among patients with other diseases (Bernard et al.,2011). To mitigate the financial hardship, cancer patients may resort to financial assistance from government or non-profit organisations or from family and friends. Even if the patient is insured, the rising out-of-pocket expenses offset the adequacy of insurance for providing affordable cancer care. In cases where neither insurance nor financial assistance is available, then patients may resort to distress financing and other coping mechanisms.

India is among those countries where the budget allocation for healthcare is very low. In the recent years, the government health expenditure has varied between 1.2% -1.6% of the GDP. This percentage is low when compared to OECD countries (average of 7.6%) and BRICS countries (average of 3.6%). In a country where more than 16% of the world's population resides, the government's healthcare expenditure is not on par with the national income level. In terms of health outcomes and other indicators, India has less favourable results. India has a low rank of 131 on the HDI index, has an infant mortality rate higher than Bangladesh and Nepal, and has a bed population and doctor population worse than China and Sri Lanka (UNDP report,2020).

Healthcare finance and delivery in India are mainly done through four channels: out-of-pocket expenditures, state and central government expenditures, social insurance schemes, and private health insurance. The OCED/WHO 2018 report states that the out-of-pocket expenditures as a share of healthcare spending are over 65% in India, and this is high when compared to countries like China (36%), Sri Lanka (32%) and

Thailand (11%). This method of finance places a financial burden on poor households and can lead to impoverishment in India. The state and government expenditures only account for about 20% of total healthcare spending. Public healthcare delivery in India includes primary health centres, community health centres and district-level secondary care hospitals. With a bed-population ratio of 0.7 to 1000 population and a doctor-to-population ratio of 0.8 to 1000 population, India has a shortage of specialists and health centres (National Health Accounts 2004-05). Shiva Kumar et al. (2011) observed that most states have a low priority when it comes to healthcare spending, and a wide disparity has been observed across different states. A north-south divide has been observed with respect to affordable healthcare, and many patients are seeking care in southern states, which have better workforces and resources. Social insurance and private health insurance schemes contribute to 10% of the total spending, and the remaining 5% is through miscellaneous channels (Pramesh et al.,2014).

India has a weak healthcare system, which is inequitable and inefficient to a large extent.[60] The privatisation of the healthcare industry has driven the cost of treatments higher, which has resulted in households spending a larger proportion of their income on healthcare. The government needs to have a better understanding of the state disparity in healthcare spending and gaps in healthcare indicators and outcomes in order to provide affordable healthcare in India.

1.3.1 Out-of-pocket Expenditures

Out-of-pocket expenditures are borne directly by the patient. The National Health Accounts (NHA) of India for 2004-05 indicate that 71.13% of the country's total health expenditure is financed through out-of-pocket payments. Jain et al. (2016) observed that out-of-pocket expenditures were a source of financing for 91% of the breast cancer patients in Punjab. Nair et al. (2013) conducted a survey and found that about one-third of cancer patients in India spend more than ₹ 50000 as out-of-pocket expenditures. Mahal et al. (2013) assessed the burden of cancer on households' out-of-pocket health spending, non-medical consumption, workforce participation, and debt and asset sales. They observed that the cancer-affected households incur additional annual inpatient care costs that range from 36% to 44% of the total annual expenditures of comparable control households. Rajpal et al. (2018) assessed the economic burden of cancer and observed that the treatment seeking might be higher among richer households, and therefore, the cancer cases among the poor may be underreported. Out-of-pocket expenses impact treatment choices and the well-being of the patient. Low-income households do not have any form of financial protection and are forced to resort to out-of-pocket payments for treatments. In order to finance the high out-of-pocket expenditures, patients and their families end up spending money from their savings.

1.3.2 Distress financing and Coping mechanisms

High healthcare cost is one of the major public health challenges in India. The extent of poverty and indebtedness is on the rise since the majority of households finance their treatment through out-of-pocket expenditures (Garg et al., 2009). Apart from high out-of-pocket expenses, the other causes of distress financing are low insurance coverage, financial constraints, and low government spending.

The poor quality of public health services has led to increased use of private health services, which in turn increases out-of-pocket expenses as a share of total health expenditure. The lack of a universal health insurance mechanism in India is also a cause of higher out-of-pocket expenditures ((National Health Accounts, 2014-15). Joe (2014) observed that among different socio-economic variables, households belonging to rural areas rely more on distress financing than their urban counterparts. Limited sources of income and lack of saving habits are the major reasons why rural households rely on distress financing to cope with the cost of illness. Apart from place of residence, factors like gender, caste and religion influence the extent of distress financing. Socially vulnerable sections of society, like scheduled castes and tribes, are highly dependent on distress financing, which further leads them into a vicious cycle of poverty. Sen et al. (2012) analysed the gender inequities in healthcare financing and found that poor men had better access to credit markets and were more likely to sell their assets or borrow money when compared to non-poor women. This clearly indicates a gender advantage for men.

The extent, nature and correlates of distress financing for meeting out-of-pocket expenses varies across countries. The common forms of distress financing are borrowing from friends and family, loans from financial institutions and money lenders, and mortgaging and selling assets. Dilip et al. (2002) observed that around 26% of the households in urban India met their health expenditure by borrowing from different sources, and 5% depended on selling assets and livestock. In order to repay money borrowed and recoup the assets sold during distress financing, households practice various coping strategies. Kabir et al. (2000) observed that the common types of coping strategies are reducing food and non-food expenditure and increasing work hours for extra income. To meet the indirect costs, various households also practice task reallocation among family members. Chakrabarty et al. (2017) observed that many families in India adopted more than one coping mechanism to overcome financial distress, the most prevalent of them being borrowing, social nets, savings, selling financial assets and delaying repayment of loans.

1.3.3 Health and Insurance Schemes for Cancer Patient

The high costs of cancer treatment can lead to an economic burden on patients and their families. Health and insurance schemes can play a significant role in reducing the burden of treatment. To improve access to healthcare, a sustainable financing system is required. The Indian healthcare system is characterised by high rates of privatisation and low rates of population covered under insurance schemes. Only 15% of the population is covered under some degree of health insurance. The funding of cancer care is a complex mixture of state and government accountabilities, with the government responsible for the majority of funding (Thakur et al.,2011).

Most of the government insurance schemes focus mainly on inpatient care and offer low financial protection for outpatient care. An assessment of the RSBY scheme indicated that the usage of this insurance for cancer treatment is low. The underlying problem with the government insurance schemes was that they were not designed to address the complexity and costs of cancer care (Public Health Foundation of India,2011).

1.4 Theoretical Framework

Health is a priceless commodity for an individual. It is a prerequisite for other activities. There are two characteristics of health which are important to an individual:

- Only when an individual is in good health can he earn an income in the labour market.
- An individual's health is an essential factor in determining the consumptive benefit that one can derive from one's income.

Economists view health as an asset and as a part of human capital. Health determines the production capabilities of an individual. An individual derives positive utility from the consumption of goods and negative utility from sick time. Health stock is affected by two factors: the depreciation of health over time due to ageing and the investment made in health. An investment in health involves the purchase of medical services and the amount of time spent on preventive efforts. The expenditure on health is influenced by labour income and wealth. According to Grossman's (1972) model, health and wealth are interrelated assets, and their values are optimally managed over time by an individual. He investigated this optimisation problem by using control theory. The marginal utility of holding an additional unit of health stock has both consumption and investment aspects. According to the model, the optimal outcome occurs when the marginal utility of health stock is equal to the marginal cost of acquiring one more unit. The key takeaways from this model are:

- Investing in health yields a positive payoff by reducing the time spent being sick.
- The reduction in sick time, or the increase in healthy time, directly enhances an individual's utility.
- A decrease in sick time also boosts wealth and wage levels, meaning that investing in health can lead to greater labour income and overall financial well-being.

- When an individual is unwell, they must sacrifice consumption to prioritize health. However, this loss can be mitigated by purchasing medical services and adopting a healthy lifestyle.

Health economics focuses on the allocation of resources and expenditures related to health. It can be divided into two main areas: the economics of health and the economics of healthcare. The economics of health uses modern microeconomic theory to explain individual health-related behaviors, while the economics of healthcare examines the factors that influence the quantity and quality of medical services produced in an economy. (Zweifel et. al, 2010)

Economic evaluation plays a crucial role in understanding the relationship between health and healthcare. It involves the comparative analysis of alternative actions in terms of both their costs and outcomes. One of the most common types of economic evaluation is cost-of-illness analysis, which assesses the economic burden of a particular disease.

1.5 Research Gaps

Empirical research on cancer in India indicates that the catastrophic expenditure on inpatient cancer treatment is the highest among all non-communicable diseases. Inadequate health financing mechanisms and the heavy reliance on out-of-pocket (OOP) payments often force many cancer patients to seek distressing and unsustainable means to finance their treatment. Previous research on the out-of-pocket expenditure associated with cancer have not approached from the perspective of a household. Additionally, much of the hospital-based evidence in India has primarily focused on the epidemiology of cancer, without providing a comprehensive understanding of the socioeconomic patterns and distributions of out-of-pocket (OOP) expenditures on cancer treatment. Furthermore, studies on the economic impact of cancer have often overlooked or inadequately addressed the indirect costs associated with the disease.

Though the government maintains a population-based cancer registry (PBCR), it lacks data pertaining to the financial aspect of cancer treatment. The Census of India and the Ministry of Health and Family Welfare (MOHFW) conduct surveys of patients and their households, but it does not collect data relating to the financial distress faced by cancer patients. There is a lack of readily available data on the specific costs that cancer patients in India will incur during treatment. While breast cancer is the most prevalent type of cancer among women in India, there are very few studies that analyse the associated costs of treating this particular cancer. In the existing literature, there are only a few studies analysing the financial impact of breast cancer in the state of Kerala.

1.6 Statement of the Problem

All states in India are experiencing an increase in the incidence of cancer and other non-communicable diseases. Cancer is one of the leading causes of death, contributing to nine per cent of the total mortality in India. According to the GLOBOCAN 2020 report, the age-standardised incidence rate of cancer was 95.7 and 99.3 per 1,00,000 for males and females, respectively, with the mortality rate being 65.4 and 61.0 per 1,00,000 for males and females, respectively. In the past two decades, studies have shown that the incidence of breast cancer has been rising at an alarming rate. Cervical cancer was once the most common cancer among women in India, but the incidence of breast cancer has now surpassed that of cervical cancer. Breast cancer is one of the leading types of cancer in terms of mortality. The main reasons for the increase in mortality are inadequate breast cancer screening, late diagnosis, and the unavailability of appropriate medical facilities. Compared to Western countries, breast cancer occurs at a younger age in women in India.

Due to the high treatment costs and the low chances of survival associated with treatment of cancer, it often evokes shock and fear among patients. The financial strain of treating breast cancer can push patients and their families into hardship, often resulting in insolvency. Many families resort to multiple coping mechanisms to overcome financial distress. Other difficulties faced by breast cancer patients include a low number of treatment facilities and a lack of access to cancer centres. There have been very few previous attempts to analyse the household burden of breast cancer patients in India, and this study aims to provide insights regarding the same.

However, considering the significant increase in the cost of breast cancer treatment and the substantial financial burden on families, there have not been enough studies to understand the economic burden of breast cancer at the national or regional level. The present study is an attempt to fill this gap and to open space for further, more in-depth studies.

1.7 Research Questions

Based on the research gaps, the present study aims to answer the following questions:

a) What are the factors that affect the economic burden of breast cancer patients and their households in Kerala?

b) What are the different types of costs incurred by breast cancer patients in Kerala?

c) What medical services and health schemes are available for breast cancer patients in Kerala?

d) What are the financial distress methods and coping mechanisms adopted by breast cancer patients in order to fund their treatment?

1.8 Objectives of the Study

The purpose of this study is to understand the extent of breast cancer, the cost burden on patients, and the hurdles and difficulties they face during the treatment period. Despite significant improvements in cancer treatment in the country, the costs have also been tremendously increasing both during and after the treatment period. The specific objectives of the study are summarised below:

1. To explore the extent and dimensions of cancer in India, with a special focus on breast cancer.

2. To identify and analyse the socioeconomic dimensions of breast cancer patients and examine the direct and indirect costs associated with breast cancer in households in Kerala.

3. To analyse the health schemes provided by the government and other organisations for breast cancer treatment and the financial coping mechanisms used by the households to fund breast cancer.

4. To identify and analyse the determinants of the economic burden of breast cancer in Kerala.

1.9 Hypothesis of the Study

Based on the objectives of the study, the following hypotheses have been formulated for the study:

Hypothesis 1: There is no difference in the direct and indirect cost incurred for breast cancer treatment based on the type of choice of healthcare provider.

Hypothesis 2: The financial assistance received through employee benefit schemes, government health schemes, and private insurance does not impact the out-of-pocket expenditures incurred during breast cancer treatment.

1.10 Methodology for the Study

The study is descriptive in nature. The data is collected from primary and secondary sources. Primary data was collected by interview method. In this study, the breast cancer patient is considered as the basic unit of analysis to determine the economic burden. Both quantitative and qualitative data were collected for the study. Secondary data was collected from NSSO data, 75th (2017-18), NCRP reports (2012-16) and GLOBOCAN report (2020).

1.10.1 Sampling Framework

Only female patients who had invasive breast cancer were interviewed. The patients were recruited and interviewed by the primary investigator. Female breast cancer patients above the age of twenty years and below the age of seventy years were selected for the study. Stage four breast cancer patients were not included in the study. The patient should have completed the treatment for breast cancer should have been completed at least a year before January 2020. Patients who sought treatment after January 2020 were excluded because of COVID-19. Patients who completed breast cancer treatment seven years at the time of the interview were excluded due to recall bias.

1.10.2 Study Area and Sample Size

The study was conducted in Kerala. Based on the NCRP (2012-16) report, states in the southern part of India had the highest incidence of breast cancer. Kerala was one of the states with high breast cancer incidence and mortality. Using Cochran's formula, the estimated sample size was 384. However, an extra ten per cent was suggested considering the chances of omission and missing responses. Hence, the finalised sample size was 400 participants.

The sampling proportion was determined based on Hospital-Based Cancer Registry (HBCR) reports of tertiary cancer hospitals in Kerala. The sample was divided based on the healthcare provider chosen for treatment. The proportion of breast cancer cases reported was higher in government cancer centres than in private cancer centres. Hence, of the 400 respondents, 250 were selected from government cancer hospitals, and 150 were selected from private hospitals. The female breast cancer patients were randomly selected from government and private hospitals. Hospitals where complete cancer treatment was available were only selected for the study.

1.10.3 Study Design

A retrospective study was conducted. The rationale for choosing a retrospective study is because a prospective study is time-consuming and costly. The interview of the patients was done during their follow-up appointment after treatment. This was done in order to minimise the limitation of patients forgetting certain details regarding their treatment. The interview with patients was done using a scheduled questionnaire. The primary investigator collected data regarding socio-economic characteristics, cost and hospital information from diagnosis to follow-up stage, indirect cost with respect to patients and caregivers, insurance and health schemes, financial distress methods and coping mechanisms. The hospital bills of each patient were collected from the tertiary cancer hospitals using the patient's UHID.

1.10.4 Conceptual Framework

The cost-of-illness (COI) methodology is detrimental in measuring the impact of a disease on the health outcomes of a country, community and individuals. In the COI methodology established by Hodgson and Meiners (1982), the cost-generating components of an illness are identified, and a monetary value is attributed to them. They describe and estimate the economic burden of a specific disease on society and, therefore, the savings that could be made if the disease were to be eradicated. Economic values are assigned to the burden associated with an illness. COI estimates are essential in formulating public health policies, allocating health resources and measuring productivity losses.

1.10.5 Tools of Analysis

Statistical tools were used to analyse the primary data. The primary data was used to assess the direct cost and indirect costs associated with the treatment of breast cancer. The total cost across different stages of breast cancer was calculated, and the economic burden was determined. The chi-square test, ANOVA test and KH test were used to test the statistically significant differences when comparing the different groups of costs incurred. Graphs, charts and Box-Jenkins plots were used to present the distribution of data. Multivariate regression was used to analyse the determinants of total medical cost of treatment and out-of-pocket expenditures. Multinominal logistic regression was used to predict whether the breast cancer patient and their household faced financial hardship due to the treatment of breast cancer. Excel and SPSS were applied for statistical analysis.

1.11 Significance of the Study

Glydmark (1995) said, “Costing in healthcare services is imperative, as money is a limited resource that will always be taken into account.” Healthcare services aim to maximize patient benefits with the limited resources available. Hence, it is essential to comprehensively assess the costs and outcomes of treatments. This evaluation ensures that resources are allocated efficiently and effectively. An illness leads to welfare loss for an individual and also affects their consumption of goods and services.

Breast cancer is the leading type of cancer globally and in India. The incidence and mortality rates of breast cancer in females have been increasing over the past two decades. Lack of data pertaining to costs incurred during cancer care is a major problem in India. Breast cancer patients and their families are in the dark regarding the economic burden they face. There is a lack of awareness in regard to insurance and health schemes. Often, families who resort to distress financing have a low understanding of the coping mechanisms, which pushes them into impoverishment. This study aims to provide insight into the financial part of cancer care and a detailed analysis of the various types of costs the patients incur. The results from this study will be valuable for government and health organisations in formulating policies to reduce the financial burden experienced by breast cancer patients. This study is significant because the economic aspect of a disease is essential for reducing disease incidence and its consequences.

1.12 Limitations of the Study

The scope of the study is limited to exploring the economic burden of breast cancer on patients and their households. The study is constrained to the quantitative aspect of the expenditure on breast cancer care and does not explore the qualitative aspects like personal hygiene, social hygiene and health habits of the households. Furthermore, it does not explore the quality-of-life concept due to time and budget constraints. The present study is focused on the direct and indirect costs of breast cancer treatment and does not include the psychological cost of treatment. The study also does not consider stage four breast cancer patients due to the variation in treatment protocols and palliative care. In spite of these limitations, this study is a substantial attempt to analyse the different aspects of breast cancer care and their financial impact on the patient and their households.

1.13 Chapter Scheme

The thesis is organised in the following manner: Chapter one briefly describes the literature on various aspects of health expenditure on cancer care, the statement of the problem, objectives of the study, research questions and hypothesis, research methodology and significance of the study. Chapter two presents the theoretical framework and the supporting empirical evidence for estimating the economic burden of breast cancer patients. Chapter three lays down the study design and the description of the data collection and analysis. It also presents a background chapter aimed at explaining the concept, staging and treatment of breast cancer. Chapter four is a secondary-data-based study that provides insight into the incidence of cancer at the global, national, and state levels. It also describes the expenditure incurred for the treatment of cancer in the state of Kerala. Chapter five describes the socio-demographic, economic and cancer staging of sample patients from primary data collection. Chapter Six presents the results of a quantitative analysis of direct medical and non-medical costs incurred during the treatment of breast cancer. Chapter seven provides the results regarding the indirect costs incurred, health and insurance schemes availed during treatment, and coping mechanisms used to fund breast cancer care. It also presents the results of out-of-pocket expenditures, catastrophic health expenditures and economic burden. The results of the qualitative survey are also included in this chapter. In chapter eight, the results are summed up, and answers to the research questions are provided. It also lays down future research areas and policy recommendations to reduce the burden of breast cancer on patients and their households.

CHAPTER II

REVIEW OF LITERATURE

2.1. Introduction

An illness can lead to unexpected increases in health expenditures, reduced functional capacity, and loss in income and productivity, further leading to impoverishment. Hence, an economic evaluation of healthcare is essential. The concept of economic burden measures the financial outcomes of disease by encompassing aspects like direct and indirect costs. A systematic assessment of the costs and consequences of treatment is essential in order to maximise the patient's benefits from the limited health resources available.

2.2. Theoretical Literature Review

The theoretical review explores various views related to health and healthcare. This section also reviews aspects related to costing in healthcare and the cost of illness methodology.

2.2.1. Health as Capital

Economists view health as an asset that can be produced. If health is perceived as being produced, then individuals are considered the ultimate producers of health. Schultz (1961) laid the foundations of human capital theory in his paper 'Investment in human capital'. He says there is a relationship between human capital accumulation and aggregate economic growth. He observed that an increase in national output can be explained by the concept of investment in human capital. He critiqued the classical notion of labour because it failed to encompass human resources as a part of capital and a product of investment.

Mushkin (1962) observed that investment in health can have long-term consequences for the community. The productivity of individuals improves when investments are made in health services, and these outlays yield a continuing return in the future. The education level of an individual was a determining factor for the treatment-seeking behaviour and selection of the appropriate kinds of health services. Becker (1962) analysed the various activities that influenced the future real income of people. According to him, the various ways to invest in human capital include schooling, on-the-job training, medical care, vitamin consumption, and acquiring information about the economic system. Investment in health involves both physical and emotional aspects. A decline in morbidity and mortality, a better diet and a positive effect on morale can enhance the productivity of an individual. Becker (1965) developed a household production model where individuals could spend resources and time on investments to improve health.

2.2.2. Demand for Health

Health is a crucial part of the well-being of an individual. Apart from being producers of health, individuals are also investors of their own health. Grossman (1972) constructed the demand model for the commodity 'good health'. Health is considered a form of durable capital that generates an output of healthy time. Individuals are born with an initial stock of health, which depreciates as they age but can be enhanced through investments in medical care and treatments. Health is demanded by individuals both as a consumption good and as an investment good. In order to determine their optimal level of health capital at any given age, individuals balance the marginal efficiency of additional health capital against its cost in terms of price of investment. Each person's demand for health capital is represented by a downward-sloping demand curve, which shows how the marginal efficiency of health capital decreases as the stock of health increases. In contrast, the supply of health capital is assumed to be perfectly elastic, meaning that it can be increased without limit at a constant price. The equilibrium stock of health capital is determined by the intersection of the demand and supply of health capital. Based on the model, Grossman made the following predictions:

- As the rate of depreciation of health stock increases over age, then the quantity of health stock demanded decreases over the lifecycle. Simultaneously, the medical expenditures on medical care increase with age.
- An individual's demand for health is positively correlated with his wage rate.
- Education increases the marginal efficiency of health capital. The more educated, the more demand there is for the optimal stock of health.

Wagstaff (1986) developed a conceptual framework to analyse the interaction of socioeconomic determinants of health and demand for health. He examined the effects of changing an individual's income and observed that a fall in income results in lower demand for health. Health education programmes and subsidising the prices of health inputs like food, housing, and electricity are effective in increasing the demand for health.

2.2.3. Economics of Healthcare

In the economics of healthcare, the link between the health status of an individual and the consumption of medical services is analysed. Healthcare refers to services provided by professionals or paraprofessionals who impact the health status of an individual. Arrow (1963), in his paper, recognised that an individual's demand for medical services and the nature of medical care markets are characterised by high levels of uncertainty. An individual suffering from an illness is uncertain about the quality of medical treatments, and his uncertainty is different from that of his physician due to the asymmetric information regarding medical knowledge. In the welfare economics of uncertainty, individuals would prefer to be insured against losses and risks of illness.

Musgrave (1995) viewed the healthcare industry as both a use and source of our national output. He observed a fundamental disagreement regarding the understanding of civilisation. Hence, there are two competing visions of healthcare: Theory X and Theory Y. Theory X says that one needs special knowledge to understand the nature of health goods and services. Consumers are not able to make wise decisions regarding their illness due to asymmetric information, and hence, healthcare providers take advantage of this situation. Theory Y says that consumers have good knowledge regarding their health and that the profits made by healthcare providers are a measure of their ability to serve the public and generate revenue.

2.2.4. Costing in Healthcare

Economists argue that the real costs of an illness are the opportunity costs, i.e., the benefits that could have been obtained from the next best of resources (McGuigan, 1993). The choice of costing method depends on several factors like the type of service, the perspective on costs, the purpose of the cost analysis, and the economic feasibility of calculating those costs. One of the critical factors in estimating the cost of a disease is to identify all the relevant costs in healthcare services. Healthcare services can be broadly classified into two types: facility-based services and peripatetic services (health services that can be delivered in a variety of different places) (Beecham, 1995). In costing, there are five general ways to value resources: direct measurement of costs, cost accounting methods, standard unit costs, fees, charges and market prices, and estimates/extrapolations (Oostenbrik, 2002).

2.2.5. Cost of Illness Methodology

The economic impact of a disease is measured by the costs associated with the disease. The Cost of Illness (COI) methodology identifies and quantifies all the costs associated with a specific disease, encompassing direct, indirect, and intangible costs. Rice (1966) provided the first basic framework as well as detailed procedures for estimating the direct and indirect cost of illness. From the patient's perspective, the direct costs of illness include expenses related to prevention, diagnosis, treatment, and rehabilitation. From the healthcare sector's perspective, direct costs encompass expenditures on research, training, and capital investments in medical facilities. These costs are calculated based on the expenditures incurred while utilising health services. Illness, disability, and premature death can lead to a loss of output to the economy, and these losses are labelled as indirect costs. The indirect costs are measured based on loss of earnings, decrease in labour force participation rates, loss of output by homemakers and omission of transfer payments.

The cost of illness methodology was criticised on the basis that it lacked consistent and accepted methodological guidelines. The methodological problems of the framework were the presence of multiple diseases, the measurement of mortality losses, the population groups for whom losses were calculated, and gaps in statistical data (Rice,1967). It was challenging to make meaningful comparisons between the results (Hodgson & Meiners, 1979). Though there were several cost-of-illness studies, only some were national in scope, while the rest were limited to selected populations or geographical areas. Most cost-of-illness studies were restricted to one or two disease categories (Hu & Sandifer, 1981).

While calculating direct costs, the estimation of costs related to services provided by facilities, research and training was a difficult task. The national health accounts did not include data on transportation costs to healthcare providers, certain household expenses, relocation costs, and property losses. Psychological costs as a component of indirect costs were omitted. Hodgson and Meiners (1982) suggested that in order to estimate psychological costs, the indicators must reflect reduced self-esteem and emotional problems, pain and suffering due to disability, economic dependence and reduced quality of life.

2.2.5.1. Indirect Costs: Human Capital Approach vs Willingness to Pay Approach

The human capital approach takes an individual's productivity into account and measures the cost in terms of the present value of future earnings. This approach has been criticised as lacking a theoretical foundation and an incomplete measure of the value of life. In this approach, some groups are undervalued relative to others; for example, women are lesser than men, and blacks are lesser than whites. Several studies have examined the role of age, sex and race discrimination on earnings (Alexis, 1978; Cohen, 1971; Corcoran, 1978). A valuation of non-market activities such as housekeeping and volunteer services have to be included in this approach.

The willingness to pay (WTP) method assesses the amount an individual is willing to spend to reduce the likelihood of illness or death. The problem with this approach is the difficulty of controlling biased responses. This happens due to the respondent's expectations regarding the use of data and their attitude towards risk. The WTP method is better described as an illustration of methodology than a serious attempt to derive representative values (Institute of Medicine,1981).

2.2.5.2.Cost of Illness: Prevalence-Based vs Incidence-Based Approach

Cost of illness studies can be classified as either prevalence-based or incidence-based. The prevalence approach involves estimating the direct costs and productivity losses for all cases of a disease or group of diseases occurring during a specific year. The incidence approach, on the other hand, calculates the lifetime costs associated with new cases of a condition or group of conditions that emerge within a given time frame. The incidence-based approach is helpful in formulating preventative measures and for analysing the management of the illness from onset to recovery or death. The prevalence-based approach is used by decision-makers to analyse conditions where the burden is underestimated and to plan cost containment policies (Tarricone, 2006).

2.2.5.3. Role of Cost of Illness Studies in Health Economics

Cost of illness studies are an important tool in health economics, providing a comprehensive measure of the economic impact of a disease. By calculating the total cost of illness, these studies help determine the financial burden a disease imposes on society. They break down the costs into various components, highlighting the contribution of different sectors in society (Kernick,2018)This information is useful for determining funding and research priorities by highlighting areas where inefficiencies may exist and savings may be made (Ament,1993; Rice,1994). Cost of illness studies estimate the economic burden of diseases across all classifications, enabling a comparative analysis of the costs associated with different diseases. The results from these studies can be incorporated into cost-effectiveness analysis to compare and analyse various treatment programmes. It is useful in explaining recent trends in costs and projecting future disease costs based on demographic, epidemiological and technological change (Hodgson,1994; Roijen & Rutten,1997). COI studies are descriptive in nature and are used by policymakers for the clinical management of illness at a national level.

Though widely undertaken, a cost of illness study gives no information regarding prevention costs, and there is a possibility that it may divert decision-makers' attention away from areas where important health gains can be made at low cost (Bayford et al., 2000). The COI method has been accepted as a measure of the burden of disease, but it relies heavily on national-level survey data. In countries like the USA, where longitudinal data on costs are available, phase-specific and long-term costs can be estimated using the COI method. However, this is impossible in developing countries due to a lack of nationwide data. The COI approach is limited because it mixes prevalence-based measures and incidence-based measures. A revised framework of the COI method, where time costs and productivity costs are included, is required to estimate the burden of disease better (Brown et al.,2011). In recent years, because of the importance of health-related quality of life (HRQOL) in assessing both the burden of cancer and the benefits of treatment, a number of instruments—both general and cancer-specific—have been developed and applied in a variety of settings.

2.3. Empirical Literature Review

This literature review explores the prevalence and economic burden of breast cancer and its determinants. It also reviews the role of health and insurance schemes, distress financing methods, and coping mechanisms. The empirical literature review is arranged thematically and chronologically.

2.3.1. Economic Burden of Cancer

The economic consequences of an illness can be substantial. It can adversely impact future earnings, educational attainment, and patient quality of life. The measurement and valuation of the economic burden can help policymakers to formulate the appropriate health tools.

Brooks et al. (2011) reviewed the additional financial costs cancer patients bear. The four key themes identified while reviewing the existing literature were measuring hidden costs, sources of additional costs on patients/families, assessing the impact of additional costs, and reducing hidden costs. The wide variety of methods to measure hidden costs made comparisons of findings difficult. Researchers have only analysed a narrow range of costs, and there has been a lack of systematic investigation of costs over time. The additional financial costs observed were transportation, fuel and parking, accommodation, childcare, over-the-counter medicines, medical equipment, and health food supplements. Most of the reviewed research highlighted the economic hardship caused by the additional costs of cancer care. Factors contributing to a higher financial burden included low income, younger age, being a single parent, undergoing chemotherapy, and living in rural areas. To cope with these additional costs, individuals often resorted to strategies such as cutting back on leisure activities, reducing consumption of electricity, water, and other resources, delaying the replacement of breast prostheses, opting for less expensive medications and inpatient palliative care, and choosing more aggressive treatments, such as mastectomy instead of breast-conserving surgery.

Yabroff et al. (2011) measured the economic burden of cancer in the United States and estimated the current and future projections of the national burden of cancer. For cancers with prolonged survival, prevalence costs in a given year were considerably lower than incidence costs for that year. Using the phase-of-care approach, it was found that cancer survivors generally incur higher costs than individuals without cancer across all phases of care. Within each phase, direct medical costs varied significantly across different types of cancer. In 2010, the prevalence costs of cancer care in the U.S. were estimated at $124.5 billion, with the highest costs associated with breast and colorectal cancers. By 2020, cancer care costs in the U.S. were projected to rise to $157.8 billion. Additionally, indirect costs, estimated using the human capital approach, were projected to increase from $115.8 billion in 2000 to $147.6 billion by 2020. Though they have health insurance, patients faced a financial burden due to high cost for drugs and medications.

Zafar et al. (2013) conducted a pilot study and assessed the out-of-pocket expenses and the insured cancer patient's experience. The comprehensive score for financial toxicity (COST) was used to measure financial toxicity. Among 246 patients with solid tumours undergoing chemotherapy or hormonal therapy, 42 per cent reported experiencing significant or catastrophic financial burdens due to cancer-related out-of-pocket (OOP) expenses. Based on patient-reported cost diaries, the median monthly OOP spending was estimated at $708. Factors such as unemployment, non-white race/ethnicity, low income, higher psychological distress, and inpatient admissions were significantly associated with financial toxicity. In terms of coping strategies, 53 per cent of patients made lifestyle changes to manage costs, 49 per cent borrowed money, and 20 per cent used credit to pay for medications. Additionally, many patients altered how they obtained medications, engaging in price shopping for cancer drugs across different pharmacies.

Fernandez et al. (2013) estimated the economic burden of cancer across 27 countries of the European Union (EU) in 2009. Also, they determined specific proportions of total cost attributable to breast, colorectal, lung, and prostate cancers through a population-based cost analysis. The country-specific data was obtained from several databases, such as WHO, EUROSTAT, SHARE, IMS Health, national ministries of health, and statistical institutes. The study analysed five categories of cancer healthcare services: primary care, emergency care, outpatient care, hospital inpatient care, and drugs. In 2009, the total economic cost of cancer in the European Union (EU) was estimated to exceed €126 billion. Of this, healthcare costs accounted for approximately €51 billion, representing 4 per cent of the EU's total healthcare expenditure. Inpatient care costs were estimated at €28.4 billion, while drug expenses amounted to over €13.5 billion. Informal care costs were notably high across EU countries, valued at €23.2 billion. Lung, breast, colorectal, and prostate cancers together accounted for 44 per cent of the total economic cost of cancer in the EU. The highest economic cost was accounted for lung cancer (€18·8 billion,15 per cent of overall cancer costs), followed by breast cancer (€15·0 billion, 12 per cent), colorectal cancer (€13·1 billion,10 per cent), and prostate cancer (€8·43 billion, 7 per cent). The combination of high productivity losses and significant direct costs for cancer treatment presents a major concern for the EU.

Lee et al. (2014) estimated the economic cost of Korea from 2000 to 2010 by cancer site, gender, and age group. The cost of illness method was used, and it consists of three components, i.e., direct, mortality and morbidity cost. Medical cost data was obtained from national health insurance claims and surveys on out-of-pocket expenses for patients covered by health insurance. Morbidity and mortality costs were estimated using the human capital approach. Between 2000 and 2010, the total number of cancer patients rose by 66.67 per cent, from 544,402 to 907,347. In the 0-14 age group, leukemia, brain cancer, and non-Hodgkin lymphoma were the leading contributors to the cancer burden. For individuals aged 15 and older, liver, stomach, colorectal, and lung cancers were the top four in both 2000 and 2010. In terms of total economic burden, liver, stomach, and lung cancers had the highest costs. The share of mortality costs in the overall burden decreased from 70.7 per cent to 51.7 per cent over the decade, while the share of direct medical costs and morbidity costs increased.

Houtven et al. (2015) analysed the economic burden of informal caregivers for lung and colorectal cancer patients. A sample of 1629 informal caregivers were identified from the Cancer Care Outcomes Research and Surveillance (CanCORS) consortium study and surveyed. Informal caregivers were classified into three groups: those surveyed during the patient's initial phase of the disease, those in the terminal phase, and those in the continuing phase. The total economic burden for caregivers in the initial phase averaged $7,028, while it increased to $14,234 for those in the terminal phase, and reached $19,701 for caregivers in the continuing phase. Time costs, which made up 91 per cent of the economic burden, averaged $12,618. The economic burden for caregivers of lung cancer patients was higher than for those caring for colorectal cancer patients. The continuing phase caregivers faced the greatest costs. Spousal caregivers had a 43 per cent higher financial burden compared to non-spousal caregivers. Moreover, caring for a patient diagnosed with stage four cancer was associated with a 53.9 per cent higher economic burden than caring for someone diagnosed at stage one.

Gordon et al. (2017) conducted a systematic review of the financial toxicity among cancer survivors. The review revealed that between 28 per cent and 48 per cent of cancer survivors experienced financial toxicity when measured by monetary indicators, and between 16% and 73% when assessed subjectively. Factors contributing to financial toxicity included being female, having low income at baseline, loss of income, younger age, receiving adjuvant and antineoplastic therapies, more recent diagnoses, advanced cancer, lack of health insurance, and living farther from treatment centres. Cancer patients reported significantly higher levels of financial toxicity compared to non-cancer individuals. Coping strategies observed were treatment non-adherence, longer delays in care, forgoing treatment, and changes or loss of insurance coverage. Since most of the studies were cross-sectional, it was not possible to draw causal conclusions between financial toxicity and its contributing factors.

Oliveria et al. (2018) estimated the economic burden of cancer care in Canada through a population-based cost study. A comprehensive approach, using cancer prevalence rates, Ontario patient-level cost data and national expenditure data, was used to estimate the direct economic burden. This study analyzed two time periods, 2005-2008 and 2009-2012, to estimate the total and per-patient net costs of cancer care in Ontario. These estimates were then extrapolated to the rest of Canada using provincial and territorial expenditure data from the National Health Expenditure Database (NHEX). The analysis revealed a significant increase in total net expenditures, from $2.9 billion in 2005 to approximately $7.5 billion in 2012. The largest share of costs was attributed to hospital care, followed by physician services and drugs, with other expenditures on par with drug costs and thus not negligible. The most notable increases during the study period were seen in chemotherapy and radiotherapy costs.

Carrera et al. (2018) reviewed the financial toxicity of cancer treatment and its impact on health and other outcomes. While the United States offers a greater variety of oncology drugs compared to many other countries, the issue of high drug prices is a major challenge in healthcare sector. While cancer drugs are crucial for survival, they can create significant financial burdens and emotional distress for patients. Objective financial burden occurs when out-of-pocket (OOP) expenses for medical treatments and medications increase over time. Subjective financial distress can be due to the accumulation of these OOP costs, a reduction in income and wealth for non-medical needs, and the psychological stress of managing the financial strain. Low-income patients, in particular, have fewer financial resources to offset treatment costs and are at a higher risk of job loss due to cancer. This financial strain often leads to emotional distress, which can interfere with a patient's ability to cope with both the physical symptoms of cancer and the demands of treatment. To manage the financial toxicity of cancer care, comprehensive and sustainable approaches like discouraging coupon programs, promoting outcome-based pricing and reimbursement models, and implementing value-based decision-making in drug formularies was recommended.

Leng et al. (2019) analysed the prevalence, determinants and consequences of catastrophic health expenditure (CHE) among urban and rural end-of-life (EOF) cancer patients in China. The data was collected by face-to-face interviews with families of 792 patients and by field research. More than 80 per cent of the patients received life-extending treatment. Catastrophic health expenditure was experienced by 94.3 per cent of urban and 96.1 per cent of rural patients. After the out-of-pocket payments for healthcare, 84.10 per cent of urban and 91.10 per cent of rural cancer households were impoverished, falling below the poverty line. Families in lower income quintile borrowed from their relatives and friends to pay for the catastrophic out-of-pocket payments. Healthcare utilization was a significant factor influencing catastrophic health expenditure, with rural patients more likely to receive outpatient care, while urban patients were more likely to be hospitalized. Households with hospitalized patients were 12.8 times more likely to face catastrophic health expenditures compared to households with outpatient care. Health insurance provided limited financial relief, with reimbursement rates averaging only 40% in rural areas and 54% in urban areas. Across both urban and rural households, income was the most important determinant of catastrophic health expenditure (CHE).

2.3.2. Economic Burden of Breast Cancer

Max et al. (2009) estimated the direct and indirect costs of breast cancer for California women in 2001 using California-specific hospitalisation and mortality data. The total hospitalization costs were estimated at $77 million. During the primary diagnosis stage, the average length of stay was 2.2 days, with a mean cost of $5,697 per discharge. Hospitalization costs for women with a secondary diagnosis of breast cancer significantly contributed to the overall costs, amounting to $29 million, or $4,328 per discharge. The total direct costs of breast cancer were estimated at $279 million, with hospital-based care accounting for two-thirds of these costs. The morbidity costs, based on the value of lost productivity, were estimated at $1.15 billion. Therefore, the total economic cost of breast cancer for women in California in 2001 was $1.43 billion. The analysis also revealed that non-Hispanic black women had the longest hospital stays and the highest mean costs per hospitalization, likely reflecting a more advanced stage of disease at the time of diagnosis. Younger women, on average, had higher hospitalization costs and longer stays, possibly due to the more aggressive treatments they typically receive.

Grunfeld et al. (2014) assessed the family caregiver burden of breast cancer patients through a longitudinal study. Patients with hormone-refractory advanced breast cancer were selected for the study. The patients and their principal caregivers were interviewed during the patient's palliative and terminal periods. Of the 89 caregivers in the study, in relation to the patient, 52 per cent were spouses, 26 per cent were sisters or daughters, and 19 per cent were friends and others. It was observed that the mean score of anxiety and depression of caregivers was higher than that of the patients during both the palliative and terminal periods. A higher level of burden was observed at the start of the terminal phase than at the start of the palliative period. Caregivers missed work more in the terminal phase (79 per cent) than in the palliative phase (53 per cent). Caregivers could not work regular hours and had to use their leaves and holidays to care for the patients. On average, the primary component of the financial burden was prescription drugs. The average financial burden was higher for those without extended health insurance than those with extended health insurance coverage.

Daroudi (2015) estimated the economic burden of breast cancer in Iran in 2010 through a prevalence-based approach. The data was collected from the last report of the cancer registry in Iran, which provided cancer statistics for 2009. In 2010, approximately 10,000 new breast cancer cases were reported, with a 5-year prevalence of 39,316. The total direct medical costs associated with breast cancer were estimated at $175,860,607.The cost of chemotherapy contributed to 43.65 per cent of direct medical costs and was estimated to be $76,755,740. The terminal care costs ($55,150,574) were the second-highest medical costs (31.36 per cent) of the total medical cost. The total cost of transportation to hospitals for treatment was estimated at $21,606,293, and the mean cost per journey was $29. The total patient time cost was estimated to be $20,441,309 in 2010, and the mean time of absence from work was 23.63 days. The mortality cost was estimated to be $729,467,259, and the total economic burden of breast cancer in Iran in 2010 was estimated to be $947,375,468. The main components of the economic burden were mortality cost (77 per cent) and direct medical cost (18.56 per cent). The cost of medical services in Iran was lower than in developed countries.

Greenup et al. (2019) determined how women consider cancer treatment costs when making decisions for breast cancer surgery and how these decisions relate to financial hardship. In the case of breast preservation surgery, costs were more influential in surgical choice as household income fell and in the lowest income group ($45,000/year). The decision to opt for a bilateral mastectomy was heavily influenced by factors like higher out-of-pocket expenses, increased debt, greater financial strain, and changes in employment. 35 per cent of respondents reported experiencing significant to catastrophic financial burden due to their breast cancer treatment, with many women in higher income brackets citing depleted savings. Additionally, 65 per cent of women were unprepared for the financial costs, with 26 per cent reporting that treatment expenses were higher than expected. The fear of cancer recurrence, along with recommendations from their healthcare providers, were the most significant factors shaping their decisions regarding breast cancer surgery.

Coughlin et al. (2020) analysed the financial distress among breast cancer survivors. Out of the 164 patients interviewed, 8% reported severe difficulty in paying for medical visits or medications. The multivariate regression analysis identified younger age and low income as factors associated with financial toxicity among breast cancer patients. Around 8% of respondents expressed that they were unable to provide for their families. In total, 65.81% of participants reported experiencing financial distress.

Afkar et al. (2021) compared the costs of breast cancer among patients who were referred to private and public hospitals in Iran in 2017. The direct medical costs for breast cancer patients referred to private hospitals averaged $9,880, compared to $3,620 for those referred to public hospitals. Both hospitalization and outpatient costs were higher for patients in private hospitals. Among the hospitalization costs, surgery accounted for the largest expense in private hospitals, at $980, while in public hospitals, hoteling costs were the highest, totaling $380. For both groups of patients, commuting and food expenses represented the largest components of total direct non-medical costs. The total mean indirect costs for patients referred to private hospitals was $1,870, while for those referred to public hospitals, it was significantly higher at $22,350. In both private and public hospitals, the mean cost of lost workdays was greater for family caregivers than for the patients themselves.

2.3.3. Economic Burden of Cancer in India

Mohanti et al. (2011) aimed to estimate the treatment costs incurred by cancer patients at a tertiary public hospital in India. Data were collected in two phases: the first from patients in the outpatient department of AIIMS, and the second from a random subset of these patients who were undergoing radiotherapy. The average cost of treatment across all plans was estimated at ₹ 1,062 per week, with nearly 59 per cent of this amount spent on transportation, food, and lodging. The total economic burden on a cancer patient at AIIMS was found to be ₹ 14,031 prior to starting radiotherapy, with an additional ₹ 8,184 for the seven-week radiotherapy course. This resulted in a total expenditure of ₹ 22,215.

Mahal (2013) assessed the economic burden of cancer on households in India using cross-sectional data collected by the National Sample Survey Organisation (NSSO). A propensity scoring matching (PSM) was used to compare the economic outcomes of 'cancer-affected' households with households with similar socio-economic status (SES) that do not include a member with cancer. It was found that 32 per cent to 42 per cent of the total spending in an average cancer-affected household is directed towards out-of-pocket expenses for inpatient and outpatient treatment. Households with higher socio-economic status (SES) spend a larger proportion on healthcare, with out-of-pocket expenses making up 60 per cent of their total spending, compared to 53 per cent for households with lower SES. Lower non-medical expenses were experienced in both high and low-SES cancer-affected households. In terms of labour force participation, cancer-affected households have a lower rate than matched households by 2.4 per cent to 3.2 per cent. Higher SES households adjusted by lowering their spending on outpatient care for members without cancer, whereas lower SES households relied more on borrowing and sale of assets and lower non-medical consumption.

Nair et al. (2013) assessed the treatment pattern and expenditure incurred by cancer patients undergoing treatment at government tertiary hospitals in India. A cross-sectional study was conducted among 508 cancer patients located in five major cities: Thiruvananthapuram, Mumbai, Bikaner, Kolkata and Aizawl. For almost 41 per cent of the patients, the cost of cancer treatment was unaffordable. About 27 per cent of the patients delayed the treatment of cancer due to financial barriers. Cancer investigations like X-rays, CTs, MRIs and biopsy are expensive, and patients spend ₹ 16739 on average. Around 33.6 per cent of the patients received treatment free of cost, while the rest spent ₹ 41,311 on average for cancer treatment, including medicines. The average indirect costs incurred by cancer patients were ₹. 27,248, which included expenses for transportation, accommodation, food, and other related costs. Patients in Thiruvananthapuram and Mumbai reported the highest overall direct and indirect costs. Furthermore, around 31 per cent of cancer patients spent more than ₹. 50,000 on investigations and treatment over the course of the past year. Around 39 per cent of the patients had to borrow money from various sources to meet the cost of treatment. As cancer treatment required repeated visits to the hospital, 44 per cent of cancer patients faced difficulties in travelling long distances to hospitals.

Sneha et al. (2017) assessed the medical expenses incurred by families during the cancer treatment of children and its implications on their quality of life. Non-medical expenses contributed to 46 per cent of total expenditures of cancer treatment. Food, travel, and accommodation costs were found to be major contributors to the severe financial strain on families, making up two-thirds of the total expenses incurred during each hospital admission. The diagnosis of cancer in children also had a significant impact on the parents' work productivity and hours. Around 73 per cent of fathers reported a reduction in productivity and adjustments to their work schedules during the course of their child's treatment. Loss of pay was observed to be more for working mothers than fathers. In order to pay for the medical expenses, 55 per cent of the families had borrowed money from their friends and relatives, and 22 per cent of families had borrowed money from money lenders. The coping mechanisms adopted by 50 per cent of the households with multiple children were restricting the need of other siblings to provide for the diseased child. Around 25 per cent of the families had sold their properties and assets, and 62 per cent had used up all their savings to meet the medical expenses. The significant factors contributing to higher medical expenses were the settlement in rural areas and the type of malignancy.

Rajpal et al. (2018) analysed the economic burden of cancer in India. The overall prevalence and economic burden of cancer were estimated using nationally representative data from the Social Consumption: Health survey (71st round) of India. The average total expenditure is estimated to be ₹ 29,066 and ₹. 84,320 for the public and private sectors, respectively. In private facilities, the expenditures incurred by males were significantly higher than those incurred by females, whereas there was not much difference between the expenditures incurred by both genders in public facilities. Patients from richer households incurred more than twice the average expenditure than patients from poorer households. About 50 per cent of low-income households raised a greater proportion of their cancer treatment expenditure through distressed means. The prevalence of distressed financing was higher in patients seeking treatment from private facilities, patients from low-income households and patients from rural areas. Catastrophic expenditures were experienced by more than 35 per cent of the cancer-affected households.

Basavaiah et al. (2018) analysed the financial impact of complex pancreatic cancer surgery in India. Ninety-eight cancer patients undergoing pancreaticoduodenectomy (PD) surgery at Tata Memorial Centre, a major tertiary cancer centre in India, were selected for the study. Among the 98 patients, only 29.6 per cent had insurance coverage, whereas the rest had to make out-of-pocket payments for hospitalisation. The estimated total mean expenditure for surgery was ₹.295,679.57. The mean expenditure for patients with complications was significantly higher than those without. The mean expenditure for male patients was found to be higher, at ₹.315,639.8, than that of female patients. The catastrophic threshold was set at 10 per cent of annual household expenditure, and it was observed that 76.5 per cent of the patients faced catastrophic impacts. Expenditure levels among patients varied according to factors such as ward type, insurance coverage, presence of complications, and gender. On average, patients in public wards spent significantly less than those in private or semi-private wards.

Barwal et al. (2019) assessed the out-of-pocket expenditure for the diagnosis of lung cancer. An institution-based cross-sectional study was done at a tertiary cancer centre in Himachal Pradesh. The total out-of-pocket expenditures incurred before the patients sought treatment services were analysed, and the pre-treatment financial burden was estimated. The average total direct costs were estimated to be ₹ 19,516.48 ± 6488.21. Medical costs contributed to about 34 per cent of the total mean direct costs. The total direct nonmedical costs incurred were ₹ 10,574.73 on average. Expenses incurred on nonmedical resources such as travel, lodging, and food contributed to about 54 per cent of the total overall expenditure. For investigative procedures and tests, the total costs incurred on average was ₹ 5370. It was observed that the participants were spending almost double the amount on diagnostic procedures compared to medication. The financial burden sustained before the initiation of treatment was observed to be ten times higher than the average per capita income of households.

Dinesh et al. (2020) analysed the economics of cancer care through a community-based cross-sectional study in Kerala. The study included 235 cancer patients from the Vypin panchayat of Ernakulam. The most common cancer observed was breast (49 per cent), followed by intestinal cancer (11 per cent) and leukaemia (7 per cent). The average direct costs were ₹ 25606, and the main contributor to this cost was medication costs. The average indirect costs were ₹ 8772, of which the patient's income loss was a major component. Around 38 per cent of cancer patients seek treatment from Ernakulam General Hospital, 46 per cent from private hospitals, and 12 per cent from Regional Cancer Centre. Ninety-six per cent of cancer patients go for a follow-up at least once a year, while 4 per cent do not go for follow-up due to the expensive treatment and their poor socio-economic status.

Dhankhar et al. (2021) conducted a systematic review to determine the out-of-pocket, catastrophic health expenditure and distress financing of cancer treatment in India. The 23 studies included in the systematic review varied in design, sampling strategy, and reporting of outcome measures. The pooled mean direct cost for inpatient cancer treatment was ₹ 83345.026 and was significantly higher when compared to other costs. The highest proportion of out-of-pocket expenses was attributable to direct medical costs, especially medications. The pooled mean out-of-pocket expenses for outpatient cancer care over a 15-day period were found to be ₹ 2,653.12. While indirect costs were not statistically significant, the estimated pooled mean for indirect out-of-pocket expenses was notably high at ₹ 11,908.53. This highlighted the substantial indirect expenditure, primarily due to wage losses for both patients and caregivers. The percentage of cancer patients facing catastrophic health expenditure was alarmingly high, at 62.7 per cent. The most common methods of financing healthcare costs included drawing from savings, borrowing money, and selling assets. Additionally, significant gaps in data were identified, largely due to inefficient healthcare management systems and the lack of population-based cancer registries in India.

Maurya et al. (2021) assessed the economic burden of cancer treatment in South India through a hospital-based cross-sectional study conducted at the Regional Cancer Centre. The study estimated that the average out-of-pocket expenditure for direct medical costs was ₹ 1,551.2, while direct non-medical costs amounted to ₹ 22,823.4. The highest direct medical costs were observed in the 51-60 age group, while the above 60 age group had the highest direct non-medical costs. The study also found that male patients incurred higher out-of-pocket expenses than female patients. In terms of geographic location, urban patients had higher healthcare expenditures compared to their rural counterparts. Indirect medical costs were significantly higher for head and neck cancer patients (₹ 30,294) compared to those with breast cancer (₹ 24,547) or cervical cancer (₹ 13,235). For stage 1 cancer patients, the direct medical costs were the highest, and for stage 3 cancer patients, indirect medical costs were the highest. Catastrophic health expenditures were experienced by 61.6 per cent of the patients.

Goyanka et al. (2021) analysed the economic and non-economic burden of cancer in India. A propensity score-matched analysis was conducted using India's household health survey data. For inpatient treatment, the per episode OOPE for cancer was ₹ 52,393 more than that for any other matched chronic ailment. In the case of outpatient care, the expenditure on drugs and diagnostics for cancer patients was five times greater than that for patients with any other ailments. For non-medical expenditures for inpatient and outpatient care, cancer patients incurred ₹ 4500 per episode more than patients with other ailments. The per-person loss in income for a cancer-affected household was 2.5 times that of a non-cancer-affected household for inpatient care. In order to cope with the high expenditures, cancer-affected households spent a greater share of their monthly income on treatment and had to borrow more money when compared to patients with other ailments. The healthcare utilisation of other members of cancer-affected households was lower when compared to non-cancer-affected households.

2.3.4. Economic Burden of Breast Cancer in India

Jain et al. (2016) estimated the economic burden of breast cancer on households in Punjab, India. Patients from 221 households across 22 districts of Punjab were interviewed for the study. The direct cost contributed to 79 per cent of the total cost of illness, while the indirect cost contributed 21 per cent. It was observed that as the stage progresses, the mean total medical cost also increases. For patients undergoing treatment in the public sector, the cost of care increased progressively with the cancer stage. The cost in the second stage was 1.61 times that of the first stage, while in the third and fourth stages, the costs were 2.21 and 2.38 times the cost of the first stage, respectively. In the private sector, the treatment cost in the second stage was 1.47 times that of the first stage, with the third and fourth stages costing 1.93 and 2.14 times more, respectively. Approximately 84 per cent of households experienced catastrophic health expenditures. Insured households typically relied on savings to manage costs, whereas non-insured households often turned to low-interest borrowing. More than half of the households reported financial distress, with coping mechanisms varying based on per capita income, cancer stage, and place of residence.

The high costs of treatment were found to significantly impact household spending, leading to reductions in expenditures for food, education, and social activities.

Alexander et al. (2019) analysed the impact of breast cancer on the patient and the family from an Indian perspective. A mixed-methods approach was employed for data collection, involving a consecutive series of breast cancer patients who sought evaluation for a breast lump at two hospitals. The study revealed that 43% of patients faced significant financial difficulties during treatment. Many resorted to extreme measures, such as selling property or mortgaging gold and land, to cover the costs. Only 29 per cent of patients had medical insurance to help with treatment expenses, and 3 per cent of patients ultimately discontinued their treatment due to financial constraints. In terms of decision-making, the primary decisions regarding cancer treatment were made by a male family member—either a husband or son—in 50% of the cases.

Wadasadawala et al. (2021) assessed the economic distress of breast cancer patients seeking treatment at a tertiary cancer centre in Mumbai during the COVID-19 pandemic. About 138 non-metastatic breast cancer patients from Tata Memorial Centre, who registered for treatment before lockdown and were continuing their treatment during lockdown, were interviewed. Breast cancer patients experienced an increase of 32 per cent in their average monthly expenditure during lockdown. Prior to the COVID-19 pandemic, the average monthly household income of breast cancer patients was ₹ 29,517, but this decreased to ₹ 7,551 after the lockdown. At the same time, daily expenses for food, medicine, and transportation rose significantly. Approximately 81 per cent of patients faced financial shortages, with 32 per cent reporting shortage of food and 28 per cent unable to afford necessary medications. To manage these increased costs, 61 per cent of patients turned to distress financing. This coping strategy was most common among patients under 40 years, those without formal education, married women, Muslim patients, and those living in rented homes. About 50 per cent of patients borrowed money, while 30 per cent used savings or household income to cover their expenses.

2.3.5. Impact of Insurance Coverage and Health Schemes on Cancer Care

In this literature review section, the relationship between healthcare insurance status and outcomes for individuals with cancer is analysed. The objective is to summarise research which assess the role of insurance coverage for uninsured and underinsured during treatment of cancer and for improving quality of life.

2.3.5.1. Health Insurance and Cancer Care

Thorpe et al. (2003) analysed health insurance and spending among cancer patients in the United States. It was observed that substantial numbers of cancer patients had no health insurance. Overall, about 5 per cent of the cancer patients were uninsured, and 56 per cent of the cancer patients were covered by Medicare insurance. Uninsurance rates were observed to be higher among minorities. Hispanic cancer patients were twice as likely to be uninsured compared to the general cancer patient population, and individuals under the age of 65 also had higher rates of uninsurance. In terms of healthcare spending, privately insured cancer patients incurred 55 per cent higher costs than uninsured patients, largely due to increased hospital expenditures for the insured. Uninsured cancer patients had fewer healthcare interactions overall, including fewer inpatient admissions, office visits to physicians, and outpatient hospital visits compared to those with insurance.

Kirsner et al. (2006) assessed the effect of Medicare healthcare delivery systems on survival for patients with breast and colorectal cancer. This study compared the survival outcomes of breast and colorectal cancer patients diagnosed under two Medicare healthcare delivery systems: fee-for-service (FFS) and managed care health maintenance organizations (HMOs). Using data from the Medicare database and the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program, the analysis found that HMO patients were more likely to be diagnosed at earlier stages (in-situ and local) than FFS patients, for both breast and colorectal cancers. Kaplan-Meier survival analyses showed that breast cancer patients enrolled in HMOs had significantly better overall survival compared to those in FFS plans. This likelihood of HMO patients using more of preventative services may be due to

HMOs' greater access to healthcare services, as well as possible differences in patient characteristics such as education, income, or health awareness.

Walker et al. (2014) determined the association of insurance status with a stage at diagnosis, treatment, and survival in cancer patients. In this study, 473,722 cancer patients from the SEER database were analysed. It covered cancers such as breast, prostate, lung, colorectal, head and neck, liver, pancreatic, ovarian, oesophageal, and non-Hodgkin lymphoma. The results showed that cancer patients with non-Medicaid insurance were less likely to have distant-stage disease (16.9 per cent) compared to those without any insurance (34.7 per cent). Conversely, uninsured patients were less likely to be diagnosed with localized disease (40.8 per cent) than those with non-Medicaid insurance (60.8 per cent). Patients with Medicaid coverage had intermediate rates of distant (29.1 per cent) and localized (42.2 per cent) disease. In terms of treatment, those with non-Medicaid insurance were more likely to undergo cancer-directed surgery and receive radiation therapy (79.6 per cent) compared to uninsured patients (62.1 per cent). Medicaid patients received definitive treatment at an intermediate rate (67.9 per cent). The survival rates were highest for patients with non-Medicaid insurance (86.2 per cent), followed by those with Medicaid (69.1 per cent), and lowest for the uninsured (66.5 per cent).

Grant et al. (2015) evaluated the association of insurance status with brachytherapy for cancer treatment. Patients suffering from breast, cervical, prostate, and endometrial cancers were included in the study, and a total of 1,90,467 patients were identified from the SEER database. In the case of breast cancer, the proportion of patients receiving brachytherapy, with or without EBRT, was 4.8 per cent for non-Medicaid insurance, 2.3 per cent for Medicaid insurance, and 1.4 per cent for those without insurance. The proportion of patients receiving no radiation therapy for breast cancer was 21.4 per cent for non-Medicaid, 28.0 per cent for Medicaid insurance, and 30.8 per cent for those without insurance. In a logistic regression analysis of all cancers included in the study, patients who received radiation therapy were less likely to undergo brachytherapy if they had Medicaid or no insurance, compared to those with non-Medicaid insurance.

Parikh-Patel et al. (2017) analysed the impact of health insurance on the quality of cancer care. Breast, ovary, endometrium, cervix, colon, lung, and stomach cancer patients were identified in the California Cancer Registry (CCR) and analysed in this study. The findings showed that patients with Medicaid, Medicare-Medicaid dual coverage, or no insurance generally received lower-quality cancer care compared to those with private insurance. Among breast cancer patients who underwent breast-conserving surgery or double mastectomy, both the dually eligible and uninsured groups were significantly less likely to receive radiation therapy than their privately insured counterparts. For cervical cancer, Medicaid and uninsured patients were much less likely to receive brachytherapy. Furthermore, colon and gastric cancer patients with Medicare-Medicaid dual coverage were less likely to have the recommended minimum number of lymph nodes removed and examined.

2.3.5.2.Impact of Insurance Coverage on Breast Cancer Care

Ayanian et al. (1993) studied the relationship between health insurance coverage and clinical outcomes among women with breast cancer. Data was obtained from the New Jersey state cancer registry, and 4675 women with invasive breast cancer were identified. Uninsured women and those with Medicaid coverage were found to have significantly more advanced disease at the time of diagnosis compared to women with private insurance. Survival rates during the 54 to 89 months following diagnosis were considerably worse for uninsured and Medicaid patients with local and regional cancers, when compared to privately insured patients. However, there was no significant difference in survival based on insurance status among patients with distant metastases at diagnosis. These disparities in disease stage and survival may be linked to limited access to care and lower rates of screening among uninsured and Medicaid patients.

Bradley et al. (2003) examined the correlates of late-stage breast cancer and death in a Medicaid-insured population in the United States. Women without Medicaid coverage before their diagnosis, as well as those living in nursing homes or receiving long-term care, were more likely to be diagnosed with cancer at a late stage. Older women had higher odds of late-stage diagnosis, while women with more comorbid conditions had lower odds of being diagnosed at later stages. Uninsured women were more likely to be diagnosed with advanced cancers, which are often expensive to treat and have a poorer prognosis, compared to women with Medicaid coverage. Age, nursing home residency, receipt of long-term care, and late-stage disease were all significant factors associated with a higher risk of death.

Voti et al. (2006) analysed the effect of race/ethnicity and insurance coverage on the receipt of standard treatment for local breast cancer. A total of 23,817 local breast cancer patients were identified from the Florida Cancer Data System. It was observed that non-Hispanics, blacks, and non-Hispanics were 19 per cent less likely to receive standard treatment when compared to whites. Standard care for local breast cancers diagnosed in widows or single women were less likely (83 per cent and 85.3 per cent, respectively) compared to those diagnosed in married women or those who were divorced (89.6 per cent and 88.8 per cent, respectively). Uninsured women and those on Medicaid were also less likely to receive proper treatment for local breast cancer compared to those with private insurance. On the other hand, Medicare patients had a higher chances of receiving protocol treatment than privately insured women.

Ali et al. (2014) examines the impact of health insurance type on the treatment of early-stage breast cancer using breast-conserving surgery (BCS) with radiation therapy (RT) among women in Florida. It was observed that 31.54 per cent of the breast cancer patients were privately insured, 1.74 per cent had Medicaid coverage, 50.12 per cent had Medicare coverage, 14.07 per cent had other insurance, and 2.54 per cent were uninsured. The majority of the women with insurance received breast-conserving surgery (BCS). Women with Medicaid or no insurance were less likely to receive surgical treatment than those with private health insurance, Medicare, or other types of government coverage. The proportion of patients who received radiotherapy after BCS was lower among Medicaid-insured (41.3 per cent) and uninsured (40.94 per cent) when compared to privately insured (45.93 per cent), Medicare-insured (47.87 per cent), and other insurance (51.05 per cent). The results from the odds ratio revealed that women with Medicare insurance and women insured by other insurance programs were more likely to receive the recommended treatment than women who were insured privately.

Diao et al. (2021) analysed the impact of government health insurance coverage of anti-cancer medicines on breast cancer patients in China. There are two government-managed health insurance programs: 'urban employee programme' for urban formal employees; and 'resident programme' for non-formally-employed residents. This study was conducted on 357 patients who received Trastuzumab as part of their treatment. It was found that insurance coverage significantly increased the proportion of patients initiating the medication, with the proportion nearly doubling after insurance was provided. Patients in the age groups of 40–49 and 50–59 years old benefited more from insurance coverage than those under 40. Rural patients and those enrolled in the 'resident program' showed greater benefits from the insurance policy than those in the 'urban employee program'. Multivariate analysis revealed that key factors influencing a patient's medication choice included their household registration, type of health insurance, disposable income in their residential area, and the location of their care.

2.3.5.3. Health Schemes and Insurance in India

In India, several government-sponsored health insurance programs aim to provide coverage for different segments of the population. These include state-specific initiatives such as Rajiv Aarogyasri in Andhra Pradesh, Vajpayee Aarogyasri in Karnataka, and various programs in Tamil Nadu and Rajasthan. At the national level, the Rashtriya Swasthya Bima Yojana (RSBY) offers health insurance to resource-poor families. For formal sector employees, there are additional schemes like the Employees State Insurance Scheme (ESIS) and the Central Government Health Scheme (CGHS), which offer extensive coverage and a wide range of benefits to the insured. The health schemes available for cancer patients in India are the Health Minister's Cancer Patient Fund (HMCPF), the Cancer Suraksha Scheme by the Kerala government, the Aarogyasri scheme in Andhra Pradesh, and state-government sponsored illness assistance funds.

Sinha et al. (2014) assessed the impact of the Rashtriya Swasthya Bima Yojana (RSBY) on healthcare utilisation in India. The per capita consumption expenditure data collected in India by the National Sample Survey Organisation (NSSO) for the years 2007-08 and 2011-12 was used for this study. Despite the implementation of the Rashtriya Swasthya Bima Yojana (RSBY), which covers a wide range of hospitalization cases, there was no significant increase in per capita utilization of institutional care. Following the program's rollout, institutional spending rose slightly in states like Bihar, Gujarat, Kerala, and Uttar Pradesh, while it decreased in states such as Chhattisgarh, Himachal Pradesh, Jharkhand, Punjab, Uttarakhand, and West Bengal. However, non-institutional expenses increased in nearly all states from 2007-08 to 2011-12. This highlights the significant financial burden placed on households by non-institutional services, which are not covered by publicly financed schemes like RSBY. There was also high increase in institutional and non-institutional medical expenses across all states.

Sood et al. (2014) evaluate the effects of a government insurance program, Vajpayee Arogyashree scheme (VAS), covering tertiary care for people below the poverty line in Karnataka. The data showed that mortality from conditions covered by the scheme was lower among eligible households below the poverty line, compared to those above it. Specifically, the mortality rate for covered conditions was 0.32 per cent in eligible households below the poverty line, compared to 0.90 per cent in ineligible households. Additionally, households enrolled in the scheme saw a 34 per cent reduction in out-of-pocket health expenses for hospital admissions related to covered conditions. There was also increased utilization of tertiary care facilities by eligible households, with these households being 12.3 per cent more likely to seek tertiary care for covered conditions.

Sood and Wagner (2016) examined how patient outcomes differed for VAS-eligible hospitalisations compared with ineligible hospitalisations (for covered conditions). The rates of post-hospitalization infection and readmissions for eligible versus ineligible hospitalisations were compared in this study. Among patients ineligible for VAS, 7.7 per cent reported post-hospitalization infections, and 32.6 per cent were rehospitalized after their initial stay. In comparison, only 0.9 per cent of VAS-eligible patients experienced infections, and 16.8 per cent had rehospitalizations, reflecting reductions of 88 per cent and 48 per cent, respectively. In terms of treatment-seeking behaviour, VAS-eligible patients were about 7 per cent more likely to seek care than those ineligible, with this difference observed mainly for cardiac symptoms, the condition most commonly covered by VAS. These results suggest that VAS led to earlier diagnosis, which further encouraged treatment-seeking behaviour.

2.4. Conclusion

Cancer incidence is rapidly growing worldwide, and it is one of the leading causes of death in many countries. This chapter reported a detailed literature review on the costs associated with cancer. The literature review was useful in highlighting the number and type of studies undertaken by researchers when estimating the cost of different cancers. The detailed review of the articles revealed significant variation in the methodologies used to estimate costs. This included differences in study design, perspective, data collection, time horizon, as well as the approaches to analysis and interpretation of results.

The theoretical literature review indicated that health is an asset and individuals are the producers of health. An investment in health leads to an improvement in the productivity of individuals and yields continuing returns for the future. Health is both a consumption and investment commodity, and the demand for health is determined by socio-economic factors, cost of health capital, and wage rate. To estimate the cost of an illness, it is important to identify all the relevant costs. The cost of illness methodology is an appropriate tool to measure the economic impact of a cancer.

The empirical literature highlighted the economic burden associated with cancer. On average, a breast cancer patient incurs a very high cost of treatment. The determinants of economic burden are the age of the patient at the time of diagnosis, stage of cancer at diagnosis, annual income of the household, employment status of the patient, location of residence, marital status, the treatment protocol, insurance coverage, health scheme coverage and the type of hospital chosen for treatment. The direct medical costs must be determined at the diagnosis, treatment, and follow-up stages.

The high out-of-pocket expenditures (OOPE) associated with breast cancer are evident in the empirical studies. The common types of distress financing adopted by the patient and their families to meet the high OOPE are selling properties, borrowing money from friends, taking loans from banks, and selling gold. Insurance coverage and health schemes provide only minimal aid in meeting the expenses.

CHAPTER III

METHODOLOGY FRAMEWORK

3.1 Introduction

The economic burden of breast cancer is determined by studying the various costs associated with the treatment of breast cancer. In this chapter, a description of the sample area, along with sample size determination, is explained. It also provides details regarding the conceptual framework used to determine the financial burden faced by a breast cancer patient and their household. The treatment protocol for breast cancer is also explained. Information regarding various government and insurance schemes is also included. Lastly, the definitions of essential terms used in this study are also provided in this chapter.

3.2 Description of Sample Area

This section examines the selected sample area and the sample profile.

3.2.1 Socio-Demographic Profile of the Sample Area

The selected sample area is Kerala. The previous chapter shows the importance and reason behind choosing the state of Kerala for the present study. In India, the crude rate of cancer incidence among females was second highest in Kerala (NCRP 2012-2016). A high crude incidence rate, 45 per 1,00,000, was observed for breast cancer in Kerala. Hence, Kerala was chosen as the sample area for this study.

In terms of geographical area, Kerala ranks 22nd in India, covering 38,863 square kilometres. The state has an estimated population of over 3.34 crore people, which constitutes approximately 2.75 per cent of India's total population. Kerala's sex ratio at birth stands at 957 females for every 1,000 males, which is above the national average of 899. The population distribution of the state across different age groups is as follows: 14.3 per cent are between 10 and 19 years, 55.9 per cent fall in the 20 to 59-year age range, and 16.5 per cent are aged 60 years or older (Health Dossier,2021). According to the ESAG 2018 report, Kerala boasts high education enrolment rates, with a Gross Enrolment Ratio (GER) of 30.8 per cent for higher education, 77.56 per cent for senior secondary education, 92.44 per cent for secondary education, 95.42 per cent for elementary education, and 95.44 per cent for primary education.

3.2.2 Health Indicators of the Sample Area

The maternal mortality ratio in Kerala has seen a substantial decrease, from 81 to 43 per 100,000 live births. Over the years, both the crude birth rate and crude death rate have declined significantly, from 15 and 6.4 in 2005 to 13.5 and 7.1 in 2019, respectively (Sample Registration Survey Bulletin, 2019). Communicable, maternal, neonatal, and nutritional diseases (CMNND) now account for 11.83 per cent of the state's total disease burden. Among these, leading causes of death include diarrheal diseases, lower respiratory infections, and drug-susceptible tuberculosis (QPR NHM MIS Report, 2020).

The National Family Health Survey 5 (2019-20) reveals that 58 per cent of deaths in Kerala are premature, with disability or morbidity contributing to 45.2 per cent of the burden. Major causes of Disability-Adjusted Life Years (DALYs) in the state include ischemic heart disease, chronic obstructive pulmonary disease (COPD), diabetes, and various musculoskeletal conditions. Non-communicable diseases account for 76.92 per cent of DALYs, while injuries contribute 11.25 per cent. Tobacco use is reported at 2.2 per cent among women and 16.9 per cent among men, while alcohol consumption stands at 0.2 per cent for women and 19.9 per cent for men. Key risk factors for DALYs and Years of Life Lost (YLLs) include metabolic issues such as high systolic blood pressure, elevated fasting plasma glucose, high body mass index, high LDL cholesterol, and lifestyle factors like smoking (National Health Profile, 2020).

3.2.3 Prevalence of Cancer in the Sample Area

In Kerala, the crude incidence rate of cancer is 164 per 1,00,000 in males and 151 per 1,00,000 in females. Across age group 0-74 years, the risk of developing cancer is one in seven among males and one in nine among females in Kerala. Among males, the leading cancer site is the lung and among females, it is the breast. Cancer contributes to 16.4 per cent of deaths due to non-communicable diseases in Kerala (Global Burden of Disease Data, 2019). The high prevalence of risk factors like tobacco and alcohol consumption, low consumption of leafy vegetables and fruit, and obesity contribute to the high incidence of cancer in Kerala.

3.2.4 Health Infrastructure in the Sample Area

As per the recent RHS data (2019-20), the number of Sub-centres (SC), Primary health centres (PHC) and Community health centres (CHC) have been increasing since 2005. According to the NHFS 5 (2019-20) report, currently, there are 5410 SCs, 784 PHCs, and 211 CHCs in Kerala. The State also has 48 District hospitals (DH), 86 Sub-district hospitals (SDH), ten government medical colleges and three cancer care centres. The three government cancer care centres are Malabar Cancer Centre (Thalassery), Regional Cancer Centre (Trivandrum) and Kochi Cancer Centre (Ernakulam). Cancer treatments are also available in a few private institutions in the state.

3.3 Data Sources

In this study, both primary and secondary data have been used to analyse the objectives. The secondary data was gathered from NSSO data, 75th (2017-18), NCRP reports (2012-16), and the GLOBOCAN report (2020). The primary data was collected by interviewing female breast cancer patients from cancer hospitals. The primary data sampling design was determined based on the annual reports of major cancer hospitals in Kerala. In this study, female breast cancer patients were the unit of analysis.

3.4 Primary Data: Sampling Methodology

The primary data for the study was collected using the following methodology.

3.4.1 Sampling Size

Cochran (1977) derived a formula for determining an appropriate sample size when estimating a population proportion, especially when the population is large and the desired margin of error (precision) and confidence level are known. The formula is useful when the population size is unknown or when working with finite populations where it is important to determine how large a sample is needed to make inferences about the population.

For a proportion, Cochran's formula is:

$$n_0 = \frac{Z^2 p(1-p)}{e^2}$$

where

n_0 = the sample size,

z = selected critical value of the desired confidence level,

p = estimated proportion of an attribute that is present in the population, '

e = desired level of precision.

To calculate the required sample size with a 95% confidence level and ±5% precision, assuming p=0, the following formula can be used for sample size estimation in a proportion:

$$\text{Sample size} = n_0 = \frac{Z^2 p(1-p)}{e^2} = \frac{(1.96)^2\,(0.5)\,(0.5)}{(0.05)^2} = 384$$

This estimate was used to determine the sample size. Using Cochran's test, the sample size was 384. However, an extra ten per cent was suggested considering the chances of omission and missing responses. Hence, the finalised sample size was 400 participants.

3.4.2 Sampling design

The sampling proportion was determined based on Hospital-Based Cancer Registry (HBCR) reports of tertiary cancer hospitals in Kerala. The tertiary cancer centres were: Regional Cancer Centre (Trivandrum), Malabar Cancer Centre (Kannur), Amrita Institute of Medical Science (Kochi), and MVR Cancer Centre (Kozhikode). The reports for the year 2019 were collected, and an average estimate of the number of breast cancer patients visiting these tertiary cancer centres per annum was obtained. The statistics obtained were as follows:

Table 3.1

Number of female breast cancer cases reported in the year 2019

Tertiary cancer centre	Size of population	Population proportion
Regional Cancer Centre, Trivandrum	1961	50.3
Malabar Cancer centre, Kannur	468	12.1
Amrita Institute of Medical Science, Kochi	455	11.7
MVR Cancer Centre, Kozhikode	974	25.9
Total	3858	100

Source: ICMR

The sample was divided based on the healthcare provider chosen for treatment. The proportion of breast cancer cases reported was higher in government cancer centres than in private cancer centres. The population proportion of government cancer centres to private cancer centres was approximately 62: 38. Hence, of the 400 respondents, 250 were selected from government cancer hospitals, and 150 were selected from private hospitals. The female breast cancer patients were randomly selected from government and private hospitals. Hospitals where complete cancer treatment was available were only selected for the study.

3.4.3 Participant Selection Method

Only female patients who had invasive breast cancer were interviewed. The patients were recruited and interviewed by the primary investigator. The inclusion criteria for the study are:

- These patients had completed standard protocol treatment for breast cancer.
- Female breast cancer patients should be above the age of twenty years and below the age of seventy years.
- The treatment for breast cancer should have been completed at least a year before January 2020.

The exclusion criteria for the study were:

- Stage four breast cancer patients undergoing palliative treatment were exempted from the study.
- Patients who had completed treatment seven years before the interview were excluded from the study.
- Patients whose cancer recurred were excluded from the study.

Patients above 70 years were excluded from the study because they usually do not complete the prescribed treatment protocol. Patients who sought treatment after January 2020 were excluded because of COVID-19. During COVID-19, breast cancer patients incurred additional costs like RT-PCR testing kits, PPE kits and other medical expenses. This would lead to an error while calculating the total cost of treatment. Hence, they were excluded. Recurrence of cancer can occur in any part of the body, and the treatment protocol is different for each. Hence, those patients whose cancer recurred were excluded from the study. Patients who completed breast cancer treatment before seven years at the time of interview were excluded due to recall bias.

3.4.4 Details of Data Collection

Data collection for the study was conducted from March 2021 to January 2022. An interview schedule was prepared in English for academic purposes and in Malayalam to facilitate the responses. A pilot study with the questionnaire was conducted before the actual survey. Twenty female breast cancer patients were selected for the pilot study. After checking the respondents' responses from the pilot study, necessary modifications were made to get a better response.

The researcher faced a few problems during data collection. The researcher had to get prior permission from the ethical board of hospitals selected for the study. It took several weeks of documentation and presentations to convince the concerned officials from the ethical board of hospitals. The researcher also had to spend a lot of time on travel because the distance between hospitals was large.

The researcher had to visit some hospitals numerous times because of the low number of breast cancer patients turning up for their follow-ups. Another problem faced by the researcher was that some respondents were reluctant to share information regarding the distress methods used to fund the cancer treatment. This led to the researcher spending a lot of time explaining the purpose of the study and convincing the respondents. In some cases, the researcher also faced the issue of recall bias. The recall bias was mainly faced while collecting data regarding indirect treatment costs.

3.5 Secondary Data Source

The secondary data for this study was collected from NSSO data, NCRP report and GLOBOCAN report.

3.5.1 NSSO Data

The National Sample Survey (NSS) was established by the Government of India in 1950 to collect socio-economic data using scientific sampling methods. The 75th round of the NSS focused on three key areas: 'Household Consumer Expenditure', 'Household Social Consumption: Health', and 'Household Social Consumption: Education'. This survey was conducted from July 2017 to June 2018, and it covered the entire Indian Union. The survey period was divided into four sub-rounds, each lasting three months, with an equal number of sample villages or blocks (called First Stage Units (FSUs)) assigned to each sub-round to ensure uniform coverage across the year. A total of 1,13,823 households across all districts of India were surveyed during this round. The stratified multi-stage sampling design was employed, where the first stage units (FSUs) were Census villages (or Panchayat wards in Kerala) for rural areas and Urban Frame Survey (UFS) blocks for urban areas. The ultimate stage units (USUs) were the households within each of these FSUs.

The data from 'Household Social Consumption: Health' have only been analysed for the purpose of this study. Apart from the prevalence of diseases, the emphasis of the health survey in the 75th round was on the utilisation of health care services from the public sector and the healthcare expenditures incurred by households in both public and private sectors. This survey ensured a comprehensive, representative sample of households across the country, thus allowing a detailed insight into various socio-economic aspects of Indian households.

3.5.2 National Cancer Registry Programme (NCRP)

The National Cancer Registry Programme (NCRP) introduced cancer registries across India. A cancer registry is a system for collecting, storing, analysing, and reporting data on cancer patients. This helps in understanding cancer trends, identifying prevention strategies, and improving treatment and management. By tracking cancer data over time, it is possible to study long-term trends and the overall burden of the disease in the population.

Cancer registries are an affordable and effective way to track cancer cases compared to other methods like clinical trials. In India, the NCRP was started in December 1981 by the Indian Council of Medical Research (ICMR), and is currently managed by the ICMR-NCDIR. The programme provides important data on cancer rates, causes, and geographical patterns, which helps in creating and evaluating cancer control policies and programs.

There are two main types of cancer registries: i) Population-Based Cancer Registries (PBC₹), which track new cancer cases in a specific population or region, ii) Hospital-Based Cancer Registries (HBC₹), which focus on cancer patients at a particular hospital, gathering information about their treatment and outcomes. The NCRP has also introduced Cancer Atlas, for specific short-term studies. Since its launch, the programme has expanded, and now includes 36 PBC₹ and 236 HBC₹ across India. However, there are still several challenges in cancer registration in the country.

3.5.3 GLOBOCAN

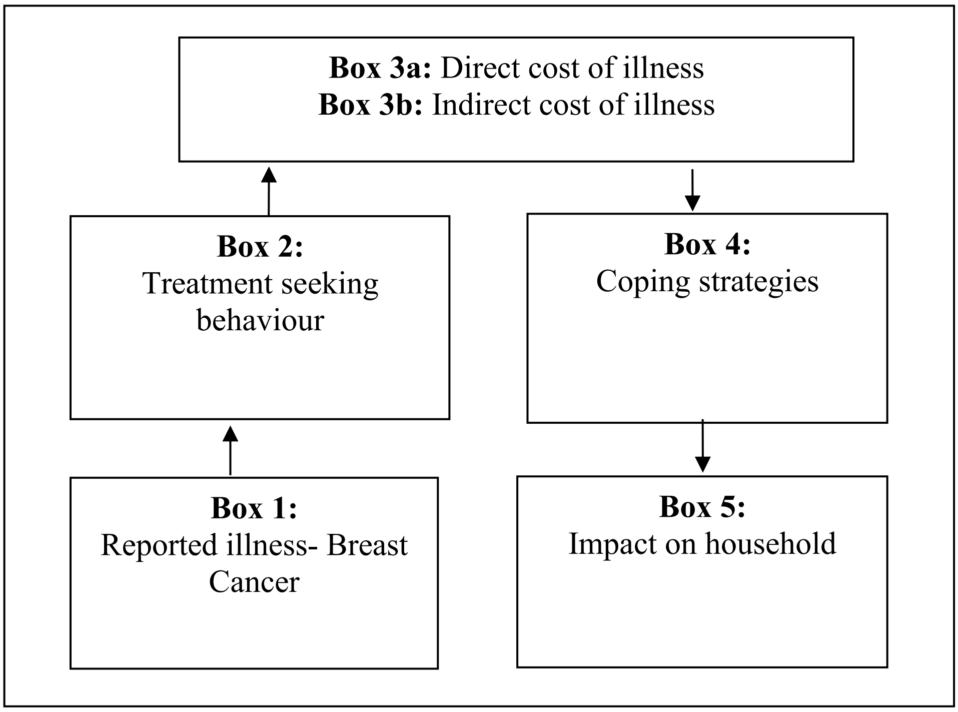
The GLOBOCAN database is released by the International Agency for Research on Cancer (IARC) and the Global Cancer Observatory. The GLOBOCAN 2020 report provides estimates of incidence and mortality in 185 countries for 36 types of cancer and all cancer sites combined for the year 2020. The main aim of the report is to inform cancer control through defined improvements in the coverage, quality, and use of population-based cancer registration data worldwide.

3.6 Conceptual Framework

The conceptual framework for the study is explained through the figure below:

Figure 3.1

Framework for analysis of economic burden of illness



In a household, when a member experiences illness (Box 1), decisions are made about whether to seek medical treatment and where to obtain it (Box 2). The cost associated with the illness is classified into direct costs (Box 3a) and indirect costs (Box 3b). Direct costs include expenses directly related to seeking treatment, such as medical expenses, as well as non-medical expenses like transportation or food.

Indirect costs refer to the loss of household income due to the illness and the time lost from productive labor, both for the patient and their caregivers. The type and severity of the illness (Box 1) and the choice of healthcare provider (Box 2) significantly influence both direct and indirect costs.

he direct and indirect costs when expressed as a percentage of household's income, it is referred to as cost burden. When the cost burden is greater than 10 per cent, it is considered catastrophic, as it can lead to financial strain and even impoverishment. When illness-related expenses exceed the household's available budget, families often resort to coping strategies (Box 4), such as borrowing money or selling assets. These coping mechanisms have long-term consequences on the household's financial stability and asset portfolios (Box 5). Over time, this can lead to the depletion of assets, further indebtedness, and a cycle of impoverishment that is difficult to escape.

3.6.1 Cost of Illness Methodology (COI)

The study uses the cost-of-illness methodology to analyse the economic burden of breast cancer on patients and their households. The main aim of cost of illness studies is to evaluate the economic burden in terms of the consumption of healthcare resources and production losses. In the cost of illness methodology, the cost-generating components are identified, and a monetary value is attributed to them. The COI methodology classifies costs into three categories: direct, indirect, and intangible. Since intangible costs have been associated with measurement difficulties, we mainly focus on direct and indirect costs in this study.

I. Direct costs: According to Hodgson and Meiner (1982), direct costs include both medical and non-medical expenses which are directly related to an illness. Medical expenditures are incurred during diagnosis, treatment, continuing care, rehabilitation, and terminal care. Examples of medical expenses include expenses for treatment, doctor visits, hospital stays, medicines, surgeries outpatient care; and other rehabilitation costs, such as those for prostheses, appliances, etc. In case of many illness, direct costs accounts for a significant part of total costs. Non-medical expenses include costs like transportation, household expenditures, food, lodging and relocating.

Direct cost = Medical cost + Non-medical cost

II. Indirect costs: Due to morbidity and mortality of an illness, individuals and their caregivers can incur productivity losses. This further leads to job absenteeism and loss of earnings. Additionally, they may also incur costs for the time a patient and their caregiver spends visiting healthcare professionals and seeking healthcare services. An illness can also result in unwanted job changes and loss of promotional opportunities (Hodgson & Meiner,1982).

The Cost of Illness (COI) methodology helps to estimate the socio-economic losses caused by diseases. This method is widely used to understand how much illness costs society as a whole. The economic burden can be assessed by using the cost of illness methodology. The total economic burden of a disease can help decision-makers in healthcare to make more informed choices about how to allocate resources. This can lead to better management of healthcare systems and improved public health outcomes.

3.6.2 Out-of-pocket Expenditures and Catastrophic Health Expenditure

The impact of the economic burden of cancer is analysed through out-of-pocket expenditures (OOPE) and catastrophic health expenditures (CHE). Out-of-pocket payments are expenditures borne directly by a patient where insurance does not cover the total cost of the health good or service. This includes consultant charges, charges for diagnostic tests, the amount spent on medicines and medical consumables, charges during a stay at the hospital, food, accommodation, and transportation charges. World Health Organization proposes that health expenditure should be called catastrophic whenever it is greater than or equal to 40 per cent of the capacity to pay (Xu et al., 2003). Other studies have defined Catastrophic Health Expenditure as the total health expenditure of more than 10 per cent of annual income (Timothy (2007), Gotsadze et al., (2009)).

For the purpose of this study, the OOPE and CHE are calculated according to the following method:

- OOPE= (Total direct medical costs incurred during diagnosis+ Total direct medical costs incurred during treatment+ Total direct non-medical costs incurred during treatment) - (Amount of money received through employee benefit scheme+ Amount of money received through government health scheme+ Amount of money received through private health insurance)
- CHE is present if the sum of total direct medical costs incurred during diagnosis and treatment and total non-medical costs incurred during treatment is higher than 10 per cent of the annual income of the patient's household.

3.6.3 Adjustment of Costs for Inflation

This study takes into account the costs incurred by breast cancer patients between 2013 and 2019. Since the healthcare sector experienced inflation, the estimates of different costs obtained from respondents have been adjusted. The adjustment is based on the inflation rates obtained from the consumer price index. The costs are adjusted to the prices of healthcare and other services in 2019.

A Consumer Price Index (CPI) is designed to measure the changes over time in the general level of retail prices of selected goods and services that households purchase for consumption. The data is collected by the Central Statistics Office (CSO) in India. The new consumer price index series for rural and urban areas is calculated using the base year 2012. For the purpose of this study, the inflation rate in two sectors is taken into account: health and food and beverages. The costs obtained from respondents have been adjusted using the inflation rates obtained from the table below. The method for adjusting the costs is as follows:

Adjusted costs= C*I + C

Where C=Cost incurred by respondents in the year, I= the inflation rate.

Table 3.2

Inflation rate for food and beverages and health from 2013 to 2019

Year	Food and beverages (Index: 2012=100)	Inflation rate for food and beverages (Reference year=2019)	Health (Index:2012=100)	Inflation rate for health (Reference year=2019)
2013	116.283	39.6 %	106.042	41.7 %
2014	128.808	26 %	111.450	34.8 %
2015	134.967	20.3 %	117.458	27.9 %
2016	139.733	16.2 %	121.608	23.5 %
2017	150.608	7.8 %	124.625	20.5 %
2018	155.275	4.6 %	133.633	11 %
2019	162.425	-	150.275	-

Source: Ministry of Statistics and Programme Implementation, India

3.7 Tools of Analysis

Statistical tools were used to analyse the primary data. The primary data was used to assess the direct and indirect costs associated with breast cancer treatment. The total cost across different stages of breast cancer was calculated, and the economic burden was determined. The chi-square test, ANOVA test and KH test were used to test the statistically significant differences when comparing the different groups of costs incurred. Graphs, charts and Box-Jenkins plots were used to present the distribution of data. Multivariate regression was used to analyse the determinants of total medical cost of treatment and out-of-pocket expenditures. Multinominal logistic regression was used to predict whether the breast cancer patient and their household faced financial hardship due to the treatment of breast cancer. Excel and SPSS were applied for statistical analysis.

3.8 Cancer-stage Profile of the Sample

The respondents were categorised based on their breast cancer stage. In invasive breast cancer, the cancer cells can grow into surrounding tissues. The American Joint Committee on Cancer (AJCC) created a staging method to determine how much cancer is present in the body, where it is located, and what subtype is present.

Staging is needed to make treatment decisions. The most common method of staging is the TNM method. The tumour, node, metastasis (TNM) system is used to stage breast cancer. In this system, the letters T, N, and M describe different areas of cancer growth. These are as follows:

- T (tumour) - Size of the main (primary) tumour
- N (node) - If cancer has spread to nearby (regional) lymph nodes
- M (metastasis) - If cancer has spread to distant parts of the body or metastasised

Table 3.3

TNM staging of breast cancer

Stage IA	• T1, N0, M0
Stage IB	• T0, N1mi, M0 • T1, N1mi, M0
Stage IIA	• T0, N1, M0 • T1, N1, M0 • T2, N0, M0
Stage IIB	• T2, N1, M0 • T3, N0, M0
Stage IIIA	• T2, N2, M0 • T3, N1, M0 • T3, N2, M0
Stage IIIB	• T4, N0, M0 • T4, N1, M0 • T4, N2, M0
Stage IIIC	• Any T, N3, M0

Source: NCCN Guidelines (2022)

3.9 Treatment Protocols for Breast Cancer

The stage of breast cancer is an important factor in making decisions regarding treatment protocol. There are two types of breast cancer treatment- local therapy and systemic therapy. Local treatments for breast cancer include surgery and radiation. They are local, meaning they treat the tumour without affecting the rest of the body.

In systemic treatments of breast cancer, drugs are used because they can reach cancer cells almost anywhere in the body. Some drugs can be given by mouth, injected into a muscle, or put directly into the bloodstream. Depending on the type of breast cancer, different types of drug treatment might be used. These include chemotherapy, hormone therapy, and targeted drugs. The types of drugs that might work best for a patient depend on the tumour's hormone receptor status, HER2 status, and other factors.

Surgery is a part of treatment for most women diagnosed with breast cancer. There are two main types of surgery to remove breast cancer: breast-conserving surgery (BCS) and mastectomy. Breast-conserving surgery is surgery to remove the cancer as well as some surrounding normal tissue. Only the part of the breast containing the cancer is removed. Mastectomy is a surgery in which the entire breast is removed, including all of the breast tissue and sometimes other nearby tissues. Lymph nodes may be removed as part of the surgery to remove the breast cancer in order to figure out the stage of the cancer. The two main types are sentinel lymph node biopsy (SLNB) and axillary lymph node dissection (ALND).

Radiation therapy is treatment with high-energy rays (or particles) that destroy cancer cells. Depending on the stage of breast cancer, radiation will be given in addition to other treatments. The main types of radiation therapy that can be used to treat breast cancer are external beam radiation therapy (EBRT) and brachytherapy. EBRT is the most common type of radiation therapy for women with breast cancer. In this treatment, a machine outside the body focuses the radiation on the area affected by the cancer. EBRT can be of types: whole breast radiation and accelerated partial breast irradiation. Brachytherapy, also known as internal radiation, is another way to deliver radiation therapy. Instead of aiming radiation beams from outside the body, a device containing radioactive seeds or pellets is placed into the breast tissue for a short time in the area where the cancer had been removed through surgery. The two types of brachytherapy are intracavitary brachytherapy and interstitial brachytherapy.

Chemotherapy (chemo) uses anti-cancer drugs that may be given intravenously (injected into your vein) or by mouth. The drugs travel through the bloodstream to reach cancer cells in most parts of the body. Chemotherapy may be given after surgery (known as adjuvant chemotherapy) or before surgery (known as neo-adjuvant chemotherapy).

Adjuvant chemotherapy might be given to try to kill any cancer cells that might have been left behind or have spread but cannot be seen in imaging tests. Neoadjuvant chemo might be given to try to shrink the tumour so it can be removed with less extensive surgery. In most cases, chemotherapy has the greatest effect when more than one drug is used at a time. Often, combinations of two or three drugs are used. Chemo is given in cycles, followed by a rest period to give you time to recover from the effects of the drugs. The schedule varies depending on the drugs used. Adjuvant and neoadjuvant chemo are often given for a total of 3 to 6 months, depending on the drugs used.

Targeted drug therapy uses medicines directed at (target) proteins in breast cancer cells that help them grow, spread, and live longer. Targeted drugs work to destroy cancer cells or slow down their growth. They can be given in the vein (IV), as an injection under the skin, or as a pill. The drugs for HER2-positive breast cancers are monoclonal antibodies, like Trastuzumab, and kinase inhibitors. For hormone receptor-positive breast cancer, drugs like CDK4/6 inhibitors, mTOR inhibitors and PI3K inhibitors are given. Women with *BRCA* gene mutations are given PARP inhibitors like Olaparib and talazoparib. In triple-negative breast cancer (TNBC), an antibody-drug conjugate (ADC) is given.

Hormone therapy is a treatment that prevents hormones like estrogen and progesterone, from attaching to receptors on breast cancer cells. It is recommended for women who have tumours that are hormone receptor-positive. Hormone therapy is often used after surgery to help reduce the risk of the cancer coming back. Hormone therapy drugs that block estrogen receptors are Tamoxifen, Toremifene and Fulvestrant. Hormone therapy drugs that lower estrogen levels are aromatase inhibitors (AIs) and ovarian suppression. Tamoxifen is usually taken after surgery for at least five years and up to 10 years. Aromatase inhibitors are either given alone or after tamoxifen.

According to NCCN Guidelines (2022) for breast cancer, The American Cancer Society has formulated the following treatment protocol:

I. Stage I breast cancer: These breast cancers are still relatively small and either have not spread to the lymph nodes or have spread to only a tiny area in the sentinel lymph node.

- Local therapy: Surgery is the primary treatment for stage I breast cancer. These cancers can be treated with either breast-conserving surgery (BCS)or mastectomy. If BCS is done, radiation therapy is usually given after surgery to lower the chance of the cancer coming back into the breast and also to help people live longer.

- Systemic treatment: If a woman has hormone receptor-positive (ER-positive or PR-positive) breast cancer, most doctors will recommend hormone therapy as an adjuvant (after surgery) treatment, no matter how small the tumour is. Some doctors may suggest chemo for smaller tumours as well, especially if they have any unfavourable features. After surgery, some women with HER2-positive cancers will be treated with trastuzumab (with or without pertuzumab) for up to 1 year.

II. Stage II breast cancers: These breast cancers are larger than stage I cancers and have spread to a few nearby lymph nodes.

- Local therapy: Stage II cancers are treated with either breast-conserving surgery (BCS) or mastectomy. Women who have BCS are treated with radiation therapy after surgery. Women who have a mastectomy are typically treated with radiation if the cancer is found in the lymph nodes.

- Systemic therapy: It is recommended for some women with stage II breast cancer. Some systemic therapies are given before surgery (neoadjuvant therapy), and others are given after surgery (adjuvant therapy). Neoadjuvant treatments are a good option for women with large tumours and women with triple-negative breast cancer (TNBC) or HER2-positive breast cancer.

III. Stage III breast cancer: In these breast cancers, the tumour is large (more than 5 cm or about 2 inches across) or growing into nearby tissues (the skin over the breast or the muscle underneath), or the cancer has spread to many nearby lymph nodes. There are two main approaches to treating stage III breast cancer:

- Starting with neoadjuvant therapy: Most often, these cancers are treated with neoadjuvant (before surgery) chemotherapy. This may shrink the tumour enough for a woman to have breast-conserving surgery (BCS) or a mastectomy is done. Often, radiation therapy is needed after surgery. For some, additional chemo is given after surgery as well. After surgery, some women with HER2-positive or, ER-positive or PR-positive cancers will be treated with trastuzumab (with or without pertuzumab) for up to a year. Women are also given adjuvant hormone therapy.

- Starting with surgery: Surgery first is an option for some women with stage III cancers. Surgery is usually followed by adjuvant chemotherapy, hormone therapy, targeted drug therapy, and HER2-positive treatment (trastuzumab, pertuzumab, or neratinib), depending on the traits of the cancer cells. Radiation is recommended after surgery.

In this section, all the treatment protocols taken by the selected respondents are analysed. For the purpose of this study, the following codes are used to analyse the treatment protocols:

- S: Surgery
- CT: Adjuvant chemotherapy

- RT: Radiation therapy
- NACT: Neo-adjuvant chemotherapy
- TT: Targeted therapy

3.10 Health and Insurance Schemes

After the economic liberalisation in 1991, the government of India opened the health insurance sector to private sector participation. This development opened the possibility for higher-income groups to access quality care from private tertiary care facilities. This was expected to provide financial risk protection to a relatively small segment of society. However, it resulted in cost escalation and inequity in health financing patterns.

The delivery of affordable cancer care is one of the biggest global health challenges. In India, though there are several health and insurance schemes implemented by central and state governments, there have been substantial differences between spending on health across individual states and union territories and the gaps in basic health indicators and outcomes. Access to health and insurance schemes for cancer care reduces the financial burden faced by households. The analysis of the effect of health and insurance schemes on the cost of breast cancer treatment is divided into three sections: employee benefit schemes, government health schemes and health insurance schemes.

3.10.1 Government Health Schemes Availed During Breast Cancer Treatment

The Government of India and State Governments have implemented schemes to assist underprivileged cancer patients. These schemes reduce the financial burden of breast cancer treatment. Though there are several government schemes, only eight schemes have been analysed for the purpose of this study. The schemes included are as follows:

a. Karunya Benevolent Fund (Government of Kerala): Patients whose annual income is less than ₹.3,00,000/—are eligible for this scheme. The patient has to apply in a particular form. A family is eligible for ₹. 2,00,000/-. The application form has to be submitted to the concerned district lottery office.

b. Sukrutham (Government of Kerala): This scheme is open to all BPL ration card holders in Kerala. A confirmed diagnosis of cancer is required to be included in the scheme. Patients who are receiving pay wards are not eligible for this scheme. The maximum benefit is ₹.3,00,000.

c. CHIS PLUS (Government of Kerala): The health card must be produced. If the patient belongs to the BPL category, he or she is eligible for a maximum of ₹.70,000/—cashless treatment or whatever amount is left in the credit.

d. Ayushman Bharat - Pradhan Mantri Jan Arogya Yojana (AB-PMJAY): PM-JAY is intended for low-income persons, viz. poor, deprived rural families and urban workers' families of specified occupations. This scheme is the largest health assurance scheme in the world, and it aims to provide health coverage of ₹. 5 lakhs per family per year for secondary and tertiary care hospitalisation. PM-JAY provides cashless access to health care services for the beneficiary at the point of service, that is, the hospital.

Other government schemes which are available in Kerala are:

i. Cancer Suraksha Scheme (Government of Kerala): Cancer patients up to the age of 18 in the BPL/APL groups are eligible to participate in this scheme and can avail of free treatment. This scheme will cover all expenditures for investigations and treatment. This scheme is available only to patients from Kerala.

ii. Thaalolam (Government of Kerala): Children below 18 years of age are eligible. This scheme applies to patients who are too poor to afford treatment, irrespective of the BPL/APL category. Maximum assistance given

under this scheme is ₹.1,00,000 for diseases other than cancer which are lethal or fatal.

iii. Snehasanthwanam for Endosulfan Victims (Government of Kerala): The victims have to produce their Endosulfan Smart Card to avail of free treatment under this scheme.

iv. Comprehensive Health Care Programme for Scheduled Tribes (Government of Kerala): Tribal patients are eligible for complete free treatment, including food and travelling expenses for themselves. One day, an APL patient is eligible for treatment worth ₹. 10,000 and a BPL patient for ₹.50,000.

v. Financial aid from the Society for the Poor (Government of Kerala): Cancer patients from low socio-economic backgrounds are helped by paying ₹.50,000 for their treatment. The amount is fixed on the basis of expenditure already incurred by the patient.

vi. Prime Minister's National Relief Fund (PMNRF): PMNRF provides financial aid to patients of low socio-economic status for treatment.

vii. Rashtriya Arogya Nidhi (RAN)(under Health Ministers' Cancer Patient Fund): This scheme provides financial aid for specific investigations and treatments. The eligible amount for one patient is ₹.2,00,000. The government of India has provided a scale for each state, including rural and urban areas. The amount can be utilised only for surgery, chemotherapy medicines, radiology scans and in-patient care.

3.10.2 Employee Benefit Schemes Received During Breast Cancer Treatment

Employee benefit schemes refer to schemes that are offered and sponsored by employers. These schemes are either mandated by laws or are provided voluntarily by employers. In India, the various employee-benefit schemes offered are classified as follows:

- Mandatory employee benefits in India include the Employees' Provident Fund, which includes the Employees' Pension Fund and Employees' Deposit Linked Insurance; the Employees' State Insurance Scheme; statutory leaves; gratuity; and Maternity Leave.

- Supplementary employee benefits include medical, accident, life, retirement, business travel insurance, and, increasingly, EAP.

- Common employee perks include vehicle or transport allowance, meal vouchers, or subsidised cafeteria.

For the purpose of this study, four schemes were observed during data collection. Only those schemes have been included in this study. The schemes included are as follows:

a) The Employees' State Insurance Scheme (ESI) is an integrated measure of Social Insurance included in the Employees' State Insurance Act. It protects employees during sickness, maternity, disablement, and death due to employment injury. It provides medical care to insured persons as well as their families. Both employers and employees contribute to the ESI scheme. The rate of contribution by employer is 4.75 per cent of the wages payable to employees. The employees' contribution is at the rate of 1.75 per cent of the wages payable to an employee. Employees earning less than ₹. 137/- a day as daily wages are exempted from payment of their share of contribution. (National Portal of India).

b) Indian Railway employee benefits scheme: All employees of Indian Railways, their family members and dependent relatives can avail to this scheme. There is an an extensive network of hospitals, clinics, and recognised private hospitals under this scheme. The railway medical authority refers an employee or their families to the hospital. These expenses are then reimbursed on the production of bills.

c) Central Government Health Scheme: Under this scheme, comprehensive medical care is provided to the Central Government employees and pensioners enrolled under the scheme. This scheme caters to the healthcare needs of eligible beneficiaries. Cashless facilities are available for treatment in empanelled hospitals and diagnostic centres for pensioners and other identified beneficiaries, and reimbursement of expenses for specialised treatment is available in other government and private hospitals.

d) Employees Provident Fund: The Employees' Provident Fund Organisation (EPFO) is a non-constitutional body that promotes employees to save funds for retirement. The contributions are made by the employee, employer, and the government (in some cases). The withdrawal from the Provident Fund is allowed only after retirement. In case of medical treatment purposes, early withdrawal is allowed.

3.10.3 Private Health Insurance Schemes Availed During Breast Cancer Treatment

The Indian healthcare system is characterised by high rates of privatisation, high out-of-pocket expenditures, and a lack of availability of social health insurance schemes. Health insurance refers to a plan that covers or shares the expenses associated with health care. These plans fall into commercial health insurance provided by government, private and stand-alone health insurance companies. In India, there has been significant growth in health insurance due to the rise in the middle class, higher hospitalisation costs, expensive health care, digitisation and increased awareness level. (Dutta,2020).

In 2000, the Government of India liberalised insurance and allowed private players into the insurance sector. The advent of private insurers in India saw the introduction of many innovative products like family floater plans, critical illness plans, hospital cash and top-up policies. This development threw open the possibility for higher income groups to access quality care from private tertiary care facilities.

Kumar (2009) examined the role of insurance in financing health care in India. It was found that insurance can be an essential means of mobilising resources and providing risk protection and health insurance facilities. However, for this to happen, systemic reforms will be required in this sector from the end of the government of India. Yadav and Sudhakar (2017) studied personal factors influencing purchase decisions of health insurance policies in India. It was found that factors such as awareness, tax benefits, financial security and risk coverage have a significant influence on the purchase decision of health insurance policyholders.

In India, there are many schemes offered by private insurance companies. The most common form of private health insurance policy in India covers the expenses incurred on hospitalisation, depending on the insured's need and choice. The health insurer usually provides either direct payment to the hospital (cashless facility) or reimburses the expenses associated with illnesses and injuries or disburses a fixed benefit on the occurrence of an illness. The type and amount of health care costs that will be covered by the health plan are specified in advance.

3.11 Government Expenditure on Cancer Care in Kerala

The governments of the state of Kerala have always focused on and invested in social sectors like education and health. In terms of the performance of healthcare indicators, Kerala has always been ahead of the rest of the country. The 'Kerala model' of development concentrated on ensuring the availability and accessibility of a dominant and wide network of government healthcare facilities to the population. In the 1980s, a demographic and epidemiological transition was observed in the state, which resulted in a rise in non-communicable disease burden and increased demand and quality of health care. A high prevalence of morbidity was reported in the state despite the low mortality rates.

By the 1990s, the private sector had overtaken the public health sector in terms of growth in terms of the number of facilities, beds, and quality. The high demand for health care, along with the high utilisation of the private healthcare sector, has led to higher out-of-pocket expenditure in Kerala (Health Dossier- Kerala,2021).

Most developed nations spend 6-8 per cent of their GDP (gross domestic product) on health. According to a recent project 'Strengthening Ecosystem for Sustainable and Inclusive Health Financing in India (SESSIHFI), by the Public Health Foundation of India: Kerala Health Accounts 2013-14, the total current expenditure on health in the state of Kerala was estimated to be ₹ 24699 crores, which is 6.2 per cent of the state's domestic product (GSDP). Of this amount, households contributed 76 per cent of the expenditure, enterprises and NGOs contributed 3.4 per cent, social health insurance pools contributed 1.1 per cent, and voluntary insurance contributed 1.34 per cent. The government contribution to this expenditure was only 19.5 per cent, which indicated that the government expenditure on health is less than 1.5 per cent of the GSDP.

The Kerala Government's 15th Five-Year Plan (2022-2027) allocates ₹2,02,496 lakh for health services, with ₹1,29,776 lakh from the state and ₹72,720 lakh from central schemes. For the year 2022-2023, Kerala's budget includes:

- ₹484.8 crore for the National Health Mission and ₹10 crore for the National Ayurvedic Mission.
- ₹250.7 crore for medical colleges and ₹500 crore for the Karunya Arogya Suraksha Padhathi health scheme.
- ₹30 crore for the Kerala Digital Health Mission, promoting e-health.

The budget also prioritizes cancer care, with ₹250 crore allocated for cancer programs, including a new state cancer control strategy with community participation. Major cancer centres like the Regional Cancer Centre, Malabar Cancer Centre, and Cochin Cancer Research Centre received a combined ₹123.5 crore for development and upgrades. To reduce travel and costs for cancer patients, the government trains local healthcare providers to administer chemotherapy in 12 districts. More than 15,000 chemotherapy treatments have been given, and over 1,000 new cancer cases were detected. Additionally, the government has allocated ₹5 crore for palliative care centers and volunteer training.

The budget also includes ₹500 crore for health insurance schemes like the Pradhan Mantri Jan Arogya Yojana (PM-JAY) and Karunya Scheme, aiming to cover 41.59 lakh families, including those previously uninsured. The goal is to reduce health-related financial burdens, particularly for low-income families.

3.12 Definitions, Statistical Terms and Methods

1) Economic burden: This refers to the financial impact of a disease on individuals, households, and society. The most common methodology for measuring the economic burden is the cost-of-illness (COI) methodology.

2) Direct cost: It refers to the medical and non-medical expenditures arising during cancer care.

3) Direct medical cost refers to the medical expenditures arising during diagnosis, treatment, rehabilitation and terminal care. These are costs which are incurred within the healthcare sector. It includes costs related to hospitalisation, outpatient and inpatient clinical services, drugs and rehabilitation.

4) Direct non-medical cost: It refers to costs that arise during the consumption of resources like transportation, lodging, food, relocating and loss of assets.

5) Indirect cost: It refers to the cost which the patient incurs due to output loss, i.e., a decrease in productivity arising from morbidity and mortality. The other components of indirect costs are time lost by the caregiver by accompanying the patient to hospitals, time lost by the caregiver from work, unwanted job changes and loss of opportunities in promotion or education due to illness.

6) Cost-of-illness analysis: In this methodology, the cost-generating components of illness are identified, measured, valued, and compared.

7) Distress financing: It refers to borrowing money or selling assets to meet the out-of-pocket expenditures to the healthcare sector.

8) Coping mechanisms: These refer to the strategies used by the patient and their family to avert the financial hardship associated with the economic burden of illness on households.

9) Out-of-pocket payments: These refer to the expenses that the patient or the family pays directly towards the healthcare sector, without reimbursement from the insurer or aid from the government and other sources.

10) Catastrophic health expenditure: If the total health expenditure is more than 10 per cent of annual income/ capacity to pay.

11) Financial hardship: It refers to the inability to meet basic living expenses for goods and services necessary for the survival of the cancer patient and their households.

12) Household: For the purpose of this study, a household is defined as a small group of persons who share the same living accommodation, pool some or all of their income and wealth, and consume certain types of goods and services collectively, mainly housing and food.

13) Cancer Registration: It is defined as the process of continuing, systematic collection of data on the occurrence and characteristics of reportable neoplasms to help assess and control the impact of malignancies on the community.

14) Cancer Case refers to all neoplasms with a behaviour code of '3' as defined by the International Classification of Diseases - Oncology, Third edition (ICD-O-3). These are considered reportable and registered in NCRP.

15) Cancer Registry is the office or institution which attempts to collect, store, analyse and interpret data on persons with cancer.

16) Population-based Cancer registries (PBC₹) systematically collect information on reportable neoplasms from multiple sources in a geographically defined population residing in the area for a period of one year.

17) Hospital-based Cancer Registers (HBC₹) record information on the treatment, management, and outcome of cancer patients registered in a particular hospital.

18) Incidence rate of cancer: It refers to the number of new cases occurring in a specified period and geographic area, conveyed either as an absolute number of cases per annum or as a rate per 100,000 persons per year.

19) Mortality rate of cancer: It refers to the number of deaths occurring in a specified region and period, and the mortality rate is the number of deaths per 100,000 persons per year.

20) The Crude Incidence Rate (CR) refers to the rate obtained by dividing the total number of cancer cases by the corresponding estimated population (mid-year) and multiplying by 100,000. Cancer rates are always expressed per 100,000 population.

21) The Age-Specific Rate (ASR) refers to the rate obtained by dividing the total number of cancer cases by the corresponding estimated population in that age group and gender/ site/geographic area/time period and multiplying by 100,000.

22) Age-adjusted or Age-Standardized Rate (AAR) Cancer incidence increases as age increases. The adjusted or Age-Standardized Rate (AAR) is obtained by applying the age-specific rates to the standard population in that age group (Boyle and Parkin, 1991).

23) Truncated Age-Adjusted Incidence Rate (TR) - This is similar to the age-adjusted rate except that it is calculated for the truncated age group 35-64 years of age.

24) Sex Ratio describes the number of females per 1000 males.

25) M/I Ratio: Per cent is obtained by dividing the mortality count by the incidence count in a given year.

CHAPTER IV

INCIDENCE OF CANCER AT GLOBAL AND NATIONAL LEVEL

4.1. Introduction

The incidence of cancer has been rapidly increasing over the past few decades, and it has been ranked as one of the leading causes of death in several countries. According to estimates from the World Health Organization (WHO) in 2019, cancer is the first or second leading cause of death before the age of 70 years in 112 of 183 countries and ranks third or fourth in a further twenty-three countries. The main reasons for the increased incidence of cancer and mortality are changes in the prevalence and distribution of risk factors, socio-economic development of the countries, ageing and growth of the populations (Gersten & Wilmoth, 1951). In developing countries, cancer transitions along with increased magnitude are occurring parallelly with changing profiles of common cancer types. Geographical diversity has been observed in the incidence of cancers in different countries.

4.2. Incidence of Cancer Globally

The GLOBOCAN report compiled by the Global Cancer Observatory (GCO)has cancer statistics and a database for 185 countries and 36 cancers by age and sex. According to the GLOBOCAN 2020 report, the estimated cancer statistics were 19.3 million new cases and 10 million cancer deaths worldwide in 2020. It was estimated that an individual has a 20 per cent risk of getting cancer in a lifetime (before the age of 75) and a ten per cent risk of dying from cancer; one in five persons will get cancer in their lifetimes, and one in 10 will die from the disease.[3] In Asia, where 59.5 per cent of the world's population resides, 50 per cent of the total cancer cases and 58.3 per cent of total cancer deaths occurred in the year 2020. Europe accounts for 22.8 per cent of the total cancer cases and 19.6 per cent of cancer deaths, followed by the Americas' which accounts for 20.9 per cent of incidence and 14.2 per cent of mortality worldwide. The share of cancer incidence is lower compared to the share of cancer deaths in Asia and Africa because of the different distribution of cancer types and higher case fatality rates in these regions. (GLOBOCAN, 2020)

The incidence rates of cancer increased with increasing levels of HDI. In low HDI countries, the cancer incidence rates ranged from 104.3 and 128.0 per 100,000 for men and women, respectively. In high HDI countries, a higher incidence rate was observed, ranging from 335.3 and 267.6 per 100,000 for men and women, respectively (Sung et al, 2020). Among men, the mortality rates in high-HDI countries were two-fold higher compared to low-HDI countries. There existed to be less variation in the mortality rates for women across different HDI levels. An observation that has been recurring is the displacement of infection-related and poverty-related cancers by those cancers that are already highly frequent in high HDI countries.

Table 4.1

New cases, death, and five-year prevalence by cancer site in 2020

	New cases				Deaths				5-year prevalence (all ages)	
Cancer	**Number**	**Rank**	**per cent (%)**	**Cum. risk**	**Number**	**Rank**	**per cent (%)**	**Cum. risk**	**Number**	**Prop. per 100000**
Breast	2261419	1	11.7	5.20	684996	4	6.9	1.49	7790717	201.58
Lung	2206771	2	11.4	2.74	1796144	1	18.0	2.18	2604791	33.42
Prostate	1414259	3	7.3	3.86	375304	8	3.8	0.63	4956901	126.13
Colon	1148515	4	6.0	1.30	576858	5	5.8	0.55	3045225	39.07
Stomach	1089103	5	5.6	1.31	768793	3	7.7	0.90	1805968	23.17
Liver	905677	6	4.7	1.11	830180	2	8.3	1.01	994539	12.76
Rectum	732210	7	3.8	0.91	339022	10	3.4	0.37	2066732	26.51
Cervix uteri	604127	8	3.1	1.39	341831	9	3.4	0.82	1495211	38.69
Oesophagus	604100	9	3.1	0.78	544076	6	5.5	0.68	666388	8.55
Thyroid	586202	10	3.0	0.68	43646	25	0.44	0.05	1984927	25.46
Bladder	573278	11	3.0	0.64	212536	14	2.1	0.18	1720625	22.07
Non-Hodgkin lymphoma	544352	12	2.8	0.62	259793	12	2.6	0.27	1544488	19.81
Pancreas	495773	13	2.6	0.55	466003	7	4.7	0.51	379958	4.87
Leukaemia	474519	14	2.5	0.50	311594	11	3.1	0.32	1340506	17.20

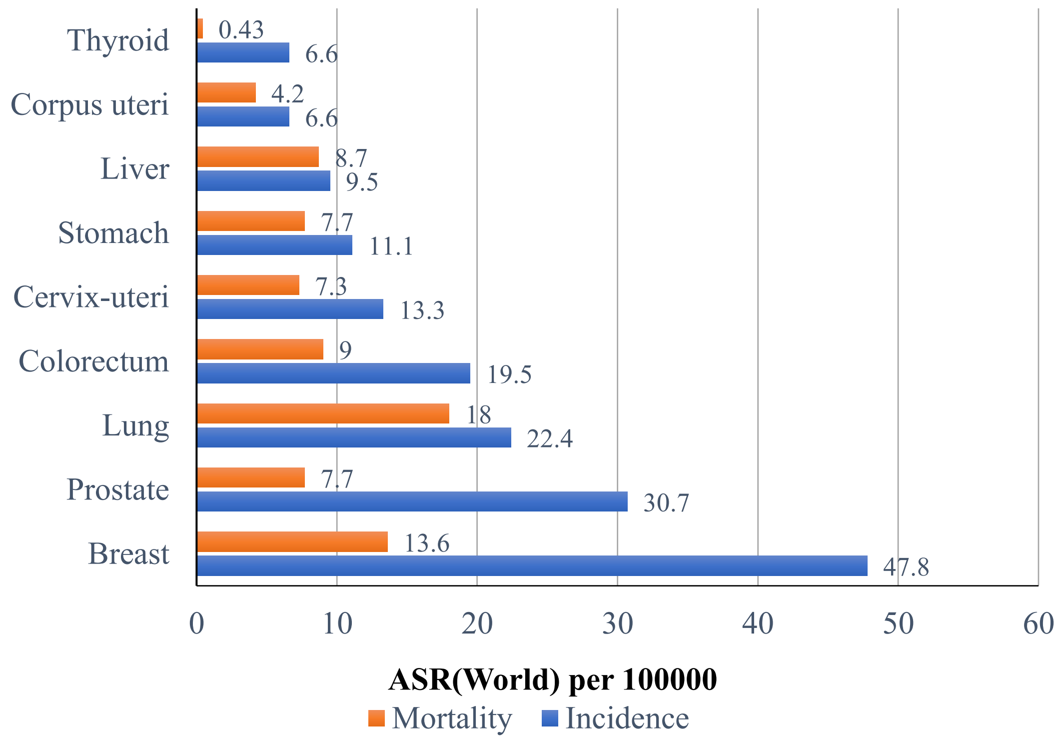
Kidney	431288	15	2.2	0.52	179368	16	1.8	0.20	1207547	15.49
Corpus uteri	417367	16	2.2	1.05	97370	20	0.98	0.22	1415213	36.62
Lip, oral cavity	377713	17	2.0	0.46	177757	17	1.8	0.22	959248	12.31
Melanoma of skin	324635	18	1.7	0.37	57043	23	0.57	0.06	1092818	14.02
Ovary	313959	19	1.6	0.73	207252	15	2.1	0.49	823315	21.30
Brain, CNS	308102	20	1.6	0.35	251329	13	2.5	0.30	837152	10.74
Larynx	184615	21	0.96	0.25	99840	19	1.0	0.13	518380	6.65
Multiple myeloma	176404	22	0.91	0.21	117077	18	1.2	0.13	450579	5.78
Nasopharynx	133354	23	0.69	0.16	80008	22	0.80	0.10	382507	4.91
Gallbladder	115949	24	0.60	0.13	84695	21	0.85	0.09	137466	1.76
Oropharynx	98412	25	0.51	0.13	48143	24	0.48	0.06	258543	3.32
Hypopharynx	84254	26	0.44	0.11	38599	26	0.39	0.05	132717	1.70
Hodgkin lymphoma	83087	27	0.43	0.09	23376	28	0.23	0.02	281112	3.61
Testis	74458	28	0.39	0.14	9334	34	0.09	0.02	296686	7.55
Salivary glands	53583	29	0.28	0.06	22778	29	0.23	0.03	160292	2.06
Anus	50865	30	0.26	0.06	19293	30	0.19	0.02	141378	1.81
Vulva	45240	31	0.23	0.09	17427	31	0.18	0.03	135892	3.52
Penis	36068	32	0.19	0.09	13211	33	0.13	0.03	102157	2.60
Kaposi sarcoma	34270	33	0.18	0.03	15086	32	0.15	0.01	82033	1.05
Mesothelioma	30870	34	0.16	0.03	26278	27	0.26	0.03	37047	0.48
Vagina	17908	35	0.09	0.04	7995	35	0.08	0.02	44613	1.15
All cancer sites	19292789	-	-	20.44	9958133	-	-	10.65	50550287	648.5

Source: GLOBOCAN 2020, The Global Cancer Observatory

From Table 4.1, it can be observed that female breast cancer is the most commonly diagnosed cancer, representing 11.7 per cent of the total new cancer cases. Lung cancer is second (11.4 per cent), followed by prostate (7.3 per cent), colon (6. per cent) and stomach (5.6 per cent). The lowest incidence was observed for vaginal cancer (0.09 per cent), followed by mesothelioma (0.16 per cent) and Kaposi sarcoma (0.18 per cent). In the case of mortality from cancer, lung cancer is the leading cause, representing 18.0 per cent of total cancer deaths. This is followed by liver (8.3 per cent), stomach (7.7 per cent), breast (6.9 per cent) and colon (5.8 per cent). The lowest mortality was observed for vaginal cancer (0.08per cent), followed by testicular cancer (0.09per cent) and penile cancer (0.13per cent). The five-year prevalence rates for breast cancer were the highest (201.58 per 100000 of the population), followed by prostate (126.13), cervix-uteri (39.07), colon (38.69) and lung (33.42).

Figure 4.1

Age-standardized (world) incidence and mortality rates of top 10 cancers



Source: GLOBOCAN 2020, The Global Cancer Observatory

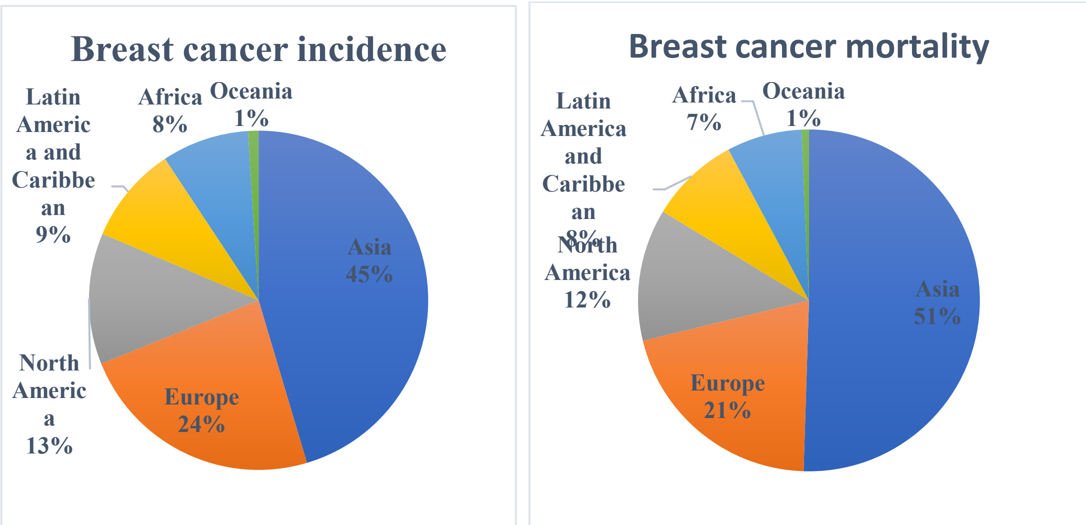
The age-standardised world incidence and mortality rates of the top ten cancers are represented in Figure 4.1. It can be observed that breast cancer has the highest incidence rate (47.8 per 100000), followed by prostate (30.7 per 100000) and lung (22.4 per 10000). The highest mortality rate was observed in lung cancer (18 per 100000), followed by breast (13.6 per 100000) and colorectum (9 per 100000).

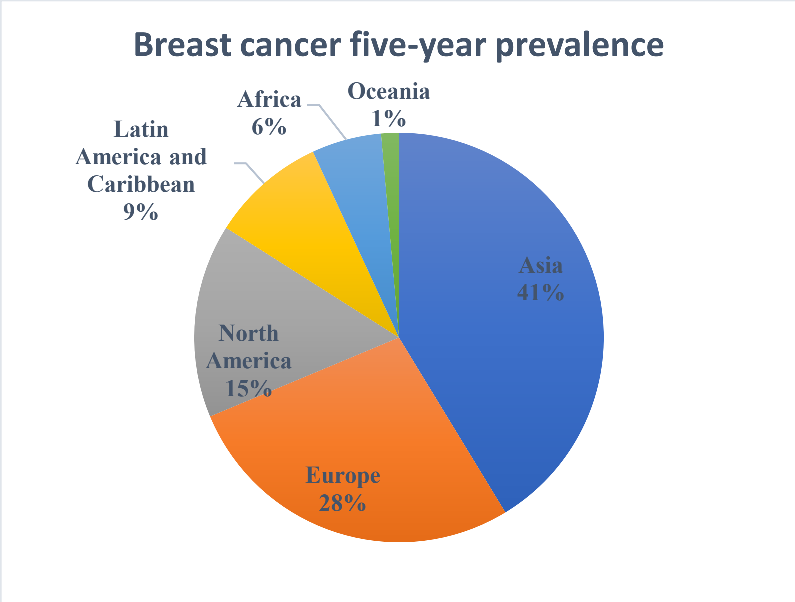
4.3. Breast Cancer at a Global Level

Female breast cancer is the leading cause of global cancer incidence in 2020. The incidence of breast cancer is estimated to be 2.3 million cases, and the mortality is estimated to be 685,000 deaths. It represents 11.7 per cent of total new cancer cases and 6.9 per cent of total cancer mortality (Sung et al., 2020). Earlier, lung cancer had the highest incidence among all types of cancer; however, according to the latest GLOBOCAN (2020) reports, breast cancer has surpassed lung cancer. Breast cancer is the fifth leading cause of cancer mortality worldwide. Statistically, breast cancer accounts for one in four cancer cases and one in six cancer deaths among women.

Figure 4.2

Breast cancer incidence, mortality and five-year prevalence among both sexes across continents



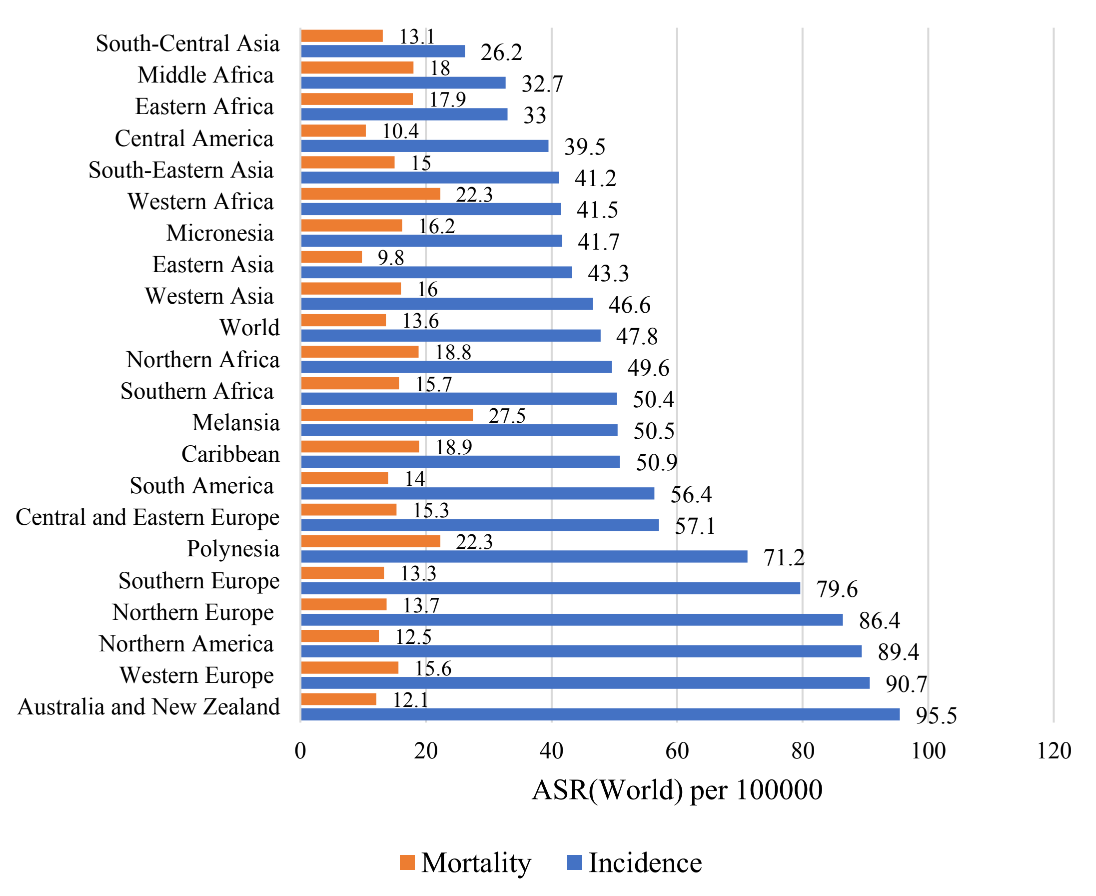


Source: GLOBOCAN 2020, The Global Cancer Observatory

The worldwide incidence, mortality, and five-year prevalence of breast cancer in both sexes in the year 2020 are illustrated in Figure 4.2. From Figure 4.2, it can be observed that the highest incidence of breast cancer occurred in Asia (45.4per cent of total breast cancer cases), followed by Europe (23.5per cent of total breast cancer cases) and Northern America (12.5per cent of total breast cancer cases). It can also be observed that almost 50.5 per cent of breast cancer mortality occurs in Asia, followed by Europe (20.7 per cent of total breast cancer deaths) and Africa (12.5 per cent of total breast cancer deaths). The five-year prevalence rate is observed to be highest in Asia (41.3 per cent of total breast cancer cases), followed by Europe (27.4 per cent of total breast cancer cases) and Northern America (15.3 per cent of total breast cancer cases).

Figure 4.3

Worldwide age-standardized incidence and mortality rates of breast cancer in 2020



Source: GLOBOCAN 2020, The Global Cancer Observatory

The age-standardized (world) incidence and mortality rates of breast cancer across world regions are represented in Figure 4.3. From the above figure, it can be observed that the world incidence rate of breast cancer is 47.8 per 100000, and the mortality rate is 13.6 per 100000 for breast cancer. The highest incidence rates were observed in Australia and New Zealand (95.5 per 100000), followed by Western Europe (90.7 per 100000) and Northern America (89.4 per 100000). The lowest incidence rate was observed in South-Central Asia (26.2 per 100000), followed by Middle Africa (32.7 per 100000) and Eastern Africa (33.0 per 100000). It can be observed that the incidence rates of breast cancer in transitioned countries are higher compared to transitioning countries. The highest mortality rates for breast cancer were observed in Melanesia (27.5 per 100000), followed by Polynesia and Western Africa (22.3 per

100000). The lowest mortality rates for breast cancer were observed in Eastern Asia (9.8 per 100000), followed by Central America (10.4 per 100000) and Australia and New Zealand (12.1 per 100000). Women living in transitioning countries have a higher mortality rate compared to women in transitioned countries.

Countries in North America, Oceania and Europe had reported that breast cancer incidence rates were rapidly increasing in the 1980s and 1990s. However, during the early 2000s, the incidence rates started dropping or stabilising. (Torre et al., 2017). Since 2007, there have been significant increases in the incidence rates in countries like the United States and regions in Europe and Oceania. The elevated breast cancer incidence in high HDI countries can be due to the following factors: increased detection through mammographic screening, high prevalence of reproductive and hormonal risk factors and lifestyle risk factors (Brinton et al., 2018). Examples of reproductive and hormonal risk factors are early age at menarche, later age at menopause, advanced age at first birth, fewer number of children, less breastfeeding, menopausal hormone therapy, and oral contraceptives; and examples of lifestyle risk factors are alcohol intake, excess body weight, physical inactivity. In countries like Denmark, Scotland, Ireland, and the United States, the incidence of estrogen-receptor-positive cancers is increasing, and the incidence of estrogen-receptor-negative cancers is falling (Anderson et al., 2013; Mullooly et al., 2017; Mesa-Eguiagaray et al., 2020). The reasons for this pattern include the high prevalence of obesity among women and the impact of increased early detection through mammographic screening in these countries (Gilliland et al., 2009; Suzuki et al., 2009)

In transitioning countries like South America and Asia, the incidence rates of breast cancer have been rising fast (Bray et al., 2004; Joko-Fru et al., 2020). The incidence rates were historically low in high-income Asian countries like Japan and the Republic of Korea, but over the past few decades, there has been an increasing trend (Heer et al., 2020). Dramatic changes in lifestyle, sociocultural, and built environments brought about by growing economies and an increase in the proportion of women in the industrial workforce have had an impact on the prevalence of hormonal and reproductive risk factors, which have further resulted in the increase in incidence and breast cancer morbidity. Countries in sub-Saharan Africa have been experiencing a rapid increase in breast cancer incidence rates since the mid-1990s (Joko-Fru et al., 2020). From Figure 4.3, it can be observed that the mortality rates in sub-Saharan

African regions are much higher compared to other regions in the world. This mainly reflects the weak health infrastructure and poor survival outcomes. In high-income countries, the survival rates were 85 to 90 per cent for diagnosed cases, but in sub-Saharan countries, the survival rate was only 66 per cent (Alleman et al., 2018). Various studies across seventeen sub-Saharan reported that 77per cent of breast cancer cases were diagnosed at stage III/IV, which is attributed to low survival rates (Jedy-Agba et al., 2016). The other reasons for the poor survival rates are a lack of population-based mammographic screening, low breast cancer awareness, lack of skilled healthcare providers and effective treatment (Birnbaum et al., 2018).

4.4. Cancer Incidence and Mortality in India

Globally, the burden of cancer is increasing at a rapid rate. In a developing country like India, with a population of more than 1.3 billion, cancer is one of the leading causes of mortality. In India, the mortality from non-communicable diseases was estimated to be 63 per cent of all deaths, and cancer accounted for almost 9 per cent of the deaths (GLOBOCAN, 2020). In economically developing countries, population growth and ageing are the main factors responsible for the increasing incidence and burden of cancer (Thun et al., 2010). The changes in lifestyle, such as smoking, alcohol use, consumption of highly calorific food, increased obesity, and a reduction in physical activity, are also partly accountable for the increase in cancer cases.

Table 4.2

New cases, death, and five-year prevalence by cancer site in India

	New cases			Deaths			5-year prevalence (All ages)	
Cancer	**Number**	**(per cent)**	**Cum. risk**	**Number**	**(per cent)**	**Cum. risk**	**Number**	**Prop. (Per 100000)**
Breast	178361	13.5	2.81	90408	10.6	1.49	459271	69.28
Lip, oral cavity	135929	10.3	1.09	75290	8.8	0.62	300413	21.77
Cervix uteri	123907	9.4	2.01	77348	9.1	1.30	283842	42.82
Lung	72510	5.5	0.67	66279	7.8	0.61	80817	5.86
Oesophagus	63180	4.8	0.57	58342	6.9	0.53	68607	4.97
Stomach	60222	4.5	0.53	53253	6.3	0.48	81270	5.89
Leukaemia	48419	3.7	0.31	35392	4.2	0.24	127493	9.24
Ovary	45701	3.5	0.74	32077	3.8	0.57	103716	15.65
Non-Hodgkin lymphoma	35828	2.7	0.28	20390	2.4	0.17	88272	6.40
Liver	34743	2.6	0.32	33793	4.0	0.32	38602	2.80

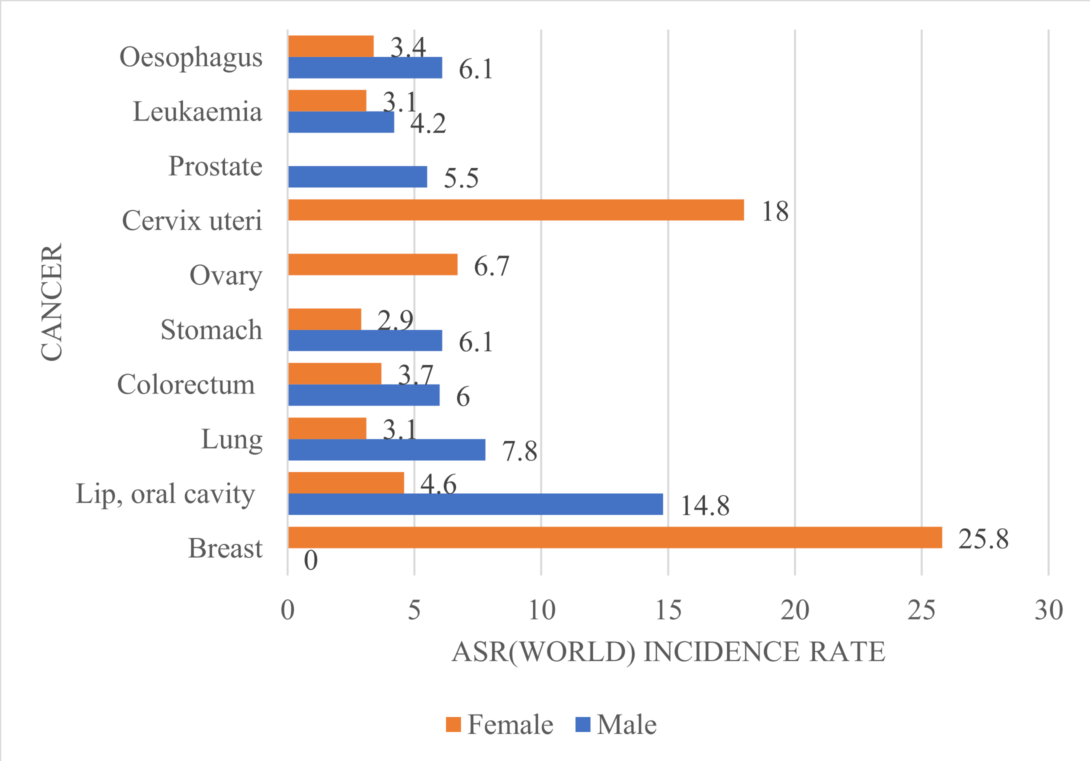
Larynx	34687	2.6	0.32	21660	2.5	0.21	82087	5.95
Prostate	34540	2.6	0.64	16783	2.0	0.28	67909	9.47
Colon	31646	2.4	0.28	19236	2.3	0.17	65493	4.75
Brain, central nervous system	31460	2.4	0.22	26656	3.1	0.20	74398	5.39
Hypopharynx	28489	2.2	0.26	11443	1.3	0.11	39750	2.88
Rectum	28260	2.1	0.24	16149	1.9	0.13	62827	4.55
Bladder	21096	1.6	0.19	11154	1.3	0.10	49257	3.57
Oropharynx	20617	1.6	0.19	12703	1.5	0.12	44398	3.22
Thyroid	20432	1.5	0.15	4895	0.57	0.04	55248	4.00
Gallbladder	19570	1.5	0.17	14736	1.7	0.13	25138	1.82
Kidney	16861	1.3	0.14	9897	1.2	0.09	39150	2.84
Corpus uteri	16413	1.2	0.29	6385	0.75	0.11	43484	6.56
Multiple myeloma	14641	1.1	0.14	12556	1.5	0.12	30640	2.22
Pancreas	12642	0.95	0.11	12153	1.4	0.11	11928	0.86
Penis	10677	0.81	0.20	4760	0.56	0.08	26280	3.66
Hodgkin lymphoma	9221	0.70	0.06	3513	0.41	0.03	24928	1.81
Salivary glands	7850	0.59	0.07	5127	0.60	0.05	20448	1.48
Nasopharynx	5697	0.43	0.05	4148	0.49	0.03	14196	1.03
Vagina	5518	0.42	0.09	2723	0.32	0.05	12315	1.86
Anus	5452	0.41	0.05	2776	0.33	0.03	12278	0.89
Testis	4681	0.35	0.06	1252	0.15	0.02	14812	2.07
Melanoma of skin	3916	0.30	0.03	2296	0.27	0.02	9637	0.70
Vulva	3447	0.26	0.06	1694	0.20	0.03	8928	1.35
Mesothelioma	1709	0.13	0.01	1543	0.18	0.01	2223	0.16
Kaposi sarcoma	66	0.00	0.00	43	0.01	0.00	156	0.01
All cancer sites	**1324413**	**-**	**10.43**	**851678**	**-**	**7.05**	**2720251**	**197.1**

Source: GLOBOCAN 2020, The Global Cancer Observatory

The number of new cases, deaths, and five-year prevalence of different cancers in India are represented in Table 4.2. It can be observed that breast cancer had the highest percentage of new cases (13.5 per cent), followed by lip-oral cavity (10.3 per cent) and cervix-uteri (9.4 per cent). The lowest number of cases was observed for Kaposi sarcoma (0.0 per cent), followed by mesothelioma (0.01 per cent) and vulva (0.06 per cent). The highest percentage of deaths was observed in breast cancer (10.6 per cent), followed by cervix-uteri (9.1 per cent). Breast cancer also had the highest five-year prevalence rate (69.28 per 100000).

Figure 4.4

Age-standardised (world) incidence rate of top ten cancers across gender in India



Source: GLOBOCAN 2020, The Global Cancer Observatory

The age-standardised world incidence rate of the top ten cancers across genders in India is illustrated in Figure 4.4. It can be observed that among females, the highest incidence rate was for breast cancer (25.8 per 100000), followed by cervix-uteri (18 per 100000) and ovarian cancer (6.7 per 100000). Among males, the highest incidence rate was observed for the lip-oral cavity (14.8 per 100000), followed by the lung (7.8 per 100000), stomach and oesophagus (6 per 100000).

4.4.1. Prevalence of Risk Factors in India

Lip-oral cavity and lung cancer are the most common types of cancer among men in India. These cancers are highly associated with tobacco consumption. According to a population-based report, it was observed that 30–60per cent of total cancers among males and 10–30per cent among females are tobacco-related (NCRP, 2020). The usage of betel quid has also been prevalent among 20-40 per cent of the Indian population (Gupta & Ray, 2004). In India, among males, the lung was the most common site of cancer associated with the use of tobacco. Among females, the mouth was the most common site of cancer associated with the use of tobacco (NCRP, 2020). Tobacco increases the risk of lung cancer by 10-20-fold, and it is also a risk factor for head and neck cancers, oesophagus, stomach, colorectal, pancreatic, hepatocellular, bladder, kidney, cervical cancers, and leukaemia (Sasco et al., 2004).

Globally, about 4·1per cent of all new cases of cancer in 2020 were attributable to alcohol consumption, and about three-quarters of alcohol-attributable cancer cases were in males. The cancer sites contributing to the most attributable cases were oesophageal, liver, and breast in females (Rumgay et al., 2021). On average, only 1.2 per cent of women in India consume alcohol, whereas the national average for men is 29.2 per cent. Alcohol consumption by both men and women is high in the North-East and Eastern states of India (Karuppusamy et al., 2021). Helicobacter pylori, hepatitis B and C viruses, and human papillomaviruses (HPV) are major risk factors for stomach, liver, and cervical cancers. The proportion of Human Papillomavirus (HPV)-)-related cancers varies from 87.8 per cent to 96.67 per cent for cervical cancer in India (Sowjanya et al., 2005; Gheit et al., 2009).

Obesity is a risk factor for breast, colorectal, endometrium, kidney, oesophageal, and pancreatic cancers. As per the National Family Health Survey (2019-2020), 22.9 per cent of males and 24 per cent of females in India are either obese or overweight. Low physical activity is a major risk factor for colon, breast, and endometrial cancers. The consumption of red and processed meats and a diet low in fibre have been associated with colorectal cancer (World Cancer Research Fund, 2007). In India, deep-fried cooking at high temperatures, dried fish, and spicy food have been attributed to stomach cancer (Mathew et al., 2000; Rao et al., 2002). In the southern region of India, a high risk of oral cavity cancers has been associated with the consumption of meat, ham or salami (processed and fried meat) two or more times a week (Rajkumar et al., 2003). According to recommendations by the World Cancer Research Fund and American Institute for Cancer Research, being lean, physically active, avoiding energy-dense foods, eating a variety of fruits, vegetables, whole grains, and pulses, and limiting the consumption of alcohol have been associated with a reduction in overall cancer risk (5 per cent), with larger reductions for colorectal (12 per cent) and stomach (16 per cent) cancers (Romaguera et al., 2012).

4.4.2. Geographical Distribution of Cancer Incidence and Mortality in India

The distribution of all types of cancer is heterogeneous in India. The variation in the prevalence of risk factors and the quality of healthcare infrastructure in various states are the underlying reasons for the difference in incidence and mortality rates. The National Cancer Registry Programme (NCRP) was started in 1981 in India. Data on cancer incidence, mortality, pattern, trend, and geo-pathological distribution of cancers are provided under this programme. There are two types of cancer registries under the programme: a) Population Based Cancer Registries (PBC₹), which record all the new cancer cases occurring in a defined population within a geographic area; b) Hospital Based Cancer Registries (HBC₹), which record information on cancer patients attending a particular hospital, with focus on clinical care, treatment, and outcome. Currently, 36 PBC₹ and 236 HBC₹ are registered under NCRP. The following data is from the report of the National Cancer Registry Programme (2012-2016).

Table 4.3

Incidence rates: crude rate (CR), age-adjusted rate (AAR) and truncated rate (TR (35-64yrs)) per 100,000 population for all sites of cancer in 31 PBCR under NCRP

	MALES			FEMALES		
Registry	**CR**	**AAR**	**TR**	**CR**	**AAR**	**TR**
NORTH						
Delhi (2012-2014)	112.3	147.0	232.2	119.6	141.0	279.0
Patiala district (2012-2016)	101.6	108.2	196.4	127.7	124.6	271.4
SOUTH						
Hyderabad district (2014-2016)	84.2	101.6	172.2	109.8	136.0	278.3
Kollam district (2012-2016)	159.4	127.7	198.0	139.1	107.1	205.7
Thiruvananthapuram district (2012-2016)	170.4	137.8	211.5	164.8	127.3	242.8

Bangalore (2012-2014)	96.8	122.1	181.7	125.1	146.8	283.6
Chennai (2012-2016)	121.8	119.9	185.2	141.4	132.8	260.5
EAST						
Kolkata (2012-2015)	109.9	91.2	145.2	105.9	89.2	175.9
WEST						
Ahmedabad urban (2012-2016)	89.1	98.3	183.2	74.7	76.7	158.0
Aurangabad (2012-2016)	56.6	70.9	121.6	62.9	75.1	158.5
Osmanabad & Beed (2012-2015)	39.3	39.5	71.5	52.8	49.4	108.2
Barshi Rural (2012-2016)	53.9	50.6	80.5	67.2	61.0	126.5
Mumbai (2012-2015)	97.3	108.4	155.1	117.6	116.2	207.6
Pune (2012-2016)	67.5	83.0	120.0	83.3	94.0	177.7
CENTRAL						
Wardha district (2012-2016)	70.4	64.5	109.7	78.7	69.9	148.9
Bhopal (2012-2015)	83.3	101.0	180.0	90.4	106.9	223.3
Nagpur (2012-2016)	89.0	91.1	158.6	93.1	89.8	188.2
NORTH-EAST						
Manipur state (2012-2016)	47.0	62.8	91.0	57.8	71.1	129.6
Imphal West district (2012-2016)	85.1	95.3	125.5	107.9	110.9	198.2
Mizoram state (2012-2016)	146.1	207.0	357.7	127.5	172.3	313.2
Aizawl district (2012-2016)	206.2	269.4	485.5	174.6	214.1	377.5
Sikkim state (2012-2016)	69.9	88.7	131.5	75.3	97.0	175.2
Tripura state (2012-2016)	67.0	80.9	145.9	52.0	58.3	127.3
West Arunachal (2012-2016)	56.6	101.1	199.9	56.3	96.3	215.7
Papumpare district (2012-2016)	94.8	201.2	372.7	105.1	219.8	499.0
Meghalaya (2012-2016)	92.6	176.8	386.0	55.7	96.5	201.1
East Khasi Hills district (2012-2016)	131.0	227.9	494.5	76.9	118.6	242.5
Nagaland (2012-2016)	74.5	124.5	223.8	56.3	88.2	193.6
Pasighat (2012-2016)	90.7	120.4	207.6	88.1	116.2	260.3
Cachar district (2012-2016)	99.2	129.0	233.4	87.0	104.8	234.2
Dibrugarh district (2012-2016)	72.5	91.9	155.9	6.0	76.8	70.7

Reporting year data is given in parentheses
Source: National Cancer Registry Programme 2012-2016, ICMR

The incidence rates: Crude Rate (CR), Age-Adjusted Rate (AAR) and Truncated Rate (TR (35-64 years)) per 100,000 population for all sites of cancer in 31 PBC₹ under NCRP are illustrated in Table 4.3. It can be observed that the highest incidence crude rate per 100000 population among males was in Aizawl district (206.2), followed by Kamrup urban (190.5), Thiruvananthapuram district (170.4), Kollam district (159.4) and Mizoram state (146.1). The lowest incidence CR per 100000 population among males was observed in Osmanabad and Beed (39.3), followed by Manipur state (47.0), Barshi rural (53.9), Aurangabad (56.6) and West Arunachal (56.6).

Among females, the highest incidence of CR per 100000 population was observed in Aizawl district (174.6), followed by Thiruvananthapuram district (164.8), Kamrup urban (150.8), Chennai (141.4) and Kollam district (139.1). The lowest incidence of CR per 100000 population among females was observed in Tripura state (52.0), Osmanabad & Beed (52.8), Meghalaya (55.7), Nagaland (56.3) and West Arunachal (56.3).

The incidence age-adjusted rate (AAR) per 100000 population among males was highest in Aizawl district (269.4), followed by East Khasi Hills district (227.9). The lowest incidence of AAR per 100000 population among males was observed in Osmanabad and Beed district (39.5), followed by Barshi rural (50.6).

Among females, the highest incidence of AAR per 100000 population was observed in the Papumpare district (219.8), followed by the Aizawl district (214.1). The lowest incidence of AAR per 100000 population among females was observed in Osmanabad and Beed district (49.4), followed by Tripura state (58.3).

Among males, the highest incidence of truncated rate (TR) per 100,000 population was observed in the East Khasi Hills district (494.5), while the lowest TR was observed in the Osmanabad and Beed districts (71.5). Among females, the highest incidence of TR per 100000 population was observed in the Papumpare district (499.0), while the lowest TR was observed in the Osmanabad and Beed districts (108.2).

Table 4.4

Crude (CMR), age-adjusted (AAMR) and truncated mortality rate (TMR) per 100,000 In 28 PBCR under NCRP

	MALES			FEMALES		
REGISTRY	**CMR**	**AAMR**	**TMR**	**CMR**	**AAMR**	**TMR**
NORTH						
Delhi (2012-2014)	17.0	22.2	34.1	14.9	17.8	32.0
Patiala district (2012-2016)	30.8	32.7	56.0	30.5	30.1	55.5
SOUTH						
Hyderabad district (2014-2016)	12.4	15.5	25.9	9.9	12.5	23.6
Kollam district (2012-2016)	84.3	66.5	98.9	51.6	38.3	67.1
Thiruvananthapuram district (2012-2016)	72.2	57.7	86.5	52.5	39.5	67.4
Bangalore (2012-2014)	33.2	42.6	59.9	34.3	41.5	69.0
Chennai (2012-2016)	36.3	35.7	52.6	30.5	28.8	47.7
EAST						
Kolkata (2012-2015)	46.1	37.9	51.9	38.3	32.1	54.3
WEST						
Ahmedabad urban (2012-2016)	24.4	27.0	50.4	16.4	16.9	33.7
Aurangabad (2012-2016)	9.7	13.5	15.3	7.1	8.5	11.1
Osmanabad & Beed (2012- 2015)	10.5	10.3	17.0	11.4	10.4	20.8
Barshi Rural (2012-2016)	38.7	35.0	49.1	42.3	36.1	60.8
Mumbai (2012-2015)	58.2	66.0	84.8	61.6	61.4	93.7
Pune (2012-2016)	28.2	35.3	46.2	30.8	35.3	58.5
CENTRAL						
Wardha district (2012-2016)	46.4	42.3	71.3	41.7	37.1	75.2
Bhopal (2012-2015)	30.8	38.3	70.1	25.5	30.9	62.5
Nagpur (2012-2016)	20.8	21.3	36.6	18.1	17.7	33.6
NORTH-EAST						
Manipur state (2012-2016)	14.7	20.5	24.9	12.9	17.3	24.1
Imphal West district (2012-2016)	26.1	29.6	30.1	23.2	24.3	33.1

Mizoram state (2012-2016)	84.2	121.4	190.4	53.5	76.4	114.2
Aizawl district (2012-2016)	115.0	152.7	253.8	69.6	89.5	126.9
Sikkim state (2012-2016)	35.9	46.4	64.8	34.2	46.2	74.3
Tripura state (2012-2016)	37.6	46.0	78.4	25.4	28.9	60.7
West Arunachal (2012-2016)	14.9	27.3	53.2	9.7	18.9	37.1
Papumpare district (2012-2016)	23.7	56.5	98.0	15.7	37.9	80.1
Meghalaya (2012-2016)	36.5	71.7	152.5	21.6	38.1	78.3
East Khasi Hills district (2012-2016)	53.1	95.0	202.9	33.1	51.5	103.2
Nagaland (2012-2016)	15.8	27.8	47.2	6.8	11.1	22.2
Pasighat (2012-2016)	20.9	30.9	40.2	15.1	22.0	34.5
Cachar district (2012-2016)	19.0	25.2	42.3	13.6	17.5	35.7
Dibrugarh district (2012-2016)	19.1	24.0	41.1	11.7	14.1	30.7
Kamrup urban (2012-2016)	58.6	66.7	101.3	31.5	37.3	65.7

Source: National Cancer Registry Programme 2012-2016, ICMR

The Crude Mortality Rate (CMR), Age-Adjusted Mortality Rate (AAMR) and Truncated Mortality Rate (TR (35-64yrs)) per 100,000 population for all sites of cancer in 28 PBC₹ under NCRP are illustrated in Table 4.4. It can be observed that the highest crude mortality rate (CMR) per 100000 population among males was in Aizawl district (115.0), followed by Kollam district (84.3) and Mizoram state (84.2). The lowest CMR per 100000 population among males was observed in Aurangabad (9.7), followed by Osmanabad and Beed (10.5) and Hyderabad district (12.4). Among females, the highest CMR per 100000 population was observed in Aizawl district (69.6), followed by Mumbai (61.6) and Mizoram state (53.5). The lowest CMR per 100000 population among females was observed in Nagaland (6.8), followed by Aurangabad (7.1) and West Arunachal (9.7).

The age-adjusted mortality rate (AAMR) per 100000 population among males was highest in Aizawl district (152.7), followed by Mizoram state (121.4). The lowest AAMR per 100000 population among males was observed in Osmanabad and Beed district (10.3), followed by Aurangabad (13.5). Among females, the highest AAMR per 100000 population was observed in Aizawl district (89.5), followed by Mizoram state (76.4). The lowest AAMR per 100000 population among females was observed in Aurangabad (8.5), followed by Osmanabad and Beed district (10.4). Among males, the highest truncated mortality rate (TR) per 100000 population was observed in Aizawl district (253.8), while the lowest TR was observed in Aurangabad (15.3). Among females, the highest TMR per 100000 population was observed in Aizawl district (126.9), while the lowest TR was observed in Aurangabad (11.1).

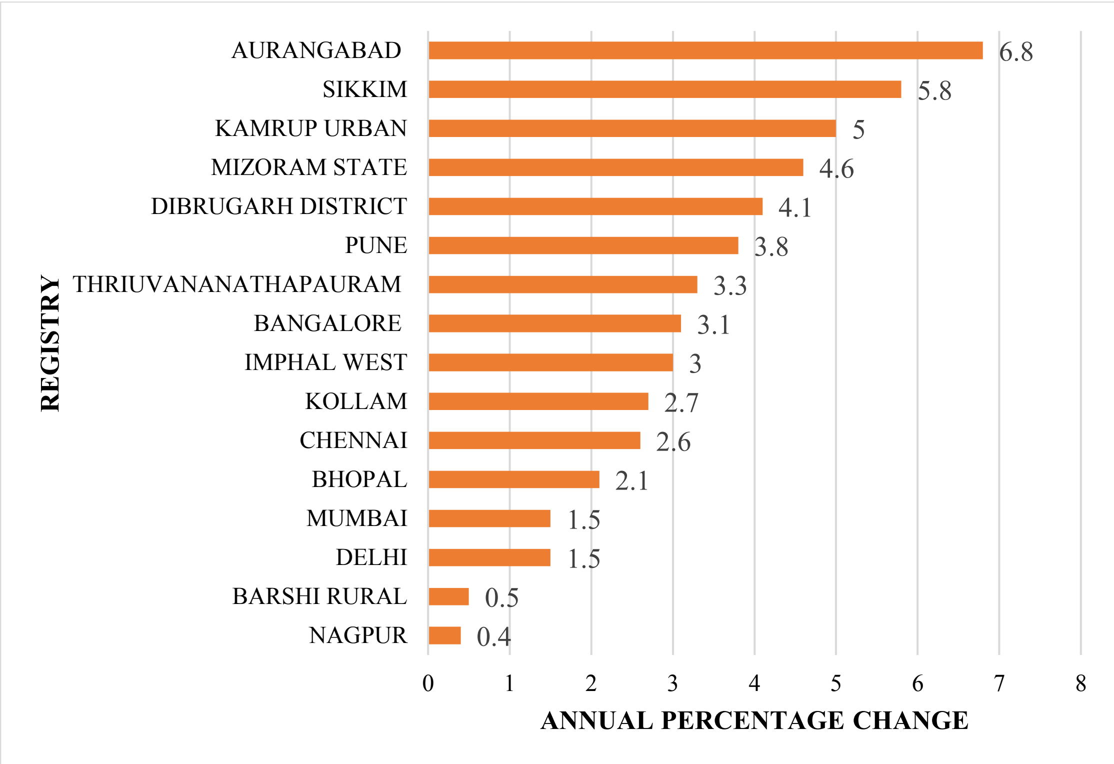
The heterogeneity in cancer distribution in India is evident from the above findings. The incidence rates of cancer in the Aizawl district were seven times higher and four times higher than in the Osmanabad and Beed districts for males and females, respectively. The cancer mortality in the Aizawl district was eleven times higher than in the Aurangabad district in the case of males and ten times higher than in Nagaland in the case of females. While comparing the crude incidence rates among different registries, it can be observed that North-Eastern and South cancer registries have reported higher crude incidence for both male and female populations. The low survival rates and the high incidence rates of cancer in the North-East region are mainly due to a lack of health infrastructure like specialised treatment facilities, skilled doctors, and long distances to cancer hospitals (NCRP-ICMR, 2021). Based on the reports by PBC₹, it was observed that there had been a steady increase in tobacco-related cancers in males and reproductive cancers in females (Mathur et al., 2020). Local cultural factors and lifestyle choices may have contributed to the variation in cancer incidence patterns and differences in India, as was seen in Thailand (Pongnikorn et al., 2018). Approximately 70 per cent of cancers in India were potentially preventable through modifiable risk factors (Gandhi et al., 2017).

4.5. Breast Cancer in India

Breast cancer has emerged as the leading cancer site among females in India. Almost 13.5 per cent of total new cancer cases reported are breast cancer. Earlier, cervical cancer was the most common cancer in Indian women, but now, the incidence of breast cancer has surpassed cervical cancer. In India, the incidence and mortality rates are highest for breast cancer compared to all other sites of cancer (Kaarthigeyan et al., 2012; GLOBOCAN,2020). A survey of cancer trends from the year 1982 to 2005 reported that breast cancer incidence almost doubled in a span of two decades. The five-year prevalence rate of breast cancer, 69.28 per 100000, is the highest among all types of cancer. Breast cancer was reported to occur at a younger age among Indian women compared to women from Western countries (Ali et al., 2011; Chopra et al., 2014).

Figure 4.5

Annual percent change (APC) in age-adjusted incidence rates (AAR) over the period 2012-2016 for female breast cancer

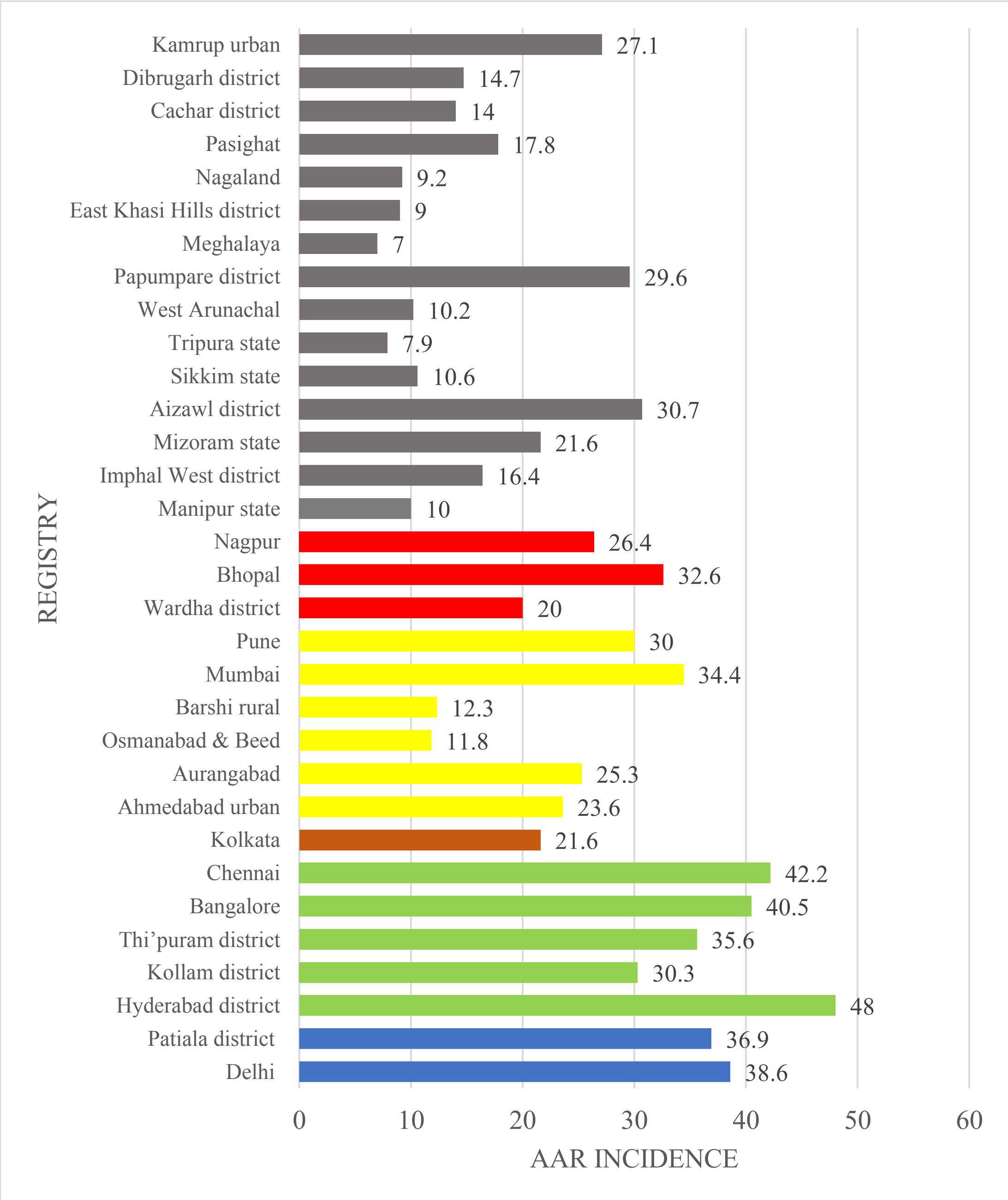


Source: National Cancer Registry Programme 2012-2016, ICMR

The annual per cent change (APC) in age-adjusted incidence rates over the period 2012-2016 for female breast cancer is depicted in Figure 4.5. It can be observed that from the selected sixteen PBC₹, every registry except Nagpur PBCR showed a significant increase in incidence rates at a 95 per cent confidence interval level. The highest APC was observed in Aurangabad (6.8 per cent), followed by Sikkim state (5.8 per cent) and Kamrup urban (5.0 per cent).

Figure 4.6

Breast cancer- comparison of age-adjusted incidence rates (AA₹) of 28 PBC₹ under NCRP



Source: National Cancer Registry Programme 2012-2016, ICMR

The age-adjusted incidence rate of female breast cancer from twenty-eight PBC₹ under NCRP is represented in Figure 4.6. The highest AAR per 100,000 was reported in Hyderabad (48.0), followed by Chennai (42.2), Bangalore (40.5) and Delhi (38.6). The lowest AAR per 100,000 was reported in Meghalaya (7.0), followed by Tripura state (7.9) and East Khasi Hills district (9.0). Overall, the southern region PBC₹ have reported a higher incidence compared to all other registries.

Table 4.5

Number (n) and relative proportion according to clinical extent of disease for breast cancer

	FEMALE		MALES	
Clinical Extent of Disease	**n**	**per cent**	**n**	**per cent**
Localised only	10629	29.0	221	32.6
Locoregional	20898	57.0	333	49.2
Distant Metastasis	3790	10.3	75	11.1
Unknown	1345	3.7	48	7.1
Total	**36662**	**100.0**	**677**	**100.0**

Source: National Cancer Registry Programme 2012-2016, ICMR

The clinical extent of breast cancer patients is illustrated in Table 4.5. According to the female breast cancer data reported by HBC₹, it can be observed that 57 per cent of the cases showed locoregional spread, followed by 29 per cent of cases with localised diseases and 10per cent of the cases with distant metastasis. Among males, 49.2 per cent of the cases showed locoregional spread, followed by 32.6 per cent of cases with localised diseases and 11.1 per cent of cases with distant metastasis. About 3.7 per cent and 7.1 per cent of the cases had an unknown spread among female and male cases, respectively.

Table 4.6

Number (n) and relative proportion of types of treatment according to clinical extent of disease for female breast cancer

Treatment	**Clinical Extent of Disease**							
	Localised only		**Locoregional**		**Distant Metastasis**		**Unknown**	
	N	**per cent**	**N**	**per cent**	**N**	**per cent**	**N**	**per cent**
Surgery	1368	12.9	1283	6.1	52	1.4	221	16.5
Radiotherapy	264	2.5	404	1.9	170	4.5	145	10.8
Systemic Therapy	1077	10.2	2576	12.3	1747	46.3	307	22.9
Multi-modality*	7880	74.3	16519	79.1	1788	47.4	664	49.6
Palliative Care	21	0.2	94	0.5	19	0.5	3	0.2
Total	**10610**	**100.0**	**20876**	**100.0**	**3776**	**100.0**	**1340**	**100.0**

**Multi-modality includes the combination of Surgery and Radiotherapy and Systemic Therapy*

Source: National Cancer Registry Programme 2012-2016, ICMR

The types of treatment according to the clinical extent of female breast cancer are reported in Table 4.6. Multi-modality was the most common choice of treatment for locoregional spread (79.1 per cent), localised spread (74.3 per cent) and distant metastasis (47.4 per cent). Multi-modality includes the combination of surgery, radiotherapy, and systemic therapy. The second most common choice of treatment for patients with distant metastasis (46.3 per cent) and localised spread (12.3 per cent) was systemic therapy. Surgery was the second most common choice of treatment for locoregional spread (12.9 per cent). Palliative care was the least common choice of treatment for female breast cancer.

4.6. Risk Factors Associated with Breast Cancer in India

The data from the various cancer registries reports that the age-adjusted incidence rate of breast cancer patients increases with age in India. Breast cancer incidence is observed to peak between the 50-69 years age group among Indian women. In Western countries, the majority of breast cancer cases were diagnosed at stages I and

II of the disease, but in India, 67 per cent of the cases were reported at an advanced stage (Leong et al., 2010). There are several factors associated with breast cancer among Indian women. Factors like breastfeeding, location (urban/rural), and increased body mass index (BMI) are strongly associated with breast cancer for women from North India. Increased duration of breastfeeding and physical activity decreased the risk of ER+ and ER-− breast cancer as well as the risk among premenopausal women. [45-46] The risk of breast cancer was lesser among women from rural areas compared to their urban counterparts due to the difference in lifestyle.[47] Increasing age, low parity and obesity increased the risk among South-Indian women, whereas factors like betel quid and tobacco chewing habits, age at marriage, age at first childbirth and age at menarche increased risk among North-Eastern women (Dey et al., 2009; Gajalakshmi et al., 2009; Nagrani et al.,2014).

Women who were unmarried, widowed/ divorced, and lower and postmenopausal women possessed elevated risks for the disease and were diagnosed at advanced stages. Early-onset breast cancer tends to be more aggressive than late-onset, with higher stage and grade at presentation with more estrogen receptor-negative or triple-negative subtypes (Ali et al., 2008; Anders et al., 2008). It was observed that younger-aged patients tend to have triple-negative breast cancer (TNBC), and the prevalence of TNBC is higher among Indian women compared to women from Western countries. Environmental compounds like polycyclic aromatic hydrocarbons (PAH) increase the risk of breast cancer. Genetic factors, like BRCA1 and BRCA2, are a major factor that increases the risk of promoting breast cancer. Among Indian women, the frequency of BRCA1/2 genetic mutations ranged from 2.9 per cent to 24.0 per cent. Furthermore, 2.8 per cent of early-onset breast cancer patients in the Indian population were found to have BRCA1/2 mutations (Bonner et al., 2005; Saxena et al., 2006; Vaidyanathan et al., 2009).

4.7. Cancer in Kerala: Results from Secondary Data Analysis

The incidence and prevalence of cancer in Kerala is steadily increasing. According to the NCRP 2012-2016 report, the average crude incidence rate of cancer per 100000 of the population is 164.9 among males and 151.95 among females in Kerala. In this section, the results from the secondary data analysis done by the researcher are presented. The data from the National Sample Survey (NSS) 75th round has been used to analyse the cancer scenario in Kerala.

In this section, the researcher has analysed the population distribution of cancer patients across the states of India and Kerala. The type of medical institution and the place of hospitalisation availed during cancer treatment have also been analysed. The main emphasis of this analysis is on the expenditure incurred by cancer patients during treatment and the financial sources of funding for cancer treatment in Kerala. For the purpose of this study, cancer patients aged between 18 and 60 years are only included in this analysis. This is to eliminate childhood cancers and incomplete treatment protocols.

Table 4.7

Sample and percentage distribution of cancer patients (between 18 to 60 years) by sex across the states in India

State	Sample			Percentage		
	Male	Female	Total	Male	Female	Total
Jammu & Kashmir	23	10	33	0.39	0.36	0.38
Himachal Pradesh	39	19	58	1.35	0.94	1.20
Punjab	43	22	65	3.76	3.03	3.49
Chandigarh	4	2	6	0.07	0.06	0.07
Uttarakhand	7	2	9	0.91	0.10	0.61
Haryana	29	13	42	2.34	2.20	2.29
Delhi	7	1	8	0.68	0.49	0.61
Rajasthan	76	28	104	10.49	11.69	10.93
Uttar Pradesh	129	59	188	15.71	22.21	18.12
Bihar	34	9	43	1.22	0.90	1.10
Sikkim	3	0	3	0.02	0.00	0.01
Arunachal Pradesh	1	0	1	0.00	0.00	0.00
Nagaland	4	0	4	0.01	0.00	0.01
Manipur	13	4	17	0.12	0.04	0.09
Mizoram	16	5	21	0.05	0.02	0.04

Tripura	10	5	15	0.13	0.13	0.13
Meghalaya	5	2	7	0.04	0.04	0.04
Assam	29	8	37	0.89	0.40	0.71
West Bengal	100	43	143	15.47	11.47	13.99
Jharkhand	23	13	36	0.99	1.20	1.07
Odisha	77	27	104	6.72	4.23	5.80
Chhattisgarh	21	9	30	0.89	0.71	0.82
Madhya Pradesh	28	7	35	1.84	1.19	1.60
Gujarat	39	18	57	4.04	3.03	3.67
Daman & Diu	2	2	4	0.01	0.02	0.01
Maharashtra	66	38	104	6.12	6.78	6.37
Andhra Pradesh	27	16	43	3.11	3.03	3.08
Karnataka	16	9	25	1.73	1.81	1.76
Goa	2	3	5	0.02	0.35	0.14
Kerala	**72**	**42**	**114**	**12.15**	**13.02**	**12.47**
Tamil Nadu	50	28	78	8.04	10.32	8.88
Andaman & Nicobar	2	1	3	0.12	0.00	0.08
Telangana	15	9	24	0.55	0.25	0.44
Total (India)	1,012	454	1,466	100.0	100.0	100.0

Source: Author's estimation from unit level data of NSS 75th round (July 2017-June 2018) on Household Social consumption: Health;

The sample and percentage distribution of cancer patients above the age of 18 years is represented across gender in Table 4.7. It can be observed that the state with the highest percentage of cancer patients across both sexes was Uttar Pradesh (18.12 per cent), followed by West Bengal (13.9 per cent) and Kerala (12.47 per cent). The northeastern states of India had a lower percentage of cancer patients than other states. Kerala had the highest percentage of cancer patients among the southern states of India.

Table 4.8:

Percentage distribution of cancer patients (between 18 to 60 years) by sector and sex hospital in Kerala

Variables	Sector			Sex		
	Rural (per cent)	Urban (per cent)	Total (per cent)	Male (per cent)	Female (per cent)	Total (per cent)
Marital status						
Unmarried	6.33	12.74	9.02	15.68	0.00	9.02
Married	85.61	79.43	83.02	83.44	82.47	83.02
widow/divorced/ separated	8.05	7.83	7.96	0.88	17.53	7.96
Total	100	100	100	100	100	100
Educational status						
Illiterate	4.44	0.00	2.58	0.00	6.07	2.58
Up to Primary	34.51	17.78	27.51	17.01	41.71	27.51
Secondary	31.84	41.75	35.99	49.27	18.02	35.99
Higher Secondary	26.67	11.94	20.50	18.00	23.89	20.50
Graduate and above	2.54	28.53	13.42	15.72	10.32	13.42
Total	100	100	100	100	100	100
Work status						
Self-employed	23.60	12.05	18.77	32.64	0.00	18.77
Regular worker	5.07	32.16	16.41	17.72	14.64	16.41
Causal labour	21.88	16.62	19.68	23.56	14.42	19.68
Domestic duties	30.21	24.91	27.99	1.55	63.76	27.99
Others	19.24	14.26	17.15	24.53	7.18	17.15
Total	100	100	100	100	100	100

Source: Author's estimation from unit level data of NSS 75th round (July 2017-June 2018) on Household Social consumption: Health;

The distribution of cancer patients from 18 to 60 years across marital status, educational status and work status in Kerala is represented in Table 4.8. It can be observed that 83per cent of cancer patients in Kerala were married. Around 30.8 per cent of cancer patients had an educational attainment level of primary schooling, 35.9 per cent had done up to secondary schooling, and 33.9 per cent had done higher secondary or more. Cancer patients in urban sectors had higher levels of educational attainment when compared to their rural counterparts. Also, male cancer patients had comparatively higher levels of educational status than female cancer patients. Around 63.7 per cent of female cancer patients were unemployed, and only 29 per cent were employed. In the case of male cancer patients, around 73 per cent were employed. Employed cancer patients in urban areas were mostly regular workers, while in rural areas, they were mostly involved in self-employment or casual labour.

Table 4.9

Percentage distribution of cancer patients (between 18-60 years) based on type of medical institution visited by sector and sex in Kerala

Variables	Sector			Sex		
	Rural (per cent)	Urban (per cent)	Total (per cent)	Male (per cent)	Female (per cent)	Total (per cent)
Type of medical institution						
Government	55.38	34.61	46.69	48.47	44.28	46.69
Trust/NGOs	1.46	7.14	3.84	4.05	3.55	3.84
Private	43.16	58.25	49.48	47.48	52.18	49.48
Total	100	100	100	100	100	100

Source: Author's estimation from unit level data of NSS 75th round (July 2017-June 2018) on Household Social consumption: Health;

The type of medical institution from which treatment was availed by cancer patients in Kerala is represented in Table 4.9. In sector-wise distribution, it can be observed that cancer patients in rural areas availed treatment from government medical institutions (55.3 per cent) more than private medical institutions (43.1 per cent). In urban areas, cancer patients availed treatment from private medical institutions (58.2 per cent) more than government medical institutions (34.6 per cent). In sex-wise distribution, it can be observed that there was no significant difference among males regarding the type of medical institution. In the case of females, more cancer patients availed treatment from private institutions (52.18 per cent) than government medical institutions (44.28 per cent). The percentage of cancer patients availing treatment from Trust/NGO institutions (3.84 per cent) was significantly lower compared to government and private medical institutions.

Table 4.10

Percentage distribution of cancer patients (between 18-60 years) based on reasons for not availing of government hospital by sector and sex in Kerala

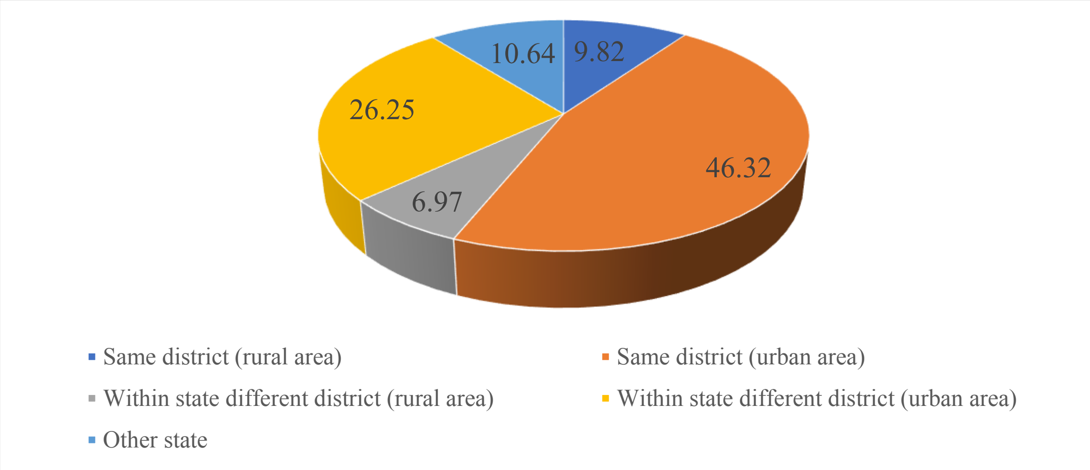
Variables	Sector			Sex		
	Rural (per cent)	**Urban (per cent)**	**Total (per cent)**	**Male (per cent)**	**Female (per cent)**	**Total (per cent)**
Reasons for not availing govt hospital						
specific services not available	8.76	25.38	17.29	16.81	17.89	17.29
available but quality not satisfactory/doctor not available	23.45	0.99	11.92	15.65	7.26	11.92
quality satisfactory but facility too far	42.54	3.87	22.68	23.97	21.08	22.68
quality satisfactory but involves long waiting	5.69	12.25	9.06	8.03	10.35	9.06
preference for a trusted doctor/hospital	10.78	45.26	28.49	18.73	40.68	28.49
other	8.78	12.24	10.56	16.81	2.74	10.56
Total	100	100	100	100	100	100

Source: Author's estimation from unit level data of NSS 75th round (July 2017-June 2018) on Household Social consumption: Health;

The reasons for not availing treatment from government hospital by cancer patients (18 to 60 years) who visited other type of medical institutions is represented in Table 4.10. The most common reason in rural areas and among males is that though the quality of government hospitals is satisfactory, the facility is too far from their place of residence. In urban areas and among females, preferring a trusted hospital/doctor was the most common reason.

Figure 4.7

Percentage distribution of place of hospitalisation for cancer patients (between 18-60 years) in Kerala



Source: Author's estimation from unit level data of NSS 75th round (July 2017-June 2018) on Household Social consumption: Health;

The location of the place of hospitalisation from the residence of cancer patients (18 to 60 years) is illustrated in Figure 4.7. It can be observed that around 46.3 per cent of cancer patients took treatment from a hospital in an urban area in the same district as their residence. Around 26.25 per cent of cancer patients took treatment from a hospital in an urban area but in a different district within the same state as their residence. Cancer patients who sought treatment from other states constituted 10.64 per cent. Around 16.9 per cent of cancer patients visited hospitals in rural areas within the state either in the same district or different districts from their residence.

Expenditure incurred by cancer patients in Kerala: The total expenditure incurred during the last 365 days for medical treatment of cancer during the stay in the hospital is analysed in the following section. The package component involves specific surgical or non-surgical medical procedures, including different items like operation theatre (OT) charges, OT consumables, medicines, doctor's fees, bed charges, etc. Normally, packages do not include additional diagnostic tests, attendant charges, physiotherapy, personal medical appliances, blood, oxygen, etc. Doctor's/surgeon's fee includes the total amount paid on account of doctor's/surgeon's fees chargeable for the period of treatment within the reference period during the stay in hospital.

Medicines include the total amount paid for medicines (used for treatment within the reference period during the stay in hospital – whether made available by the hospital or procured from outside). Diagnostic tests include the total amount paid for diagnostic tests carried out on the patient during the stay in hospital within the reference period – whether using the hospital‘s diagnostic facilities or not. Bed charges include the amount paid for bed charges during a stay in hospital within the reference period. Other medical expenses include the amount paid for attendant charges, physiotherapy, personal medical appliances, blood, oxygen, etc. This item also includes all other expenditures involved in medical treatment.

Total direct medical expenditure includes the summation of package components, doctor's/surgeon's fees, medicines, diagnostic tests, bed charges, and other medical expenses. Transport for a patient includes the amount paid for transport charges (by ambulance or other vehicle) for the patient – whether accompanied by other household members or not – for the journey to the hospital for admission and for the return journey. In addition, charges for any journey performed on medical advice during the period of stay in hospital are also included. Other non-medical expenses incurred by the household include the amount paid for (registration fee, food, transport for others, expenditure on escort, lodging charges, etc). Total medical expenditure includes the summation of total medical expenditure, transport charges and other non-medical expenses.

The total amount reimbursed by the medical insurance company or employer includes the amount reimbursed or expected to be reimbursed by the employer (public/private), any insurance companies (public/private), or any other agencies from out-of-pocket expenditures incurred by cancer patients. The total expenditure, exclusive of the amount reimbursed, is borne by the household. The money needed for this may be spent from current household income or accumulated household savings. The various sources of finance are the proceeds of the sale of cattle, jewellery, or other physical assets. It also includes financing by borrowing and contributions from friends and relatives as outright assistance.

Table 4.11

Average expenditure incurred by cancer patients (between 18-60 years) on various components of treatment by sex during hospitalisation in Kerala

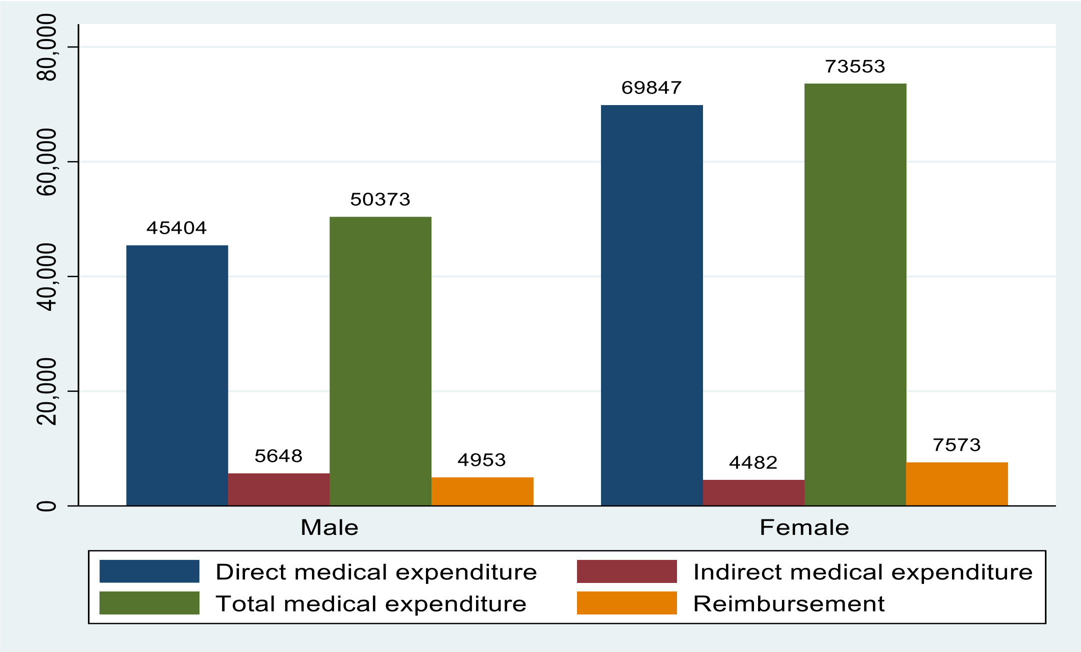
Health expenditure (INR₹)	**Male**		**Female**		**Total**	
	Mean	**Median**	**Mean**	**Median**	**Mean**	**Median**
Package component (₹.)	139759	87500	40968	25000	93659	30000
Doctor's/ surgeon's fee (₹.)	4432	1000	15355	400	9114	800
Medicines (₹.)	7968	5000	33420	4800	19288	4800
Diagnostic tests (₹.)	5800	3000	7759	4550	6606	3050
Bed charges (₹.)	8451	2400	21390	10000	13329	2700
Other medical expenses (₹.)	7815	2000	5746	1300	6974	1800
Total direct medical expenditure (₹.)	45404	23350	69847	22510	55748	23350
Transport for the patient (₹.)	1226	450	1263	600	1242	500
Other non-medical expenses (₹.)	4172	1550	3165	2500	3734	1800
Total medical expenditure (₹.)	50373	28000	73553	23510	60227	24250

Source: Author's estimation from unit level data of NSS 75th round (July 2017-June 2018) on Household Social consumption: Health;

The average expenditure incurred during hospitalisation by cancer patients aged between 18 and 60 years in the last 365 days is represented in Table 4.11. It can be observed that the mean expenses on the package component were the highest (₹ 93,659), followed by medicine expenses (₹ 19,288). The mean and median for total direct medical expenditure incurred were ₹ 55,748 and ₹ 23,350, respectively. Non-medical expenses were significantly less when compared to medical expenses. On average, the total medical expenditure incurred by cancer patients was observed at ₹ 60,227. The average total medical expenditure incurred by female cancer patients was relatively higher than that of male cancer patients.

Figure 4.8

Average health expenditure (INR₹) for cancer patients (between 18-60 years) by sex during hospitalisation in Kerala



Source: Author's estimation from unit level data of NSS 75th round (July 2017-June 2018) on Household Social consumption: Health;

The average expenditure incurred by cancer patients and the reimbursement they received are illustrated in Figure 4.8. It can be observed that the average total medical expenditure incurred by female cancer patients was relatively higher than that of male cancer patients. Across both sexes, the direct medical expenditure was significantly higher than the indirect medical expenditure. Reimbursement received by patients was significantly lower than the total medical expenditure. Cancer patients received only around 10 per cent of the average total medical expenditure as their reimbursement.

Table 4.12

Percentage distribution of source of finance for expenses for cancer patients (between 18-60 years) by sex in Kerala

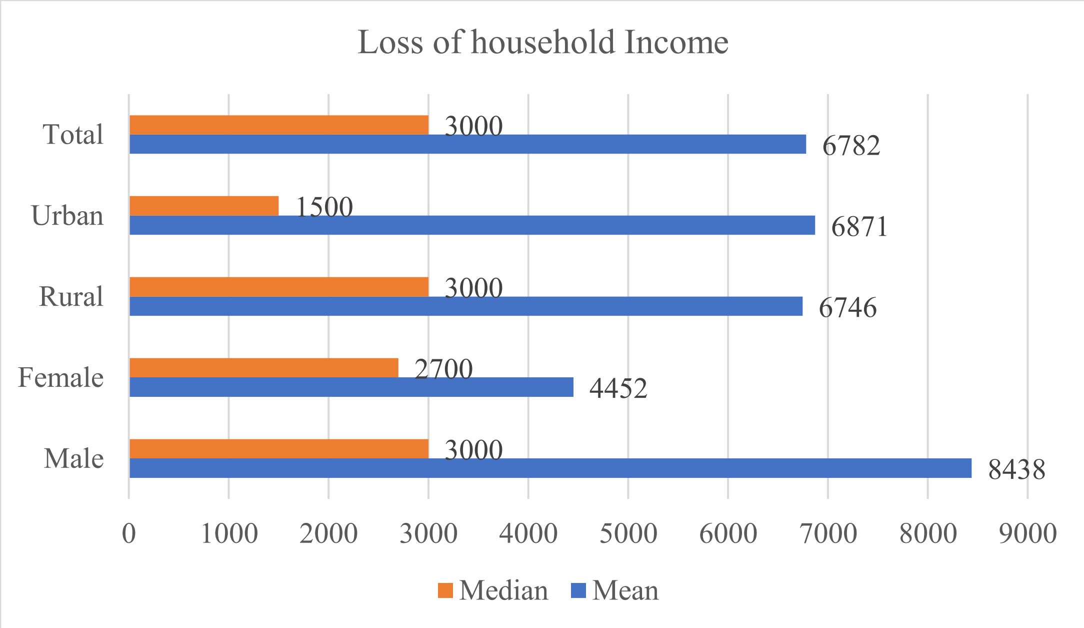
The major source of finance	**Male (per cent)**	**Female (per cent)**	**Total (per cent)**
Household income	73.68	75.33	74.38
Borrowings	17.35	12.37	15.23
Sale of assets	1.34	1.81	1.54
Contribution from relatives and friends	7.63	10.48	8.84
Total	100	100	100
The second most important source of finance			
Household income	10.61	12.56	11.60
Borrowings	39.83	33.15	36.44
Sale of assets	1.24	6.13	3.72
Contribution from relatives and friends	48.32	33.78	40.95
Other sources	0.00	14.37	7.28
Total	100	100	100

Source: Author's estimation from unit level data of NSS 75th round (July 2017-June 2018) on Household Social consumption: Health;

The major and second most important source of finance for expenses for cancer patients aged between 18-60 years in Kerala is represented in Table 4.12. It can be observed that household income was the most common major source of finance for healthcare expenses among both male and female cancer patients (74.3 per cent). The second most important source of finance among cancer patients was contributions from relatives and friends (40.9 per cent). The sale of assets was the least common source of finance.

Figure 4.9

Loss of household income (INR₹) for cancer patients (between 18-60 years) in Kerala



Source: Author's estimation from unit level data of NSS 75th round (July 2017-June 2018) on Household Social consumption: Health;

Loss of household income can happen if the cancer patient is a working member of the household. Figure 4.9 represents the loss of household income that cancer patients incurred in Kerala. The ailment of a non-working member, too, causes disruption of the usual activity of the working member of the household, which in turn results in loss of household income. It can be observed that, on average, a cancer patient's household incurs a loss of ₹ 6782 due to treatment. In sector-wise distribution, there was not much significant difference in the mean loss of household income across rural and urban sectors. In sex-wise distribution, the mean loss of household income among males (₹ 8438) was almost double compared to the mean loss of household income among females (₹ 4452).

4.8. Conclusion

Breast cancer is the most common type of cancer in the world. The highest incidence and mortality of breast cancer was reported in Asia. The main factors for the rising number of breast cancer cases were changes in lifestyle, sociocultural, and hormonal risk factors. In India, cancer is one of the leading causes of mortality. Similar to the pattern of cancer across the world, breast cancer had the highest number of new cases and prevalence in India.

In India, among females, the highest incidence rate was for breast cancer, followed by cervix-uteri and ovarian cancer. Among males, the highest incidence rate was observed for the lip-oral cavity, followed by the lung, stomach, and oesophagus. Across the 31 PBC₹ in India, the highest CR incidence rate was observed in the Aizawl district, and the lowest CR incidence was observed in Osmanabad and Beed. The highest crude mortality rate was observed in the Aizawl district, and the lowest rate was observed in Aurangabad. It was observed that North-Eastern and South cancer registries have reported higher crude incidence for both male and female populations. Local cultural factors and lifestyle choices have contributed to the variation in cancer incidence patterns and differences across states in India.

The incidence and prevalence of cancer in Kerala is steadily increasing. By analysing the PBC₹ in India, it was observed that the female CR of cancer incidence in Thiruvananthapuram is the second highest compared to other PBC₹ in India. The third and fourth highest CR of incidence among males was reported in Thiruvananthapuram and Kollam PBC₹, respectively. Breast cancer is the most common type of cancer among females in Kerala, and the incidence of breast cancer has increased by 42 per cent over the period 2012-19 (Budget speech 2022-2023, Government of Kerala).

The secondary data analysis of NSS 75th round (July 2017-June 2018) on 'Household Social consumption: Health' revealed that across both sexes, Kerala had the highest percentage of cancer patients among the southern states of India. In rural sectors of Kerala, more cancer patients took treatment from government medical institutions than from private medical institutions, and in urban sectors, it was vice-versa. On average, a cancer patient in Kerala incurs around ₹ 60227 as a total medical expenditure. The package component was the highest contributor to the total medical expenditure. The direct medical expenditure incurred is significantly higher than the indirect medical expenditure. Female cancer patients incurred a higher average medical expenditure than male cancer patients. The reimbursement received by cancer patients for treatment was meagre compared to the total medical expenditure. This led to a high out-of-pocket expenditure, which further resulted in patients seeking other sources of finance to fund cancer treatment. Thus, cancer is such a disease that causes not only physical distress but also financial distress.

CHAPTER V

SOCIO-ECONOMIC AND DISEASE PROFILE OF BREAST CANCER PATIENTS

5.1 Introduction

Socio-economic factors influence the health outcomes of an individual. Various research suggested that in both developing and developed countries, the degree of inequality in income distribution and the degree of racial segregation in a geographic area is associated with health inequalities. Social integration, social networks, and social support are considered key to health (Lynch et al., 2000; Hou et al., 2005; Reardon et al., 2006). The economic cost of an illness represents the burden on society. Socio-economic status plays an important role in the treatment-seeking behaviour of breast cancer patients. Apart from socio-economic factors, the disease profile is also an important factor in seeking healthcare. This chapter focuses on describing the socio-economic profile and TNM staging of breast cancer patients interviewed for the study.

5.2 Distribution of Sample by Socio-economic and Demographic Variables

Increasing research and policy, attention is being given to how the socioeconomic environment influences health. The socioeconomic environment shapes resources, opportunities, and exposures. It could also influence health outcomes either directly or indirectly (Robert,1998). Levels of education, employment, income, and income security in a community create and shape risks and benefits for health, many of which accumulate over the life course.

Many studies on social determinants of health have reported socioeconomic inequalities in health. People with lower socioeconomic status (SES) have, on average, poorer health and die younger than those with higher SES. Research suggests that the associations between education and health are driven by increases in human capital, psychosocial resources, living conditions, and better health care and lifestyle (Huisman et al., 2003; Fors et al.,2007)

5.2.1 Distribution of Sample by Age, Educational Attainment and Marital Status

In this section, the respondents' age, educational attainment and marital status are explained. The educational attainment of an individual is an important factor that determines the treatment-seeking and choice of provider behaviour of breast cancer patients. The support of partners has been found to play an important role in the timely treatment of breast cancer.

Table 5.1

Distribution of sample according to age of the respondents by TNM stage

TNM stage	Age of the respondent								Total	
	20 to 30 years		31 to 40 years		41 to 50 years		51 to 60 years			
	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent
Stage IA&IB	2	11.8%	19	14.6%	19	11.5%	12	13.6%	52	13.0%
Stage IIA	7	41.2%	33	25.4%	61	37.0%	33	37.5%	134	33.5%
Stage IIB	5	29.4%	46	35.4%	41	24.8%	24	27.3%	116	29.0%
Stage IIIA	0	0.0%	20	15.4%	26	15.8%	12	13.6%	58	14.5%
Stage IIIB	2	11.8%	6	4.6%	11	6.7%	4	4.5%	23	5.8%
Stage IIIC	1	5.9%	6	4.6%	7	4.2%	3	3.4%	17	4.3%
Total	**17**	**100.0%**	**130**	**100.0%**	**165**	**100.0%**	**88**	**100.0%**	**400**	**100.0%**

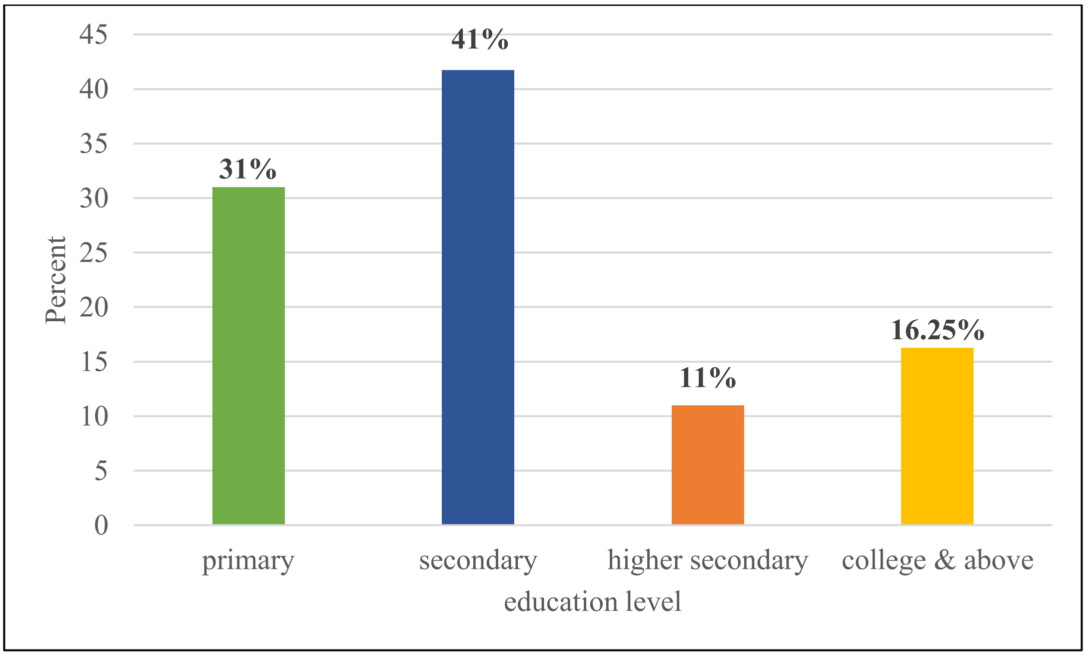
Source: Survey data

The age of the patient is an important factor in determining the treatment protocol. The researcher observed that if a patient during her diagnosis is above the age of 60 years, then they are given less intensive treatment because of health issues. Many studies reported a higher disease load in females and an increase in the number of chronic conditions with age.[19] Hence, for the study breast cancer patients below the age of 61 years were chosen for this study.

From Table 5.1, it can be observed that 4.3 per cent of the total respondents belonged to the age group of 20 to 35 years. This was the lowest frequency observed. Around 41.3 per cent of the respondents belonged to the age group 41 to 50 years, 32.5 per cent belonged to the age group 31 to 40 years, and 22.0 per cent belonged to the age group 51 to 60 years. It can be observed that as age increases, the prevalence of advanced-stage breast cancer also increases. Across all age groups, higher frequency was observed for stage IIA and IIB breast cancer.

Figure 5.1

Level of educational attainment of respondents



Source: Survey data

The education level of the respondents is illustrated in Figure 5.1. It can be observed that 41.75 per cent of the respondents had completed secondary education, and 31 per cent had completed primary education. Only 27.25 per cent of the respondents have an educational level of higher secondary and above. The educational attainment of an individual influences treatment-seeking and choice behaviour. It also affects the awareness regarding breast cancer.

Table 5.2

Distribution of sample according to marital status by TNM Stage

TNM stage	Marital Status of Respondent								Total	
	Married		Divorced		Widow		Unmarried			
	N	%	N	%	N	%	N	%	N	%
Stage IA&IB	37	12.0%	1	7.1%	12	18.5%	2	16.7%	52	13.0%
Stage IIA	103	33.3%	4	28.6%	21	32.3%	6	50.0%	134	33.5%
Stage IIB	91	29.4%	7	50.0%	17	26.2%	1	8.3%	116	29.0%
Stage IIIA	46	14.9%	0	0.0%	10	15.4%	2	16.7%	58	14.5%
Stage IIIB	17	5.5%	1	7.1%	4	6.2%	1	8.3%	23	5.8%
Stage IIIC	15	4.9%	1	7.1%	1	1.5%	0	0.0%	17	4.3%
Total	**309**	**100.0%**	**14**	**100.0%**	**65**	**100.0%**	**12**	**100.0%**	**400**	**100.0%**

Source: Survey data

Research studies have found an association between marital status and cancer mortality. It has been observed that increased social support has been suggested as one of the primary drivers for the inverse association between being married and cancer mortality, particularly because married cancer patients were more likely than unmarried patients to be diagnosed at an earlier disease stage and to receive definitive treatment. It was observed from Table 5.2 that 77.3 per cent of the total number of respondents were married. Around 16.3 per cent of the respondents were widows. Divorced and unmarried respondents were the lowest in number, 3.5 per cent and 3 per cent, respectively.

5.2.2 Distribution of Sample by Occupation, Monthly Income, Number of Employed Family Members and Annual Income of the Household

In this section, the occupation of the respondents and their monthly income is analysed. Along with that, the number of employed family members in the household and the annual income of the household are also analysed.

Table 5.3

Distribution of the sample according to the occupation of the respondents

Occupation	Frequency	Per cent (%)
Unemployed	279	69.8%
Government service	29	7.2%
Unorganised sector	43	10.8%
Private company employee	20	5.0%
Business	6	1.5%
Retired employee	23	5.8%
Total	**400**	**100.0%**

Source: Survey data

It can be observed from Table 5.3 that 69.8 per cent of the respondents were unemployed. Among the employed respondents, the highest frequency, 10.8 per cent of the total respondents, was observed in the unorganised sector. The employees of the unorganised sector did not have health protection schemes provided from their place of employment. Around 7.2 per cent of the respondents were employed in the government sector. Private company employees constituted 5 per cent of the total respondents. The researcher observed that respondents who worked in the government sector and private companies could avail of employee benefit schemes provided by the employer and the government. Respondents who had business on their own constituted 1.5 per cent of the total respondents. Around 5.8 per cent of the respondents were retired employees. It was observed that retired employees receive a monthly pension, but they are not eligible for any employee benefits or government schemes.

Table 5.4
Distribution of the sample according to the monthly income of the respondents

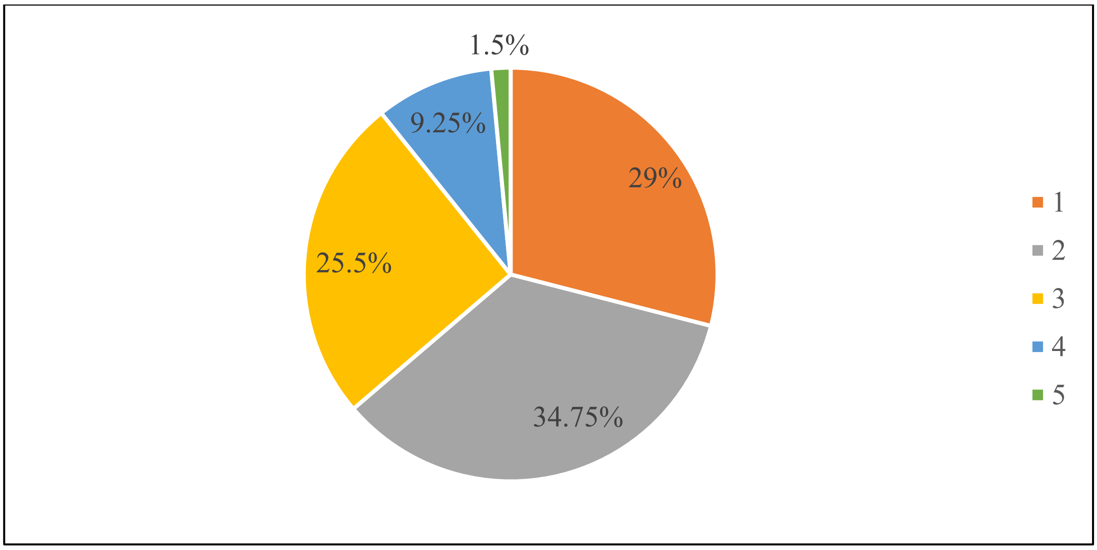
Monthly income	Frequency	Percent (%)
Not applicable	279	69.8%
Up to ₹10,000	54	13.5%
₹ 10,001- 25,000	51	12.8%
₹ 25,001- 50,000	14	3.5%
50,001- 1,00,000	2	0.5%
Total	**400**	**100.0%**

Source: Survey data

Income has an important role as an enabling resource for health care access and use in the Andersen health behavioural model. [21] From Table 5.4; it can be observed that 69.8 per cent of the respondents did not have any source of monthly income. Around 13.5 per cent of the respondents had a monthly income below ₹ 10000, and 12.8 per cent had a monthly income between ₹ 10001 and ₹ 25000. Only very few respondents had a monthly income above ₹ 25000. Around 3.5 per cent of the total respondents had a monthly income between ₹ 25001 and ₹ 50000, and 0.5 per cent of the total respondents had a monthly income between ₹ 50001 and ₹ 100000.

Figure 5.2

Distribution of the sample by the number of employed family members in the household of the respondent



Source: Survey data

The employed members of the household have a source of income, and this indirectly affects the financial support a patient receives during her breast cancer treatment. From Figure 5.2, it can be observed that there was only one employed member in 29per cent of the households. There were two employed members in 34.75 per cent of the households and three employed members in 25.5 per cent of the households. There were only a few households with more than three employed members. In 9.25 per cent of the households, there were four employed members, and in 1.5 per cent of the households, there were five employed members.

Table 5.5

Distribution of sample by annual income of the household by TNM stage

TNM stage	Annual income of the household								Total	
	below ₹ 1 lakh		between ₹ 1 lakh to ₹ 5 lakhs		between ₹ 5 lakhs to ₹ 10 lakhs		between ₹ 10 lakhs to ₹ 25 lakhs			
	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent
Stage IA&IB	2	4.4%	38	16.0%	9	9.6%	3	13.0%	52	13.0%
Stage IIA	21	46.7%	72	30.3%	37	39.4%	4	17.4%	134	33.5%
Stage IIB	11	24.4%	73	30.7%	28	29.8%	4	17.4%	116	29.0%
Stage IIIA	8	17.8%	30	12.6%	13	13.8%	7	30.4%	58	14.5%
Stage IIIB	3	6.7%	15	6.3%	5	5.3%	0	0.0%	23	5.8%
Stage IIIC	0	0.0%	10	4.2%	2	2.1%	5	21.7%	17	4.3%
Total	**45**	**100.0%**	**238**	**100.0%**	**94**	**100.0%**	**23**	**100.0%**	**400**	**100.0%**
Chi-Square Value=38.44; degrees of freedom=15**										

Source: Survey data *** Significant at 0.01 level*

The income of the household is an indicator of material resources, and it is positively associated with longevity. Income might affect the health of people by enabling those with high income to lead healthy lifestyles, while those at the lower level of the income distribution have fewer of these enabling resources. (Chetty et al.,2016). The annual income of the households of the respondents is depicted in Table 5.5. From the table, it can be observed that 11.3 per cent of the households had an annual income below ₹ one lakh. Around 59.5 per cent of the households had an annual income between ₹ one lakh and five lakhs. The annual income of 23.5 per cent of the households was between ₹ 5 lakhs to 10 lakhs. Only a few households, 5.8 per cent of the households, had an annual income above ₹ 10 lakhs. The chi-square value (38.445) was found to be significant at 1per cent, which indicates that there is a significant difference in the annual income of the households of the respondents among different TNM stages of breast cancer.

5.2.3 Distribution of Sample According to Primary Caregiver and Their Occupation

During the treatment of breast cancer, a patient's family is most involved in caring for the patient. They help them to adapt and manage their disease. During this phase, the caregivers experience a high burden caused by greater responsibilities and changes in their family and social life. In this section, the relation of the respondent and the primary occupation of the caregiver is discussed in detail.

Table 5.6

Distribution of sample according to relation to primary caregiver

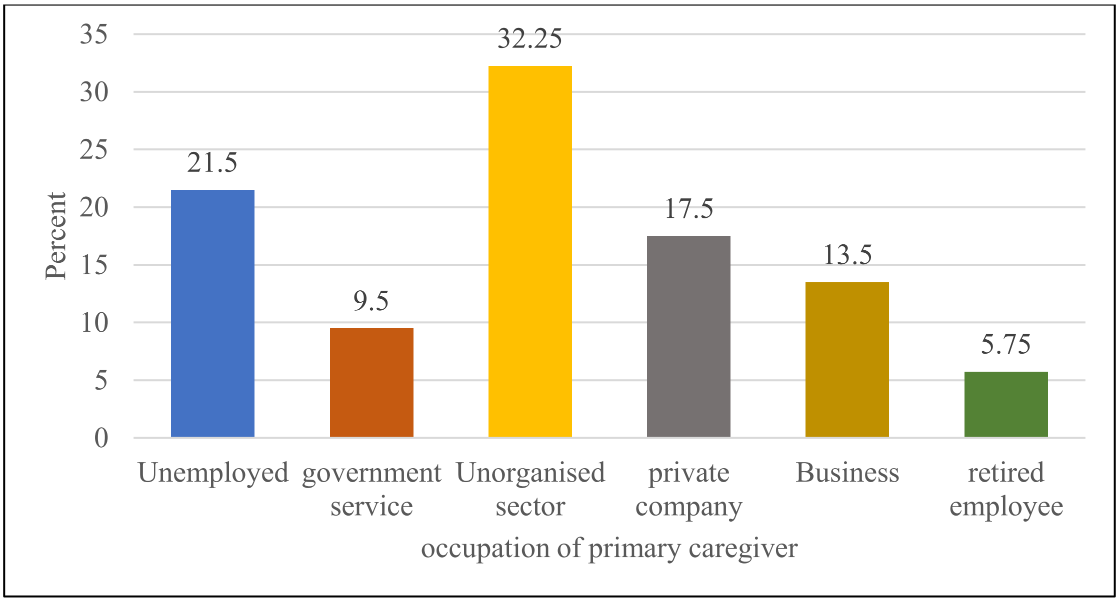
Relation to primary caregiver	Frequency	Percent (%)
Spouse/partner	219	54.8%
Children	153	38.3%
Siblings	21	5.3%
Second-degree relative	3	0.8%
Parents	3	0.8%
Friends	1	0.3%
Total	**400**	**100.0%**

Source: Survey Data

It can be observed from Table 5.6 that for 54.8 per cent of the total respondents, the primary caregiver is their spouse. In the case of 38.3 per cent of the respondents, the children of the respondents were their primary caregivers. For 6.1 per cent of the respondents, the primary caregiver was either their siblings or their second-degree relative. Only 1.1 per cent of the respondents had either their parents or friends as the primary caregiver.

Figure 5.3

Distribution of sample according to occupation of primary caregiver



Source: Survey data

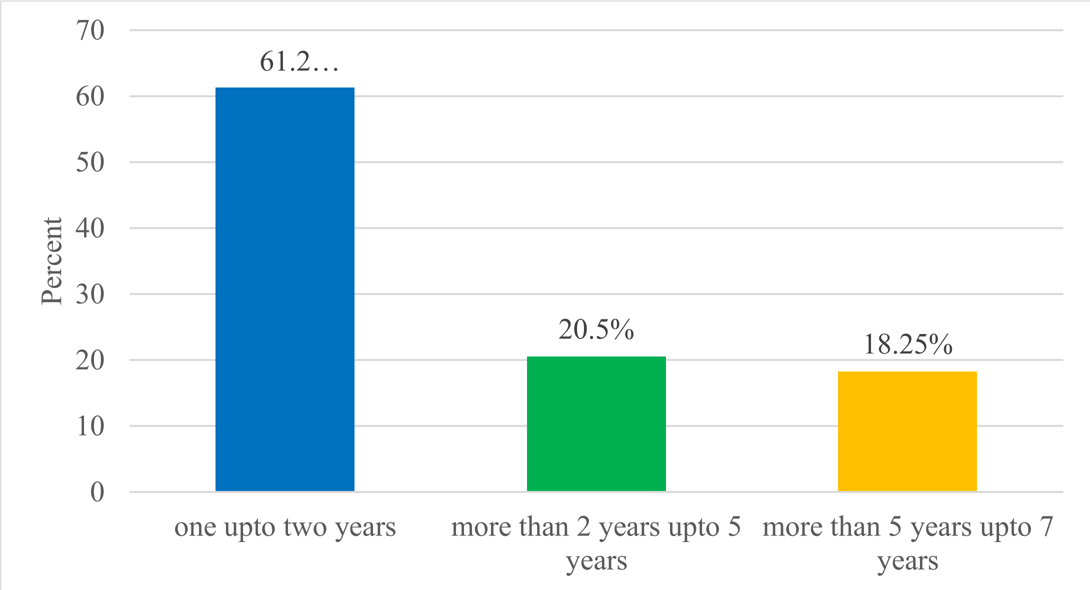
From Figure 5.3, it can be observed that 32.25 per cent of the primary caregivers were employed in the unorganised sector, and 21.5 per cent of the primary caregivers were unemployed. Around 17.5 per cent of the primary caregivers were employed in a private company, and 13.5 per cent of the caregivers had a business on their own. Around 9.5 per cent of the primary caregivers were employed in the government sector, and 5.75 per cent were retired employees.

5.3 Distribution of Sample Based on the Number of Years Since Treatment Was Completed and the Distance to the Follow-Up Hospital

In this section, the duration of completion of treatment from the date of treatment is illustrated. The distance from the follow-up centre to the respondent's household is also analysed.

Figure 5.4

Distribution of sample according to years since treatment was completed



Source: Survey data

The respondents were selected randomly for the study. Breast cancer patients who completed the treatment before August 2019 were selected for the study. From Figure 5.3, it can be observed that 61.25 per cent of the total respondents had completed the treatment between one to two years before the date of the interview. Around 38.75 per cent of the respondents had completed treatment more than two years from the date of the interview.

Table 5.7

Distribution of sample according to distance to the follow-up hospital

Distance to the follow-up hospital	Frequency	Percent (%)
within 30 km	124	31.0%
from 31 to 60 km	125	31.3%
from 61 to 100 km	141	35.3%
more than 100 km	10	2.5%
Total	**400**	**100.0%**

Source: Survey data

The distance to the follow-up hospital from the respondent's household is depicted in Table 5.7. Around 62.3 per cent of the respondents lived within 60 km of the follow-up hospital. Only 37.8 per cent of the respondents lived more than 60 km from the follow-up hospital.

5.4 Distribution of Sample Based on Diagnosis, Treatment, and Follow-Up Variables

In this section, the years since the treatment was completed, the distance to the follow-up centre and the treatment plan are analysed. Also, the choice of provider for diagnosis, treatment and follow-up are discussed.

Table 5.8

Distribution of sample based on TNM stage

TNM stage of breast cancer		
	N	**Per cent (%)**
stage I A and I B	52	13.0%
stage II A	134	33.5%
stage II B	116	29.0%
stage III A	58	14.5%
stage III B	23	5.8%
stage III C	17	4.3%
Total	**400**	**100%**

From Table 5.8, it can be observed that 13per per cent of the sample had stage I, 62.5 per cent had stage II, and 24.5 per cent had stage III breast cancer.

Table 5.9

Distribution of sample according to treatment protocol by TNM stage

Treatment protocol	TNM Stage												Total	
	IA &IB		IIA		IIB		IIIA		IIIB		IIIC			
	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent
S only	24	46.2%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	24	6.0%
S+RT	6	11.5%	15	11.2%	4	3.4%	0	0.0%	0	0.0%	0	0.0%	25	6.3%
S+CT	20	38.5%	57	42.5%	17	14.7%	0	0.0%	0	0.0%	0	0.0%	94	23.5%
S+CT+RT	0	0.0%	27	20.1%	61	52.6%	28	48.3%	0	0.0%	4	23.5%	120	30.0%
NACT+S+ CT+RT	0	0.0%	1	0.7%	0	0.0%	15	25.9%	11	47.8%	9	52.9%	36	9.0%
S+CT+RT+ TT	0	0.0%	6	4.5%	14	12.1%	7	12.1%	1	4.3%	1	5.9%	29	7.2%
NACT+S+ CT+RT+TT	0	0.0%	0	0.0%	0	0.0%	5	8.6%	7	30.4%	2	11.8%	14	3.5%
S+CT+TT	2	3.8%	25	18.7%	13	11.2%	0	0.0%	0	0.0%	0	0.0%	40	10.0%
NACT+S+ CT	0	0.0%	2	1.5%	4	3.4%	0	0.0%	0	0.0%	0	0.0%	6	1.5%
NACT+S+ RT	0	0.0%	1	0.7%	2	1.7%	3	5.2%	4	17.4%	1	5.9%	11	2.8%
NACT+S+ CT+TT	0	0.0%	0	0.0%	1	0.9%	0	0.0%	0	0.0%	0	0.0%	1	0.3%
Total	**52**	**100.0%**	**134**	**100.0%**	**116**	**100.0%**	**58**	**100.0%**	**23**	**100.0%**	**17**	**100.0%**	**400**	**100.0%**

Chi-square value = 530.11; Degree of freedom = 50;**

Source: Survey data *** Significant at 0.01 level*

The treatment protocol taken by respondents of this study is illustrated in Table 5.9. It can be observed that the most common type of treatment protocol received by Stage IA and IB breast cancer patients was surgery only (46.2 per cent). Among stage IIA breast cancer patients, the most common type of treatment protocol was surgery followed by adjuvant chemotherapy (42.5 per cent). Surgery followed by adjuvant chemotherapy and radiation was the most common type of treatment protocol among stage IIB and stage IIIA breast cancer patients (52.6 per cent and 48.3 per cent, respectively). Among stage IIIB and IIIC breast cancer patients, neoadjuvant chemotherapy followed by surgery, adjuvant chemotherapy and radiation were the most common type of treatment protocol (47.8 per cent).

Surgery was part of the treatment protocol of all the respondents chosen for this study. Around 29.8 per cent of the respondents had surgery followed by adjuvant chemotherapy and radiation, and this was the most common type of treatment protocol observed in this study. Around 21.2 per cent of the respondents had received targeted therapy as part of their treatment. Pearson Chi-square value (530.11) was found to be significant at 1per cent, which indicates that there is a significant difference in the treatment plan across different TNM stages of breast cancer.

Table 5.10

Distribution of sample according to number of chemotherapy cycles across TNM stage

No: of chemo cycles	TNM Stage												Total	
	IA &IB		IIA		IIB		IIIA		IIIB		IIIC			
	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent
0	30	57.7%	15	11.2%	2	1.7%	0	0.0%	0	0.0%	0	0.0%	47	11.8%
4	21	40.4%	45	33.6%	16	13.8%	0	0.0%	0	0.0%	0	0.0%	82	20.5%
6	1	1.9%	48	35.8%	52	44.8%	19	32.8%	10	43.5%	2	11.8%	132	33.0%
8	0	0.0%	24	17.9%	38	32.8%	32	55.2%	8	34.8%	11	64.7%	113	28.2%
12	0	0.0%	2	1.5%	8	6.9%	7	12.1%	5	21.7%	4	23.5%	26	6.5%
Total	**52**	**100%**	**134**	**100%**	**116**	**100%**	**58**	**100%**	**23**	**100%**	**17**	**100%**	**400**	**100%**
Chi-square value = 253.25; Degrees of freedom = 20**														

Source: Survey data *** Significant at 0.01 level*

Treatment of breast cancer usually involves surgery followed by chemotherapy or radiation. From Table 5.10, it can be observed that almost 87.8 per cent of the respondents had taken chemotherapy as part of their treatment. Only 12.3 per cent of the respondents had not taken any chemotherapy drugs during treatment. Around 20.3per cent of the respondents had taken four-cycle chemotherapy, and this was mostly taken by respondents who had early-stage breast cancer, i.e., stage IA, IB and IIA. The most common mode of chemotherapy was six cycles. Almost 32.8 per cent of the respondents had taken six-cycle chemotherapy, and this was mostly taken by respondents who had stage II cancers. The eight-cycle and twelve-cycle chemotherapy is usually given in two phases: neo-adjuvant and adjuvant. These are mostly taken by respondents who had stage III cancers. Around 28.2 per cent of the respondents had taken eight-cycle chemotherapy, and 6.5 per cent had taken twelve-cycle chemotherapy. The chi-square value (253.25) was found to be significant at 1per cent, which indicates that there is a significant difference in the number of chemotherapy cycles taken across different TNM stages of breast cancer.

Table 5.11

Distribution of sample according to duration of radiation received across TNM stage

Duration of radiation faction	TNM Stage												Total	
	IA &IB		IIA		IIB		IIIA		IIIB		IIIC			
	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent
No radiation	46	88.5%	83	61.9%	35	30.2%	0	0.0%	0	0.0%	0	0.0%	164	41.0%
3 to 4 weeks	6	11.5%	47	35.1%	76	65.5%	49	84.5%	11	47.8%	2	11.8%	191	47.8%
4 to 6 weeks	0	0.0%	2	1.5%	5	4.3%	3	5.2%	1	4.3%	0	0.0%	11	2.8%
6 to 8 weeks	0	0.0%	2	1.5%	0	0.0%	6	10.3%	11	47.8%	15	88.2%	34	8.5%
Total	**52**	**100%**	**134**	**100%**	**116**	**100%**	**58**	**100%**	**23**	**100%**	**17**	**100%**	**400**	**100%**
Chi-square value = 330.25 **; Degrees of freedom = 15														

Source: Survey data *** Significant at 0.01 level*

From Table 5.11, it can be observed that almost 59 per cent of the respondents had taken radiation as part of their treatment. The number of radiation factions usually ranges from 15 to 30. These are given over a time period ranging from three to eight weeks. The time period is determined by the patient's health to endure the radiation treatment. It can be observed that the most common mode of radiation was faction given over a time period ranging between three to four weeks. Almost 47.8 per cent of the respondents had received this mode of treatment, and it was mostly taken by respondents who had stage II breast cancer and stage IIIA breast cancer. Around 11per cent of the respondents had radiation factions given over a time period ranging from four to eight weeks. This mode was common among patients with stage III breast cancer. Almost 41 per cent of the respondents had not taken radiation as part of their treatment. This was mostly observed among stage I and stage IIA breast cancers. The chi-square value (330.25) was found to be significant at 1per cent, which indicates that there is a significant difference in the number of radiation factions taken across different TNM stages of breast cancer.

It can be concluded from Table 4.8 and Table 4.9 that among stage I breast cancer, the most common type of treatment was either a combination of surgery and chemotherapy or a combination of surgery and radiation. Among stage II breast cancer, it was mostly surgery along with a lower number of chemotherapy cycles and a lower number of radiation factions. Stage III breast cancer respondents had to undergo treatment with a higher number of chemotherapy cycles and radiation factions.

Table 5.12

Distribution of sample according to number of injections of Trastuzumab taken in targeted therapy across TNM stage

Number of trastuzumab injections received	TNM Stage												Total	
	IA &IB		IIA		IIB		IIIA		IIIB		IIIC			
	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent	N	per cent
no injections	50	96.2%	101	75.4%	88	75.9%	46	79.3%	15	65.2%	14	82.4%	314	78.5%
3 to 5 injections	1	1.9%	14	10.4%	14	12.1%	6	10.3%	4	17.4%	2	11.8%	41	10.3%
6 to 10 injections	0	0.0%	11	8.2%	6	5.2%	1	1.7%	2	8.7%	1	5.9%	21	5.3%
11 to 15 injections	0	0.0%	3	2.2%	4	3.4%	2	3.4%	2	8.7%	0	0.0%	11	2.8%
16 to 20 injections	1	1.9%	5	3.7%	4	3.4%	3	5.2%	0	0.0%	0	0.0%	13	3.3%
Total	**52**	**100.0%**	**134**	**100.0%**	**116**	**100.0%**	**58**	**100.0%**	**23**	**100.0%**	**17**	**100.0%**	**400**	**100.0%**
Chi-square value = 22.48 **; Degrees of freedom = 20														

Source: Survey data *** Significant at 0.01 level*

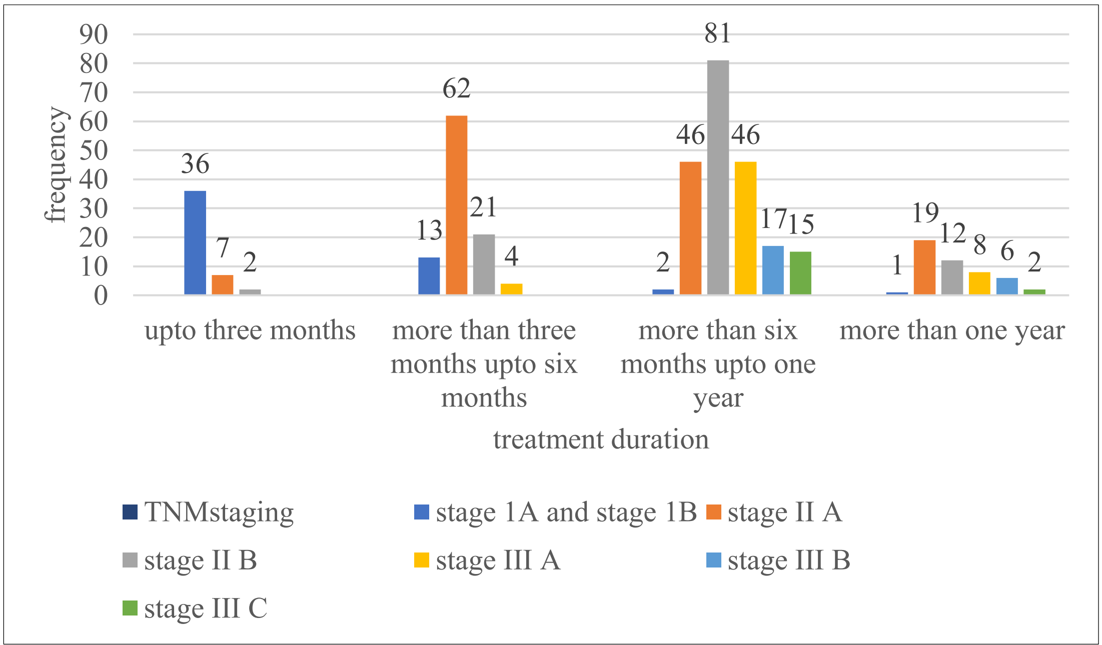
Trastuzumab injections are given to patients who have HER2-positive breast cancer. The injections are given across a time period ranging from three to twenty months. From Table 5.12, it can be observed that 78.8 per cent of the respondents had not received Trastuzumab as part of their treatment. Around 15.3 per cent of the respondents received Trastuzumab injections ranging between three to ten injections. Only 6.1 per cent of the respondents received Trastuzumab injections ranging from eleven to twenty. The chi-square value (22.482) was found to be insignificant at 1per cent, which indicates that there is no significant difference in the number of Trastuzumab injections taken across different TNM stages of breast cancer.

5.4.1 Distribution of Sample According to Treatment Duration

The duration of treatment depends on the treatment protocol. In early-stage breast cancer, treatment is usually completed in less than six months, except in cases where targeted therapy is given. Stage II breast cancer treatment usually varies between three months and one year, except in cases where targeted therapy is given. Stage III breast cancer treatment usually varies between six and eighteen months. This is because neo-adjuvant and adjuvant chemotherapy is given as part of treatment, and it takes three to six months to complete these chemotherapy cycles.

Figure 5.5

Distribution of sample based on treatment duration across TNM stage



Source: Survey data

From Figure 5.5, it can be observed that 69.2 per cent of the respondents who had stage I breast cancer had their treatment completed within three months. In the case of 30.7 per cent of stage I breast cancer respondents, the treatment duration was more than three months due to targeted therapy. Around 80.5 per cent of respondents who had stage IIA cancer and 87.9 per cent of respondents who had stage IIB had their treatment completed in a duration of more than three months up to one year. Except in the case of four cases, respondents who had stage III cancers had to undergo treatment, which took a minimum of six months to complete. In cases where respondents were given targeted therapy, the treatment took at least six months to complete. The chi-square value (286.61) was found to be significant at 1 per cent, which indicates that there is a significant difference in the treatment duration across different TNM stages of breast cancer.

5.4.2 Distribution of Sample Based on Choice of Provider for Diagnosis, Treatment and Follow-Up

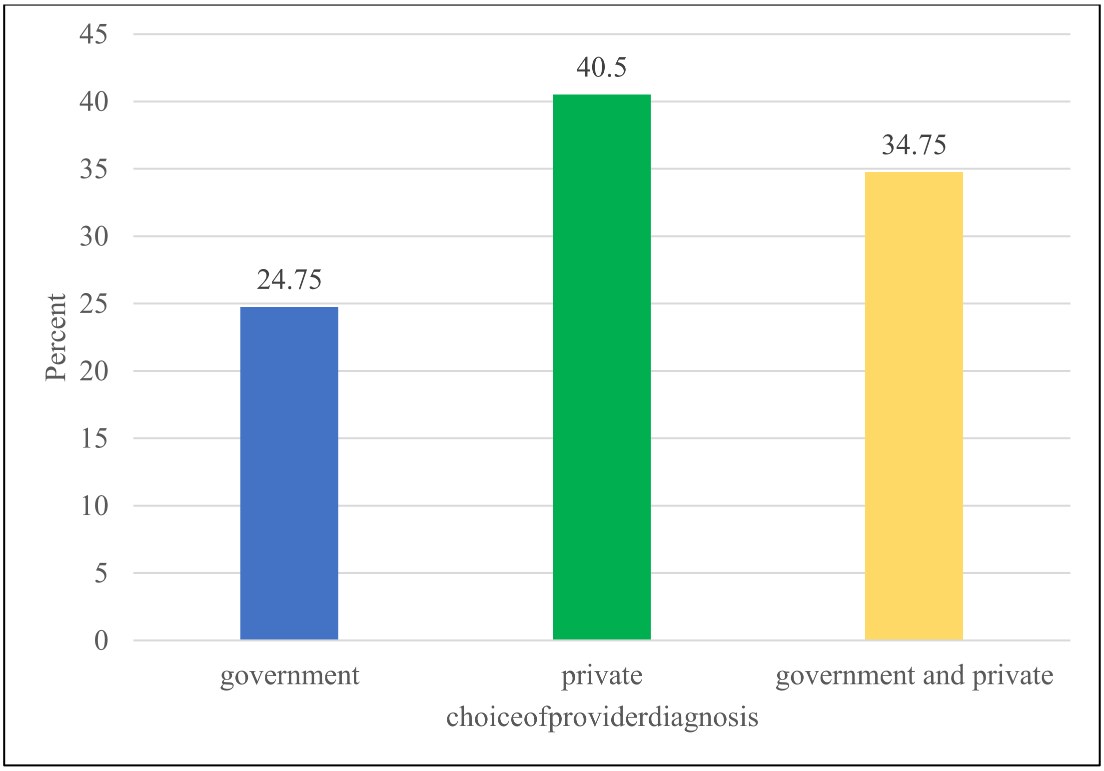
In this section, the choice of provider of respondents from diagnosis to follow-up is discussed in detail.

5.4.2.1 Choice of Provider for the Diagnosis of Breast Cancer

Patients undergo various tests like blood tests, imaging tests and biopsies to diagnose breast cancer and the TNM stage. In this section, the respondents' choice of healthcare provider is illustrated.

Figure 5.6

Distribution of sample based on choice of provider for diagnosis



Source: Survey data

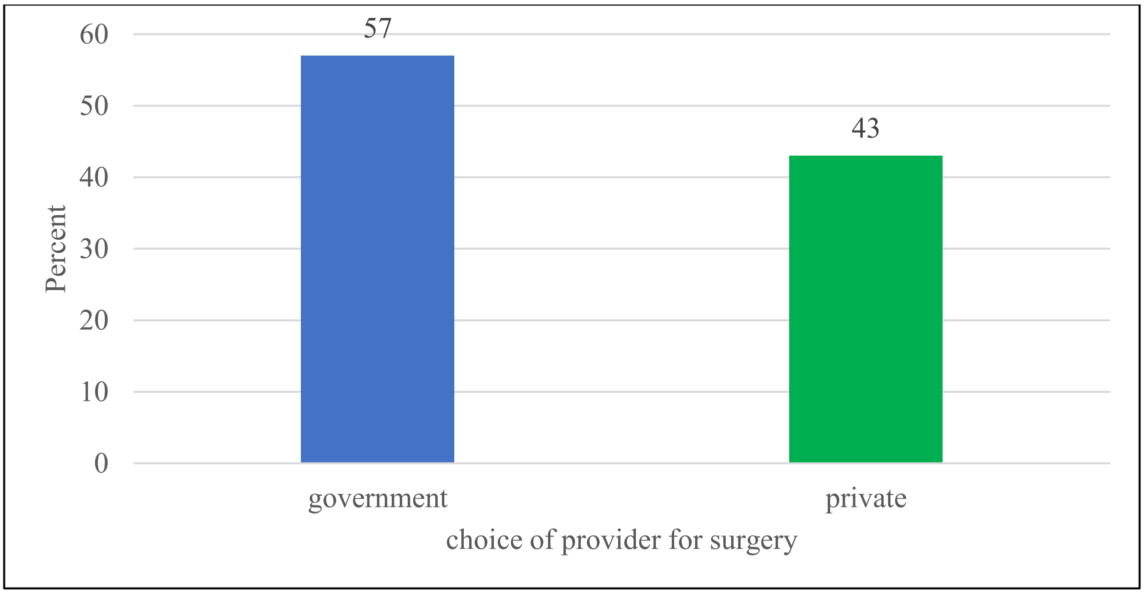
It can be observed from Figure 5.6 that 40.5 per cent of the respondents went to a private healthcare centre for diagnosis of breast cancer. Around 34.75 per cent of the respondents went to both private and government healthcare centres for diagnosis. Only 24.75 per cent of the respondents had their complete diagnosis done at a government healthcare institution.

5.4.2.2 Choice of Provider for Treatment of Breast Cancer

The treatment of breast cancer includes surgery, radiation, chemotherapy and targeted therapy. In this section, the choice of healthcare provider for each type of treatment is analysed.

Figure 5.7

Distribution of sample based on choice of provider for surgery

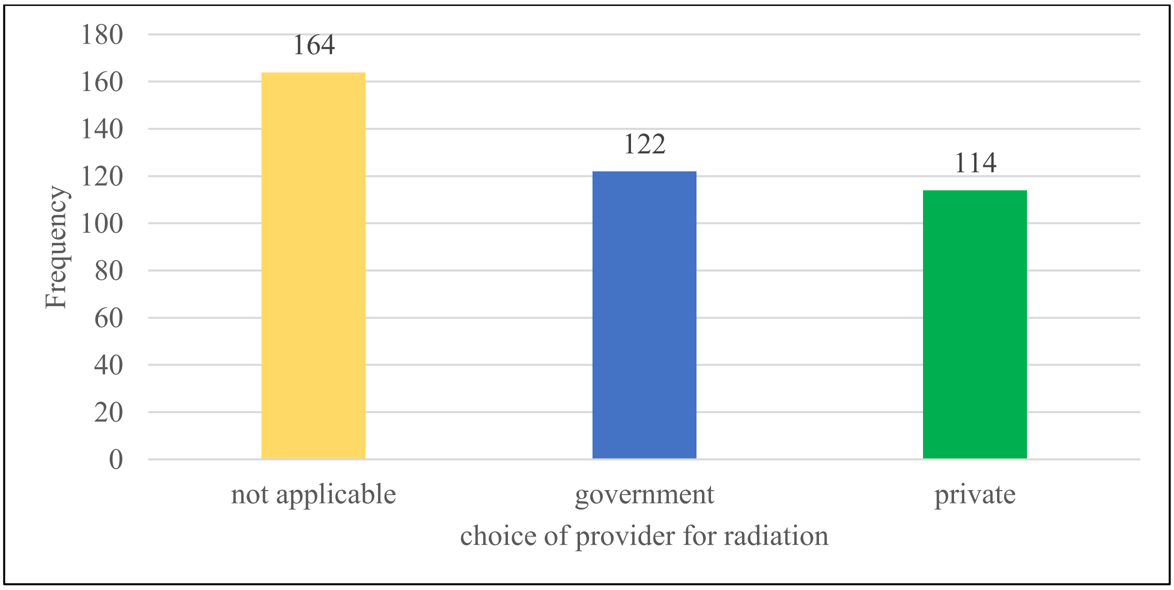


Source: Survey data

It can be observed from Figure 5.7 that 57 per cent of the respondents had done their surgery in a government healthcare institution, and 43 per cent of the respondents had done their surgery in a private healthcare institution.

Figure 5.8

Distribution of sample based on choice of provider for radiation

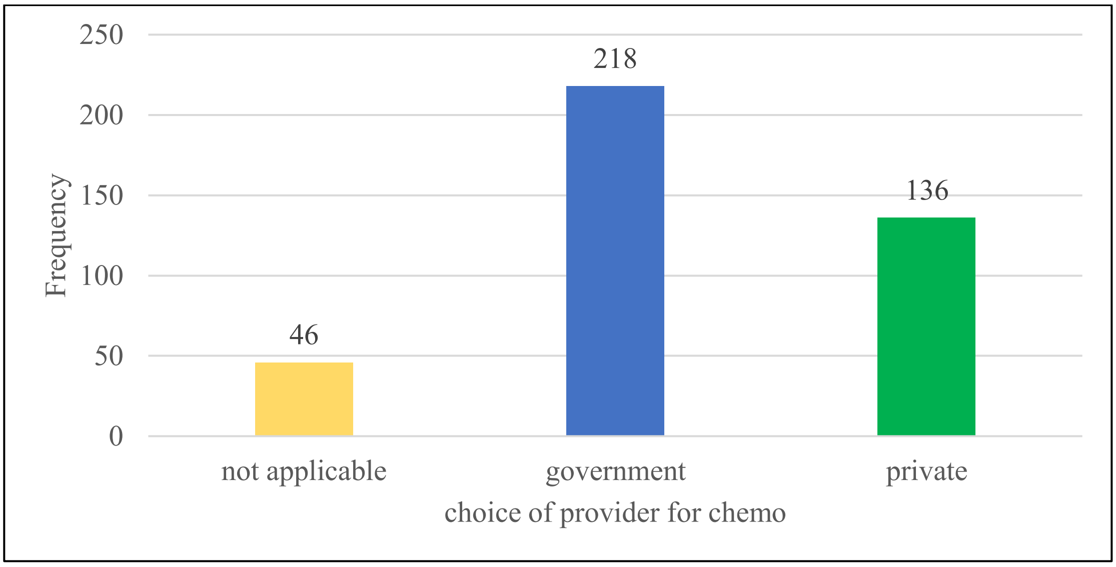


Source: Survey data

It can be observed from Figure 5.8 that a total of 235 respondents had received radiation as a part of their treatment. Around 51 per cent of the respondents who received radiation had gone to a government health institution, and 48.9 per cent of the respondents who received radiation had gone to a private health institution.

Figure 5.9

Distribution of sample based on choice of provider for chemotherapy

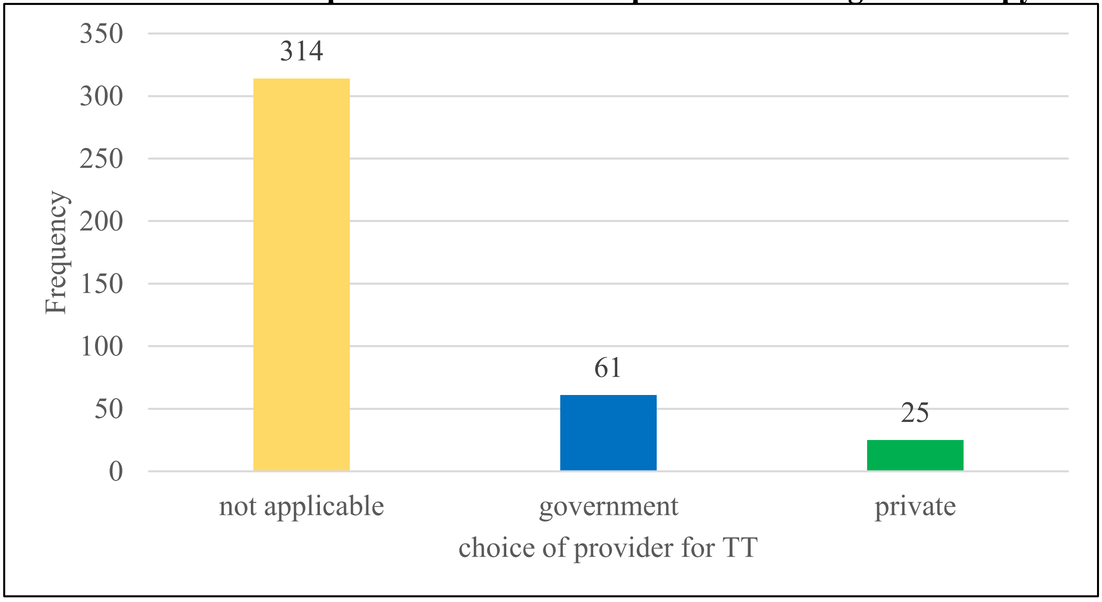


Source: Survey data

From Figure 5.9, it can be observed that a total of 354 respondents had received chemotherapy as part of their treatment. Around 61.5 per cent of the respondents who received chemotherapy had gone to a government health institution, and 38.5 per cent of the respondents who received chemotherapy had gone to a private health institution.

Figure 5.10

Distribution of sample based on choice of provider for targeted therapy



Source: Survey data

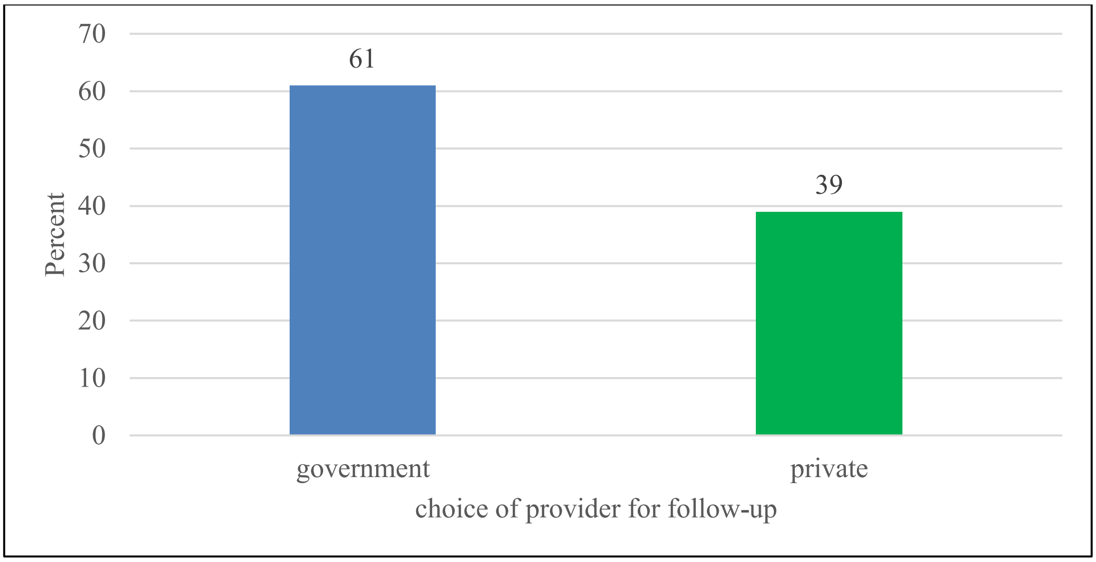
It can be observed from Figure 5.10 that only 86 respondents had received targeted therapy. Around 70.9 per cent of the respondents who received targeted therapy had gone to a government health institution, and 29 per cent of the respondents who received targeted therapy had gone to a private health institution.

5.4.2.3 Choice of Provider for Follow-Up of Breast Cancer

After the treatment, breast cancer patients have to visit the hospital for follow-up. This may happen once in six months or one year. In this section, the choice of healthcare provider for follow-up is analysed.

Figure 5.11

Distribution of sample based on choice of provider for follow-up



Source: Survey data

From Figure 5.11, it can be observed that 61 per cent of the respondents visited a government health institution for follow-up, and 39 per cent of the respondents visited a private health institution for follow-up.

5.5 Conclusion

This chapter gives a detailed description of the socioeconomic and disease profiles of the respondents. In the age-wise distribution of the sample, it was observed that the majority of the respondents belonged to the age group 31 to 50 years. It was observed that almost 69 per cent of the respondents had completed secondary education. The marital status-wise distribution of the sample revealed that the majority of the respondents were married. The number of employed respondents was low. Around 70 per cent of the respondents were unemployed. The monthly income of the majority of the employed respondents was below ₹ 25000. Most of the respondents had less than three employed family members in their household. The annual household income distribution of the sample showed that around 70 per cent of the sample had an annual income below ₹ 5 lakhs. The primary caregivers of the majority of the respondents were either their spouses or their children. Around 80 per cent of the respondents' primary caregivers were employed.

Based on the TNM stage of breast cancer,13 per cent of the respondents had stage I, 62.5 per cent had stage II and 24.5 per cent of the respondents had stage III breast cancer. The most common type of treatment protocol was surgery with chemotherapy and radiation. Targeted therapy was given to only a few respondents. Among those respondents who received chemotherapy, the most common mode was four to six cycles of chemotherapy. The majority of the respondents who received radiation as a part of their treatment had been given radiation factions over three to four weeks. A higher number of chemotherapy cycles and radiation factions were given to respondents who had stage III breast cancer. Most of the respondents who had been given targeted therapy as part of their treatment had received less than ten injections. Respondents who received targeted therapy took a longer time to complete their treatment.

The majority of respondents preferred to go to a private healthcare centre for diagnosis. This may be due to the higher quality of services available in private facilities and the delay in services in government centres. In the case of surgery and chemotherapy, the majority of the respondents had gone to a government healthcare institution. There was not much difference in the preference for government or private healthcare institutions in the case of radiation. The majority of the respondents who received Trastuzumab injections as a part of targeted therapy preferred to go to a government healthcare institution due to the high cost of injections. For follow-up, the majority of the respondents went to a government healthcare institution.

CHAPTER VI

ECONOMIC COST OF BREAST CANCER

6.1. Introduction

The total economic burden of cancer is the total of all resources consumed as a result of cancer and its prevention and care (Fryback & Craig,2004). The economic costs associated with cancer pose a financial risk for households. In developing countries, limited resources for health care and a lack of protection against catastrophic health spending have led to over-reliance on OOP health expenditure. The high costs of cancer treatment result in households being devoid of adequate means for other essential needs such as food and education (Minh et al.,2012; Campbell et al., 2017). The cost of illness (COI) methodology is used to estimate the economic burden that an illness imposes on a society. The aim of a cost of illness study is to identify and measure all the costs of a particular disease, including the direct and indirect costs.

In this chapter, the costs associated with the treatment of breast cancer are analysed. The cost incurred by respondents from diagnosis to follow-up is analysed. The direct and indirect medical costs associated with breast cancer are discussed in detail in this chapter.

6.2. Economic Impact of Cancer

Cancer and its treatment result in the loss of economic resources and opportunities for patients, their families, and society overall. The incidence of cancer has two immediate effects: it reduces the normal level of productive activity of the patient, and secondly, the household may need to increase its consumption of health services or goods at the expense of other goods and services. Households may reduce their consumption of non-health goods and services, or they may try to maintain current levels of non-health consumption by liquidating household assets or resorting to loans. They may also have to cut back on other nonmarket activities and their investment in people, e.g., education, health and social capital formation (Steinberg et al., 2002).

In order to understand the financial burden of cancer, it is important to analyse the household out-of-pocket expenditures. Household out-of-pocket spending can be defined as "the direct outlays of resident households, including gratuities and payments in-kind, made to health practitioners and to suppliers of pharmaceuticals, therapeutic appliances, and other goods and services, whose primary intent is to enhance and restore the health of individuals or population groups" (WHO, 2003). Direct medical costs include financial payments towards the partial or full cost of health care services or technologies (e.g., hospital inpatient and outpatient care, primary health care, diagnostic tests and drugs). Non-medical intervention costs include financial payments for (public or private) transport to health care facilities; subsistence costs while attending a hospitalised household member; special food needs; and any other household financial resources that are consumed as a result of the health condition.

An important consequence of cancer is that individuals are unable to perform their usual day-to-day activities. This results in a prolonged absence from paid work, which leads to an increase in the need to pay for health services and goods out of other household resources (particularly savings). On the other hand, the inability to carry out unpaid but productive household activities because of ill health (including child care, meal preparation, etc.) may lead to time being taken off from paid work by another household member or necessitate the purchase of these services or goods on the open market. Because of the sensitivity and complexity of questions around income and lost production, many economic impact studies of cancer have used time measures such as lost days of work as a proxy measure for lost output, to which a monetary value is then attached.

Households mitigate the adverse circumstances of one of their members being ill by using coping mechanisms, including the substitution of labour within the household (to preserve production and income flows) and the disposal of assets (to pay for health care).[6] Another important aspect of cancer is the impoverishment and consumption impact. In the absence of social security and other forms of formal/informal compensating mechanisms, households face increased health expenditures and lower productivity capacity. This can result in accentuated household poverty and a reduction in the number of resources available for non-health consumption, food items in particular. Insurance coverage has been observed to have an impact on cancer households.

The time spent by caregivers taking care of cancer patients also has an economic impact. Time spent by a household member providing informal (and financially uncompensated) care to a sick person could have been spent on other productive activities or leisure. Another impact is that the time spent accessing and receiving health care could have been alternatively spent on non-health-related activities.

Estimating and projecting the economic burden of cancer, including healthcare expenditures, productivity loss, and morbidity for patients and their families, are increasingly important issues for healthcare policymakers, healthcare systems, physicians, employers, and society overall. When estimating the economic burden of disease, the monetary valuation of resources used to treat disease and the loss of opportunities due to disease is measured as cost.

6.3. Direct Medical Cost Incurred by Breast Cancer Patients

Breast cancer patients incur direct medical costs during diagnosis, treatment and follow-up stages. In this section, the medical expenditures incurred by the respondents at each stage are analysed in detail.

6.3.1. Costs Incurred During Diagnostic Stage

The common symptoms of breast cancer are a new lump or mass, swelling of all or part of a breast (even if no lump is felt), skin dimpling, breast or nipple pain, nipple retraction (turning inward), nipple discharge (other than breast milk), swollen lymph nodes under the arm or near the collar bone. The stage of breast cancer can be determined through diagnostic tests. The diagnosis of breast cancer can be broadly classified into the following three categories:

I. Imaging tests: These tests use X-rays, magnetic fields, sound waves, or radioactive substances to create pictures of the inside of your body. The different types of imaging tests are:

a) Chest x-ray

b) Computed tomography (CT) scan

c) CT-guided needle biopsy

d) Magnetic resonance imaging (MRI) scan

e) Mammogram

f) Ultrasound

g) Positron emission tomography (PET) scan

h) PET/CT scan

i) Bone scan

II. Breast Biopsy: If breast symptoms or the results of an imaging test (such as a mammogram) suggest you might have breast cancer, then a breast biopsy is done. During a biopsy, a doctor removes small pieces of breast tissue from the suspicious area so they can be looked at in the lab to see if they contain cancer cells. The different types of biopsies are:

a) Fine needle aspiration (FNA)

b) Core needle biopsy

c) Surgical (open) biopsy

d) Lymph node biopsy

III. Breast Cancer Gene, Protein, and Blood Tests: Lab tests and other special tests are done in order to classify breast cancer better. The different types of tests are:

a) Tests for certain proteins on tumour cells: These include testing for hormone receptor proteins like estrogen receptor (ER) and progesterone receptor (PR), HER2 protein, and PD-L1 protein. The two tests are the immunohistochemistry (IHC) test and the fluorescence in situ hybridisation (FISH) test.

b) Molecular tests for gene changes: These include testing for *BRCA1* and *BRCA2* mutations, *PIK3CA* gene mutation, MSI and MMR, tumour mutational burden (TMB) and *NTRK* fusion genes.

c) Blood tests: These are used to determine a person's overall health. The different types of tests are complete blood count (CBC), blood chemistry tests and tumour markers tests.

Table 6.1

Distribution of samples based on the cost incurred during diagnosis of breast cancer when the choice of a healthcare provider is government

TNM stage of respondents	Mean cost (₹)				
	Mean cost of lab tests	Mean cost of imaging tests	Mean cost of biopsy tests	Mean cost of miscellaneous tests	Mean total cost of diagnosis
IA and IB	2,850.29	7,373.52	4,370.58	4,278.23	18,872.64
II A	3,256.42	8,100.71	3,878.09	4,356.66	19,591.90
II B	3,591.03	10,397.93	4,034.48	4,224.82	22,248.27
III A	3,801.66	10,904.44	3,928.88	5,388.33	24,023.33
III B	4,400.00	12,800.00	4,500.00	4,520.00	26,220.00
III C	6,500.00	18,500.00	6,500.00	11,200.00	42,700.00
Total	**3,378.58**	**9,056.16**	**4,045.85**	**4,469.14**	**20,949.74**

Source: Survey data

The costs incurred by a government healthcare provider during the diagnosis of breast cancer are presented in Table 6.1. It can be observed that respondents who had stage III cancers had incurred higher costs during the diagnosis stage. Respondents who had early-stage breast cancer like IA and IB had incurred comparatively lower costs during diagnosis. The mean total cost of diagnostic tests incurred by respondents who went to government healthcare providers is ₹ 20,949.74. The mean cost of imaging tests, ₹ 9,056.16, contributed the highest to the mean total costs, i.e., 43.2 per cent of the total mean costs. The mean cost of lab tests was ₹ 3,378.58, the mean cost of biopsy tests was ₹ 4,045.85, and the mean cost of miscellaneous tests was ₹ 4,469.14.

Table 6.2

Distribution of samples based on the cost incurred during diagnosis of breast cancer when the choice of healthcare provider is private

TNM stage of respondents	Mean Cost (₹)				
	Mean cost of lab tests	Mean cost of imaging tests	Mean cost of biopsy tests	Mean cost of miscellaneous tests	Mean total cost of diagnosis
IA and IB	4,526.66	9,853.33	4,966.66	8,154.66	27,501.33
II A	4,912.76	11,713.82	5,173.40	8,212.55	30,012.55
II B	4,848.55	12,962.66	5,128.44	8,384.00	31,323.66
III A	4,943.00	15,178.66	5,292.66	9,506.50	34,920.83
III B	4,872.14	17,035.71	5,671.42	8,931.42	36,510.71
III C	4,827.27	17,077.27	5,509.09	10,246.18	37,496.18
Total	**4,855.46**	**13,354.19**	**5,229.69**	**8,694.64**	**32,122.88**

Source: Survey data

The costs incurred by respondents who visited a private healthcare facility during diagnosis are presented in Table 6.2. The total mean cost of diagnosis for respondents who went to private healthcare facilities was ₹ 32,122.88. The mean cost of imaging was ₹ 13,354.19 and contributed to 41.5 per cent of the total mean costs. Lab tests contributed the lowest, i.e., 15per cent of the total mean costs. The mean cost of biopsy was ₹ 5,229.69, and the mean cost of miscellaneous was ₹ 8,694.64. Diagnostic costs for stage III breast cancer were the highest and were the lowest for stage I breast cancer.

Table 6.3

Distribution of samples based on the cost incurred during diagnosis of breast cancer when the choice of healthcare provider was both private and government

	Mean cost (₹)				
TNM staging	**Mean cost of lab tests**	**Mean cost of imaging tests**	**Mean cost of biopsy tests**	**Mean cost of miscellaneous tests**	**Mean total cost of diagnosis**
IA & IB	4,248.75	8,955.00	4,619.00	6,033.00	23,855.75
II A	4,399.88	10,802.66	4,790.66	7,293.44	27,171.22
II B	4,502.14	12,406.90	4,744.76	7,732.61	29,386.42
III A	4,191.31	12,725.00	4,786.84	6,134.73	27,837.89
III B	4,461.25	15,862.50	4,850.00	4,660.00	29,833.75
III C	4,837.00	16,450.00	4,738.00	5,346.00	31,371.00
Total	**4,399.78**	**11,778.66**	**4,753.09**	**6,864.78**	**27,758.95**

Source: Survey data

From Table 6.3, the costs incurred by respondents who visited both government and private healthcare facilities for diagnostic tests can be observed. The total mean cost of diagnostic tests was ₹ 27,758.95. Imaging tests contributed to 42.6 per cent of the total mean costs. The mean cost of lab tests was ₹ 43,99.78, which contributed the least to the total mean costs. The mean cost of biopsy tests was ₹ 4,753.09, and the mean cost of miscellaneous tests was ₹ 6864.78.

Table 6.4

ANOVA table depicting the cost (₹) of diagnostic tests among different choices of healthcare providers

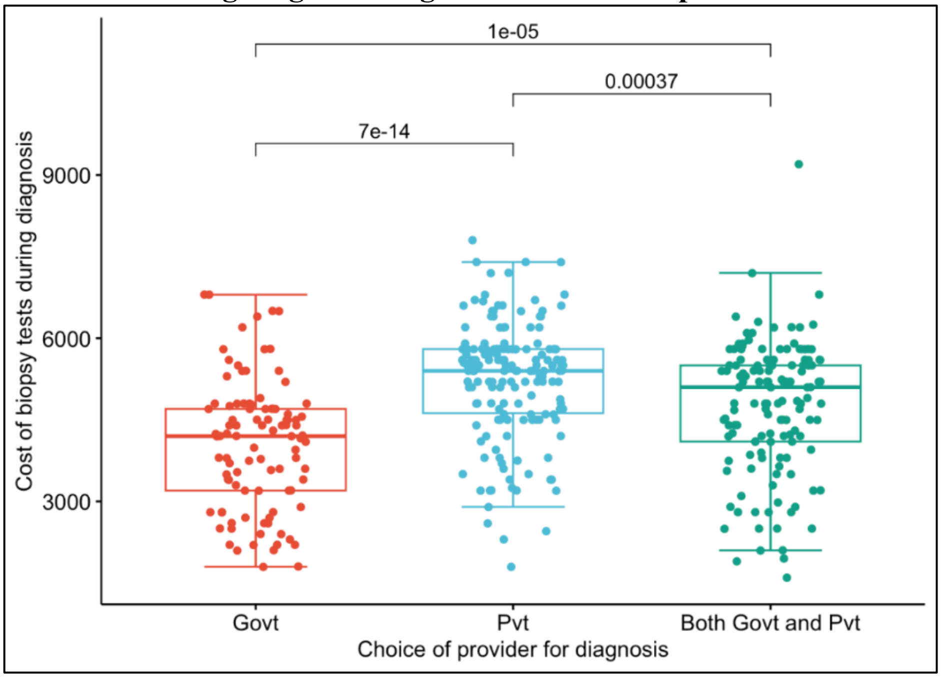
Cost	Choice of provider for diagnosis	Mean ± SD	Mean ± SD	KS Test	H Test
Cost of biopsy tests during diagnosis	Both Govt and Pvt	4,771±1,236	4,753±1,192	***	***
	Govt		4,046±1,186	***	
	Pvt		5,230±1,086	***	
Cost of imaging tests during diagnosis	Both Govt and Pvt	11,743±4,085	11,779±3,558	***	***
	Govt		9,056±3,513	***	
	Pvt		13,354±3,993	***	
Cost of lab tests during diagnosis	Both Govt and Pvt	4,332±1,301	4,400±1,245	***	***
	Govt		3,379±1,058	***	
	Pvt		4,855±1,162	***	
Cost of other miscellaneous tests during diagnosis	Both Govt and Pvt	7,013±3,913	6,865±3,765	***	***
	Govt		4,469±2,217	***	
	Pvt		8,695±3,994	***	
Total medical cost incurred during diagnosis	Both Govt and Pvt	27,841±8,840	27,759±7,675	***	***
	Govt		20,950±6,157	***	
	Pvt		32,123±8,511	***	

Source: Survey data *** - *significant at 1% level*

The ANOVA Table determining whether there is a significant difference among various costs incurred during diagnosis across choice of healthcare provider is represented in Table 5.5. Non-parametric tests like the Kolmogorov–Smirnov test (KS test) and the Kruskal-Wallis H test (H test) were done to analyse the distribution of the sample and to determine whether there are statistically significant differences between the three groups. The results from the KS test and H test reveal that the values are significant at a 1 per cent level, which leads to rejecting the null hypothesis that there is no difference between the three groups of choice of healthcare provider. Hence, it can be concluded that in the case of the cost of biopsy tests, imaging tests, lab tests, miscellaneous tests and total medical costs incurred during the diagnosis stage, there is a significant difference in costs across the three groups of providers: government, private and both government and private.

Figure 6.1A

Box-plot depicting costs of biopsy test incurred during diagnosis stage across choice of provider

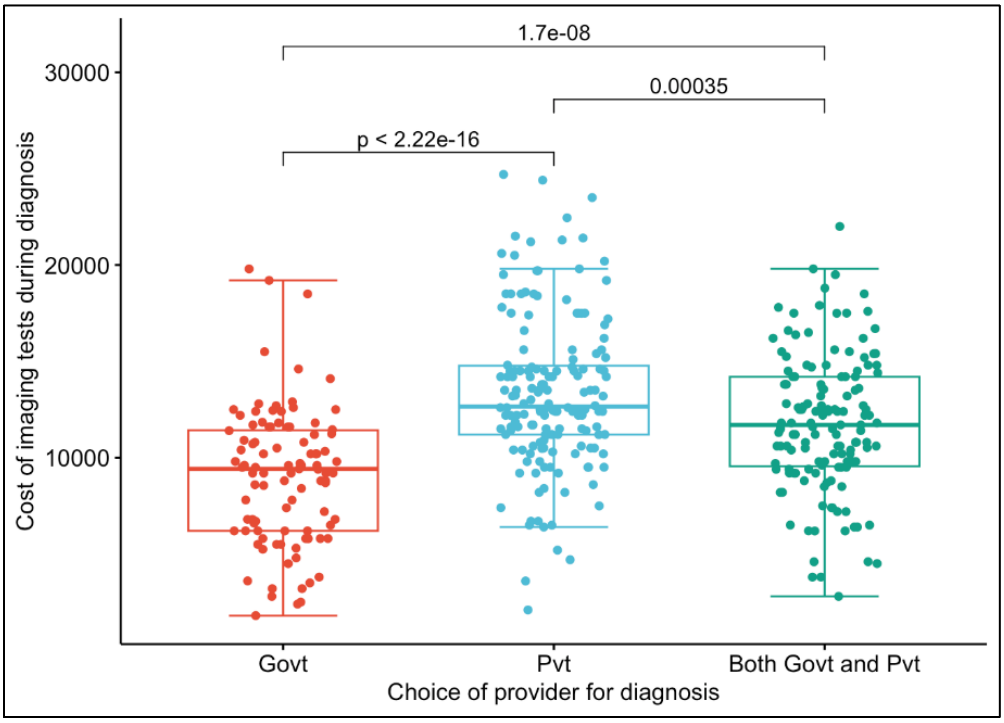


Source: Survey data

From Figure 6.1A, it can be observed that the mean value of the cost of biopsy tests incurred in private hospitals is higher than the other groups -government hospitals and both government and private. The p-values are represented at the top of the figure. The p-values from the H test observed for the choice of healthcare provider groups: government and private (7e-14), government and both government and private (1e-05), and private and both government and private (0.00), were lesser than 0.01 and, hence, statistically significant at 1per cent level. Therefore, we can conclude that the mean cost of biopsy tests incurred across government hospitals, private hospitals and both government and private hospitals are significantly different.

Figure 6.1B

Box plot depicting costs of imaging tests incurred during the diagnosis stage across a choice of provider

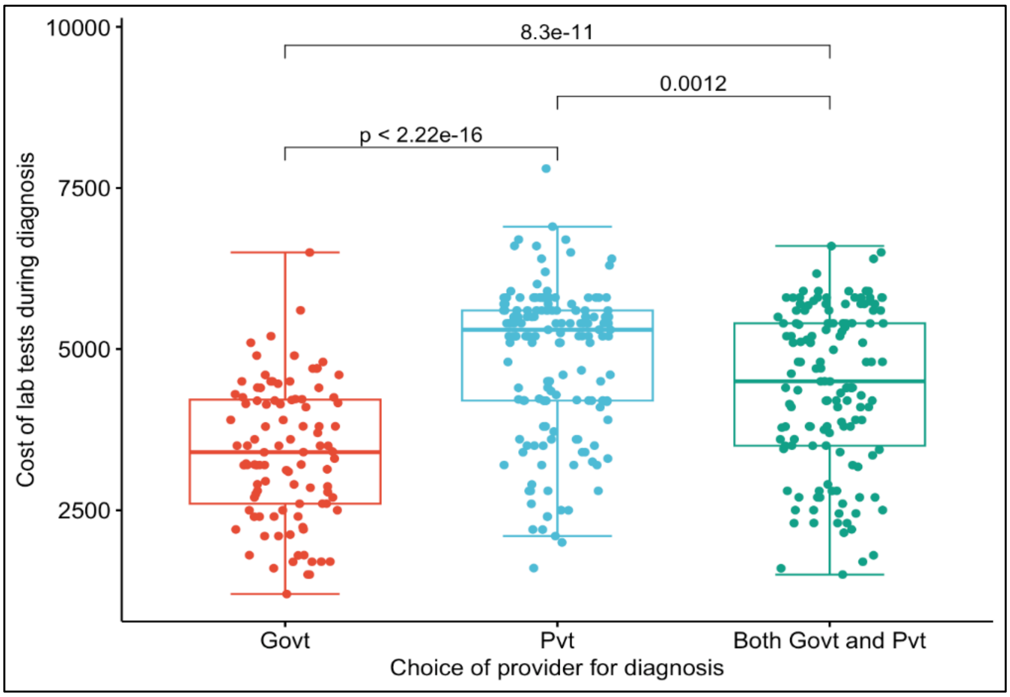


Source: Survey data

The distribution of costs incurred for imaging tests for diagnosis across choice of healthcare provider is depicted in Figure 6.1B. The p-values from H test observed for choice of healthcare provider groups: government and private ($p<2.22e-16$), government and both government and private (1.7e-08), and private and both government and private (0.00), were lesser than 0.01 and, hence statistically significant at 1 per cent level. Therefore, we can conclude that the mean cost of imaging tests incurred is significantly different across different healthcare providers.

Figure 6.1C

Box plot depicting costs of lab tests incurred during the diagnosis stage across a choice of provider

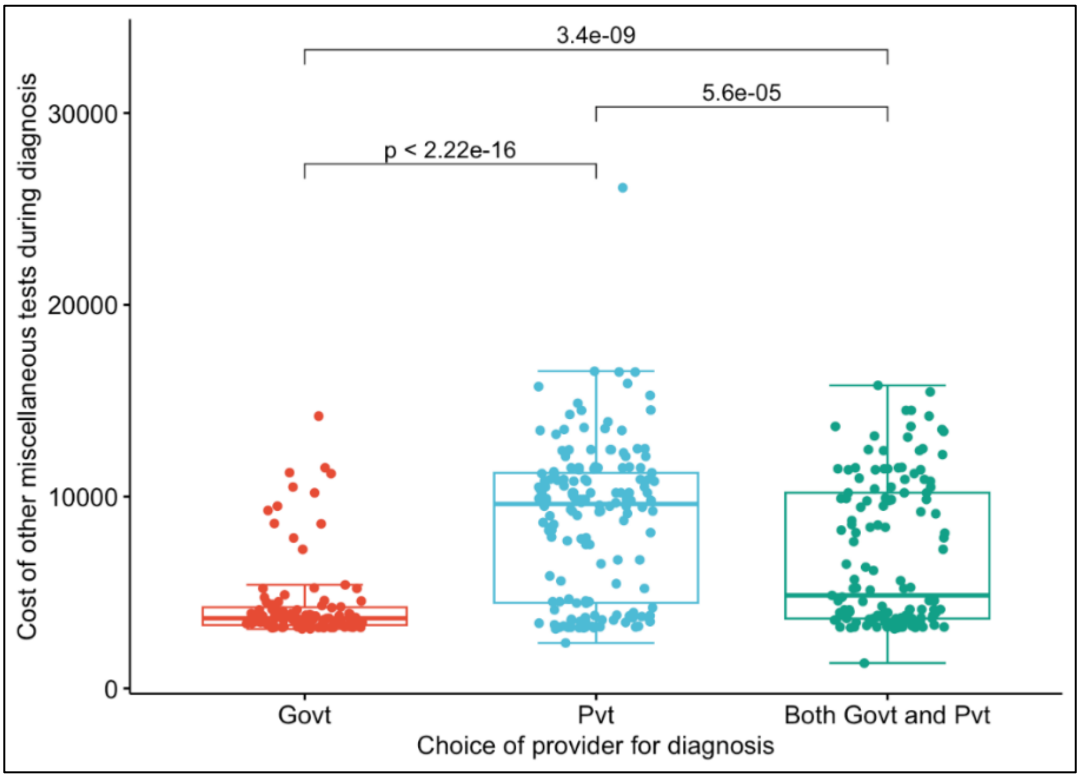


Source: Survey data

The distribution of costs incurred for lab tests for diagnosis across choice of healthcare provider is depicted in Figure 6.1C. The p-values from H test observed for choice of healthcare provider groups: government and private (p<2.22e-16), government and both government and private (8.3e-11), and private and both government and private (0.00), were lesser than 0.01 and, hence statistically significant at 1 per cent level. Therefore, we can conclude that the mean cost of lab tests incurred during diagnosis is significantly different across different healthcare providers.

Figure 6.1D

Box plot depicting costs of miscellaneous tests incurred during the diagnosis stage across choice of provider

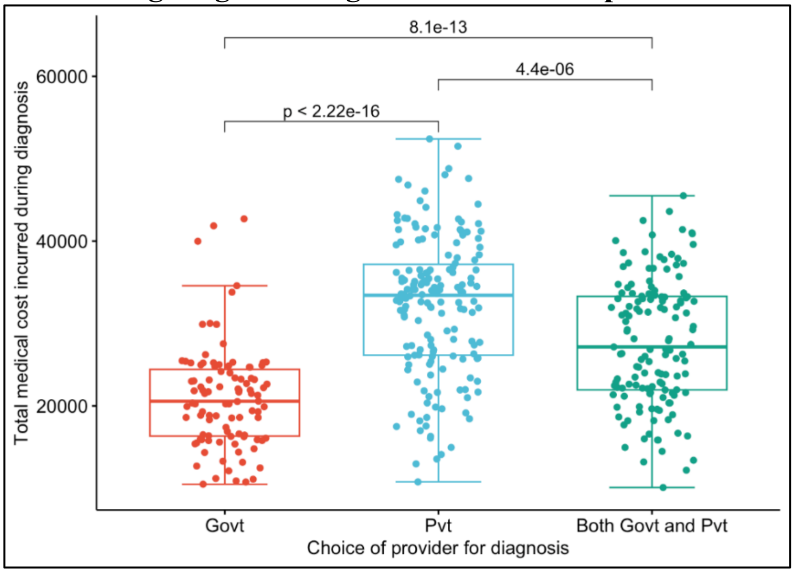


Source: Survey data

From Figure 6.1D, it can be observed that the mean value of the cost of miscellaneous tests incurred in government hospitals is lowest when compared to other healthcare provider groups -government hospitals and both government and private. The p-values from the H test observed for choice of healthcare provider groups: government and private (p<2.22e-16), government and both government and private (3.4e-09), and private and both government and private (5.6e-05), were lesser than 0.01 and, hence statistically significant at 1 per cent level. Therefore, we can conclude that the mean cost of miscellaneous tests incurred during diagnosis is significantly different across different healthcare providers.

Figure 6.1E

Box-plot depicting total medical cost incurred during diagnosis stage across choice of provider



Source: Survey data

The distribution of total medical costs incurred during diagnosis across a choice of healthcare provider is depicted in Figure 6.1E. The mean total medical costs were highest in the case of private hospitals. The p-values from the H test observed for choice of healthcare provider groups: government and private (p<2.22e-16), government and both government and private (8.1e-13), and private and both government and private (04.4e-06), were lesser than 0.01 and, hence statistically significant at 1 per cent level. Therefore, we can conclude that the mean total medical costs incurred during diagnosis were significantly different across different healthcare providers.

6.3.2. Costs Incurred During Treatment of Breast Cancer

Surgery, radiation, chemotherapy, and targeted therapy are included in the treatment stage in this study. Hormone therapy is included in the follow-up stage because the duration of hormone therapy is a minimum of five years and overlaps with the follow-up time period. Hence, in this section, the direct medical costs incurred during surgery, radiation, chemotherapy, and targeted therapy are analysed in detail.

6.3.2.1. Direct Medical Costs Incurred During Surgery

During surgery, a patient incurs the following types of costs:

i. Cost of imaging tests: Patients must undergo ECG, X-ray, and ultrasound tests before undergoing a surgical procedure.

ii. Cost of biopsy test: During the surgery, a biopsy of the lymph nodes is taken in order to determine the spread of breast cancer.

iii. Cost of surgical procedure: This includes anaesthetist fee, surgeon fee, operation theatre charges, nurse fee, tumour removal procedure charges and dressing charges.

iv. Cost of pharmaceutical products and surgical consumables.

v. Cost of lab tests: Before and after the surgery, several blood tests like CBC, calcium, sodium etc are done in order to determine the health of the patient.

vi. Cost of room and ICU ward

vii. Miscellaneous costs: These include registration, consultation, lymphedema removal charges, and post-surgery check-up charges.

Table 6.5

Distribution of sample based on the medical cost incurred during surgery when the choice of healthcare provider is government

TNM stage	Mean Cost (₹)							
	Mean cost of imaging tests	Mean cost of biopsy test	Mean cost of surgical procedure	Mean costs of pharma and consumables	Mean cost of lab tests	Mean cost of room and ICU ward	Mean miscellaneous costs	Mean total medical cost of surgery
IA& IB	998.3	1,621.8	25,448.0	6,011.3	2,513.1	3,275.3	1,701.0	41,569.0
IIA	1,231.3	1,609.0	25,739.6	6,593.0	3,395.9	2,916.4	1,922.3	43,407.8
IIB	1,150.4	1,676.4	26,419.4	6,624.9	3,470.0	3,004.6	2,026.1	44,372.1
IIIA	1,087.5	1,464.3	24,966.6	9,451.9	3,713.8	4,450.6	1,960.5	47,095.5
IIIB	1,300.7	1,705.7	24,084.1	7,649.3	3,753.4	3,041.4	1,837.5	43,372.2
IIIC	1,290.0	1,995.5	25,342.3	8,676.4	4,353.3	3,400.5	2,031.6	47,089.8
Total	**1,162.1**	**1,633.4**	**25,681.5**	**7,028.9**	**3,390.1**	**3,216.2**	**1,924.8**	**44,037.2**

Source: Survey data

The cost incurred by respondents who went to government hospitals for surgery as a part of breast cancer treatment is presented in Table 6.5. The mean total medical cost of surgery was ₹ 44,037.2. The mean surgical procedure cost was ₹ 25,681.5, contributing the highest to the total mean costs (58.3 per cent of the mean total cost of surgery). The mean cost of pharmaceutical products and surgical consumables cost was ₹ 7,028.9 and was the second-highest contributor to the total mean cost of surgery. The mean cost of the imaging test was ₹1,162.1, the lab test was ₹ 3,390.1, and the mean cost of the biopsy test was ₹ 1,633.4. The mean cost of room and ICU ward was ₹ 3,216.2, and the mean miscellaneous costs were ₹ 1,924.8.

Table 6.6

Distribution of samples based on the medical cost incurred during surgery when the choice of a healthcare provider is private

TNM staging	Mean Cost (₹)							
	Mean cost of imaging tests	**Mean cost of biopsy test**	**Mean cost of surgical procedure**	**Mean costs of pharma and consumables**	**Mean cost of lab tests**	**Mean cost of room and ICU ward**	**Mean miscellaneous costs**	**Mean total medical cost of surgery**
IA& IB	2,148.9	5,846.5	44,318.4	6,317.5	4,492.1	4,163.1	4,849.2	72,135.9
IIA	2,122.5	5,174.4	41,178.7	5,512.3	4,693.8	3,841.3	4,736.1	67,259.5
IIB	1,838.6	5,594.5	42,510.5	5,441.7	4,287.1	3,951.0	4,751.1	68,374.7
IIIA	1,963.1	5,323.6	42,862.1	5,836.1	4,324.8	4,260.6	4,869.3	69,439.8
IIIB	1,642.2	5,230.0	39,814.4	4,936.6	4,261.1	4,722.2	5,341.1	65,947.7
IIIC	2,002.5	5,117.5	51,242.5	8,657.5	4,173.7	4,425.0	4,084.3	79,703.1
Total	**1,987.0**	**5,393.7**	**42,585.5**	**5,751.9**	**4,446.6**	**4,052.0**	**4,776.6**	**68,993.6**

Source: Survey data

The cost incurred by respondents who went to private hospitals for surgery as a part of breast cancer treatment is presented in Table 6.6. It was observed that the mean total medical cost of surgery was ₹ 68,993.6. The mean cost of surgical procedures was ₹ 42,585.5 and was the highest contributor to the total mean cost of surgery. The mean cost of pharmaceutical products and surgical consumables cost was ₹ 5,751.9. The mean cost of the imaging test was ₹ 1,987, the mean cost of the lab test was ₹ 4,446.6, and the mean cost of the biopsy test was ₹ 53,93.7. The mean cost of room and ICU ward was ₹ 4,052, and the mean miscellaneous costs were ₹ 4,776.6. The highest mean total medical cost was observed among stage IIIC breast cancer respondents.

Table 6.7:

ANOVA table representing the different medical costs (₹) incurred during breast cancer surgery among different choices of healthcare providers

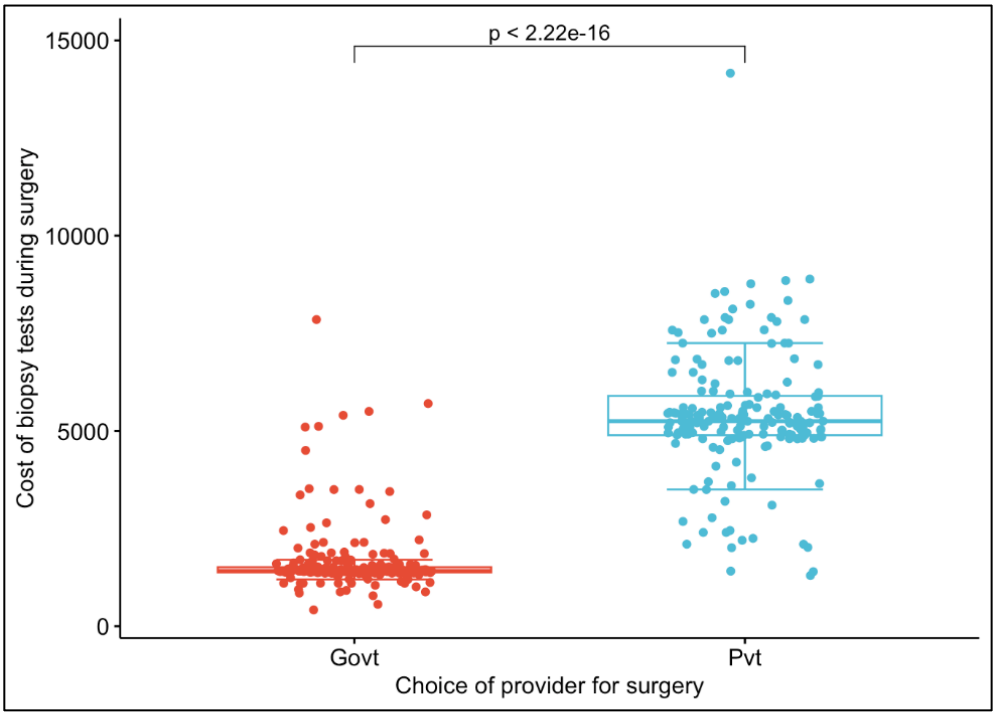
Cost	Choice of provider for surgery	Mean ± SD	Mean ± SD	KS Test	H Test
Cost of biopsy tests during surgery	Govt	3,250±2,238	1,633±842	***	***
	Pvt		5,394±1,624	***	
Cost of imaging tests during surgery	Govt	1,517±894	1,162±813	***	***
	Pvt		1,987±772	***	
Cost of lab tests during surgery	Govt	3,844±1,712	3,390±1,808	***	***
	Pvt		4,447±1,364	***	
Cost of miscellaneous services during surgery	Govt	3,151±1,754	1,925±872	***	***
	Pvt		4,777±1,228	***	
Cost of pharmaceuticals and medical consumables during surgery	Govt	6,480±3,009	7,029±3,434	***	***
	Pvt		5,752±2,129	***	
Cost of room and ward facilities during surgery	Govt	3,576±1,900	3,216±2,202	***	***
	Pvt		4,052±1,258	***	
Cost of surgical procedure	Govt	32,950±10,836	25,682±6,443	***	***
	Pvt		42,586±7,418	***	
Total medical cost incurred during surgery	Govt	54,769±16,208	44,037±10,248	***	***
	Pvt		68,994±10,793	***	

Source: Survey data

The ANOVA Table determining whether there is a significant difference among various costs incurred during surgery across choice of healthcare provider is represented in Table 6.7. The results from the KS test and H test reveal that the values obtained were significant at a 1 per cent level. Hence, it can be concluded that there is a significant difference in costs incurred in government and private hospitals in case of the cost of biopsy tests, imaging tests, lab tests, surgical procedures, room and ward facilities, pharmaceuticals and medical consumables, miscellaneous services and total medical costs during surgery.

Figure 6.2A:

Box plot depicting costs of biopsy tests incurred during surgery across choice of provider

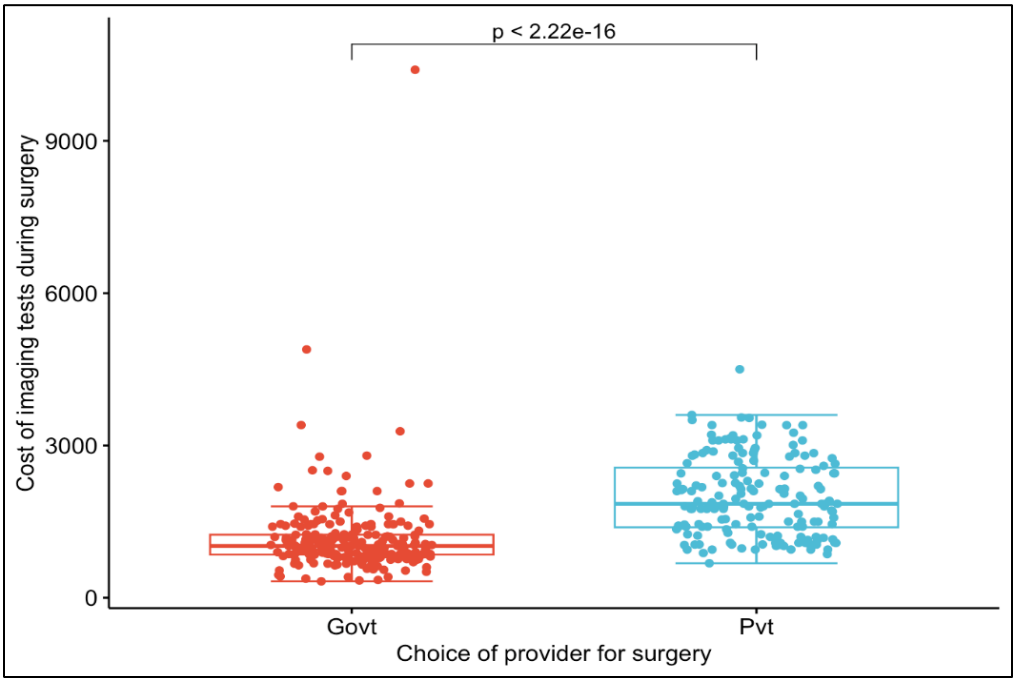


Source: Survey data

The distribution of costs incurred for biopsy tests during surgery across a choice of healthcare providers is depicted in Figure 6.2A. The p-value from the H test observed across government and private hospitals ($p<2.22e-16$) was less than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of biopsy tests incurred during surgery is significantly different across government and private hospitals. From ANOVA Table 6.7, it can be observed that the mean cost of biopsy tests incurred during surgery was ₹ 3,250±2,238 across both government and private hospitals.

Figure 6.2B

Box plot depicting costs of imaging tests incurred during surgery across choice of provider

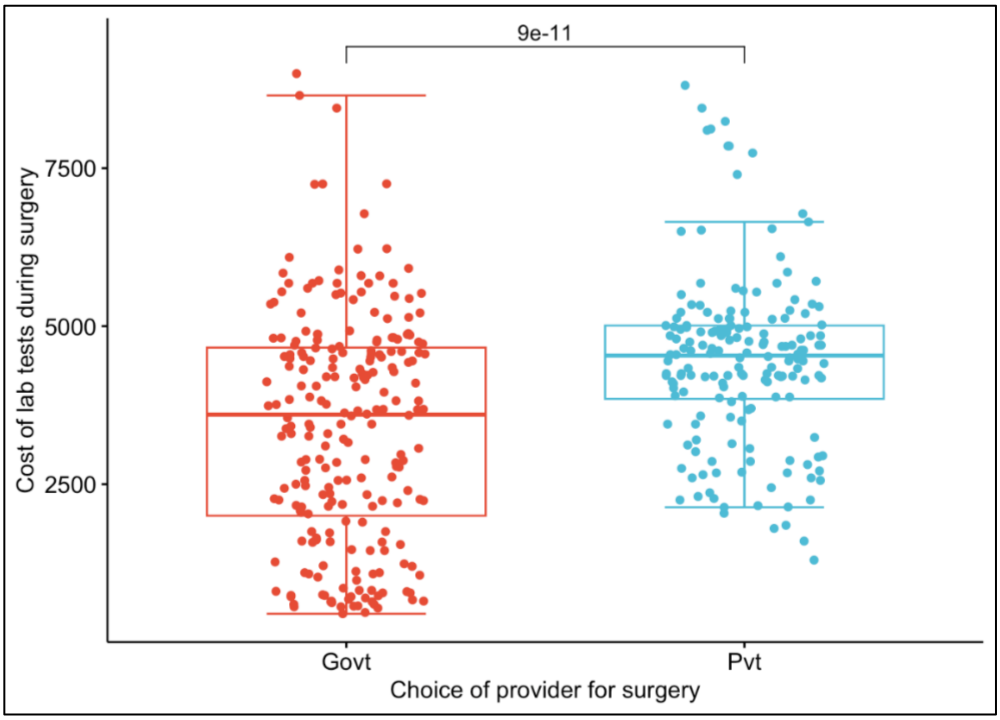


Source: Survey data

The distribution of costs incurred for imaging tests during surgery across a choice of healthcare provider is depicted in Figure 6.2B. The p-value from the H test observed across government and private hospitals (p<2.22e-16) was less than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of imaging tests incurred during surgery is significantly different across government and private hospitals. From ANOVA Table 6.7, it can be observed that the mean cost of imaging tests incurred during surgery was ₹ 1,517±894.

Figure 6.2C

Box-plot depicting costs of lab tests incurred during surgery across choice of provider

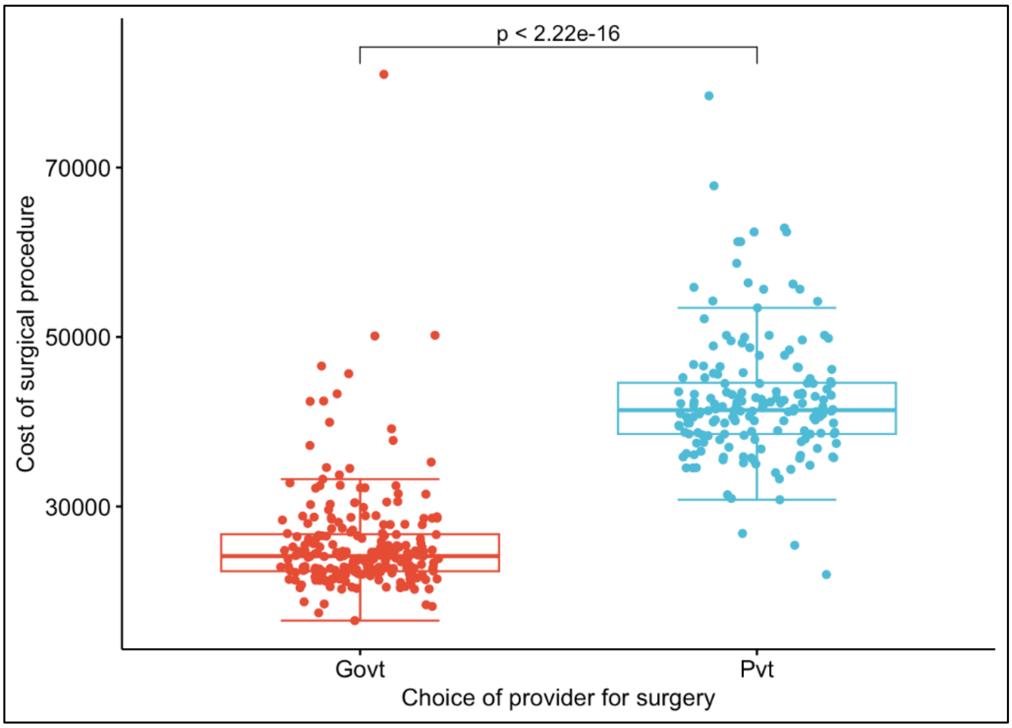


Source: Survey data

The distribution of costs incurred for lab tests during surgery across a choice of healthcare provider is depicted in Figure 6.2C. The p-value from the H test observed across government and private hospitals (9e-11) was less than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of lab tests incurred during surgery is significantly different across government and private hospitals. From ANOVA Table 6.7, it can be observed that the mean cost of lab tests incurred during surgery was ₹ 6,480±3,009

Figure 6.2D

Box plot depicting costs of surgical procedure incurred during surgery across choice of provider

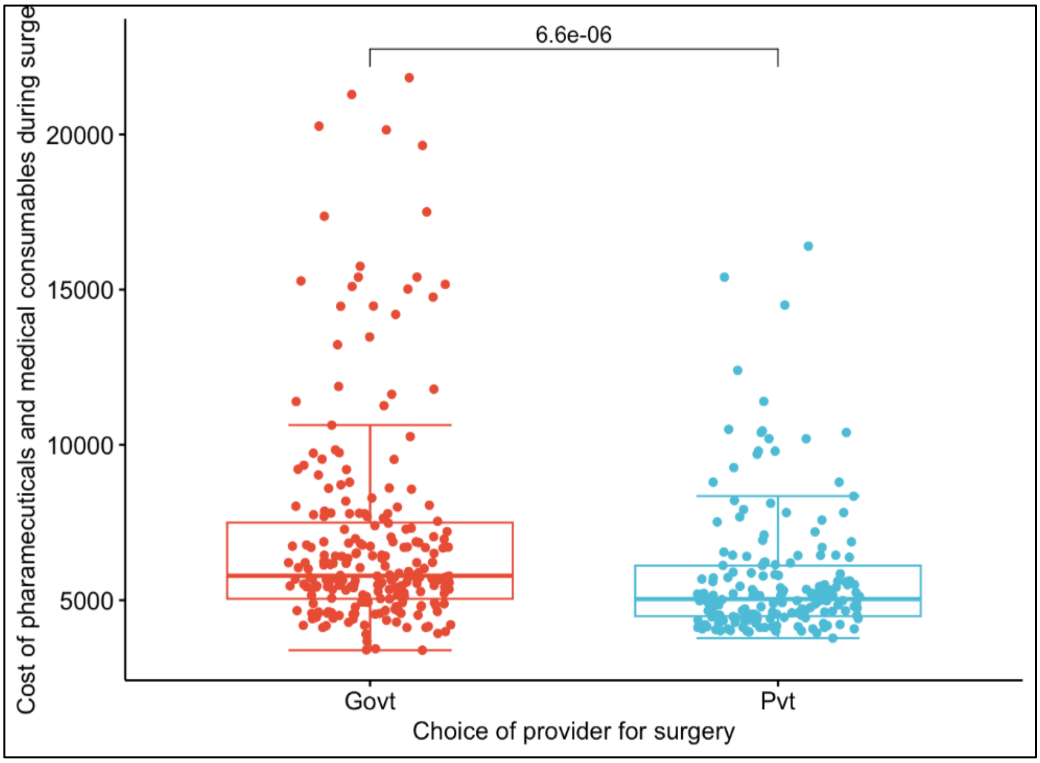


Source: Survey data

The distribution of costs incurred for lab tests during surgery across a choice of healthcare provider is depicted in Figure 6.2D. The p-value from the H test observed across government and private hospitals (p<2.22e-16) was less than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of surgical procedures incurred during surgery was significantly different across government and private hospitals. From ANOVA Table 6.7, it can be observed that the mean cost of surgical procedures incurred during surgery was ₹ 3,2950±10,836.

Figure 6.2E

Box-plot depicting costs of pharmaceuticals and medical consumables incurred during surgery across choice of provider

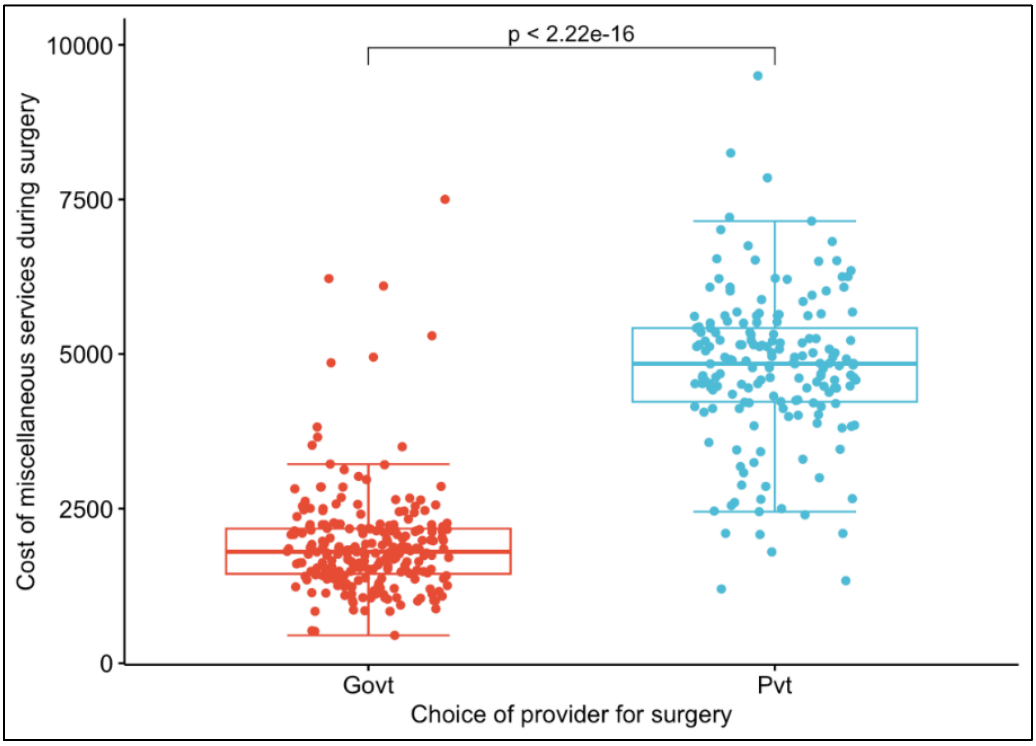


Source: Survey data

The distribution of costs incurred for pharmaceuticals and medical consumables during surgery across a choice of healthcare provider is depicted in Figure 6.2E. The p-value from the H test observed across government and private hospitals (6.6e-06) was less than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of surgical procedures incurred during surgery was significantly different across government and private hospitals. From ANOVA Table 6.7, it can be observed that the mean cost of pharmaceuticals and medical consumables incurred during surgery was ₹ 6,480±3,009.

Figure 6.2F

Box plot depicting costs of miscellaneous services incurred during surgery across choice of provider

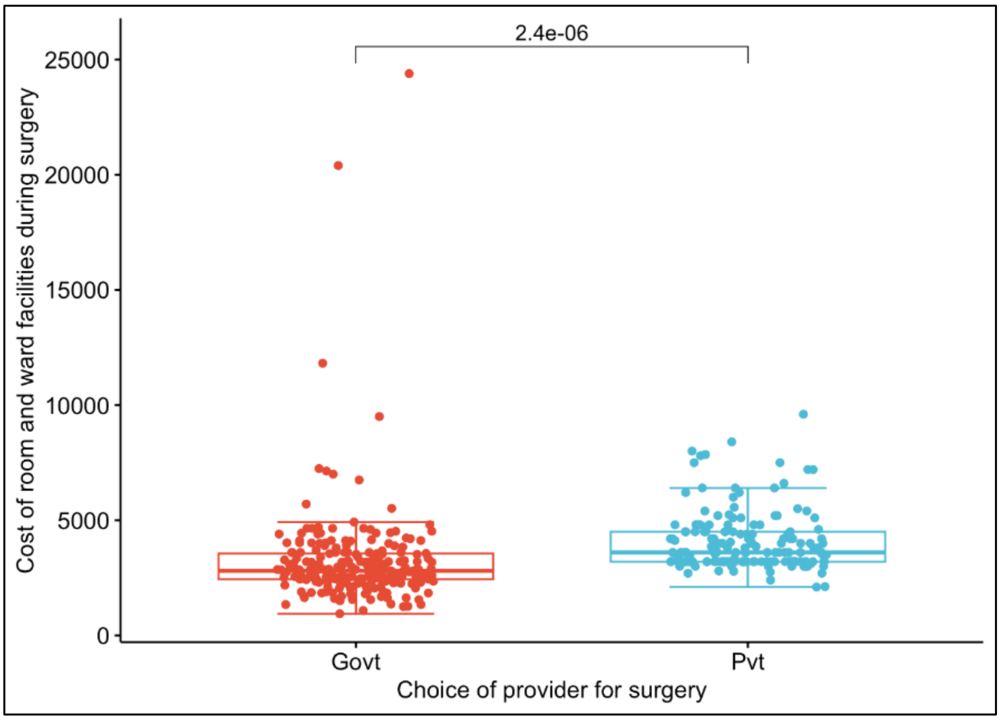


Source: Survey data

The distribution of costs incurred for miscellaneous services during surgery across a choice of healthcare provider is depicted in Figure 6.2F. The p-value from the H test observed across government and private hospitals (p<2.22e-16) was less than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of miscellaneous services incurred during surgery was significantly different across government and private hospitals. From ANOVA Table 6.7, it can be observed that the mean cost of miscellaneous services incurred during surgery was ₹ 3,151±1,754.

Figure 6.2G

Box-plot depicting costs of room and ward facilities incurred during surgery across choice of provider

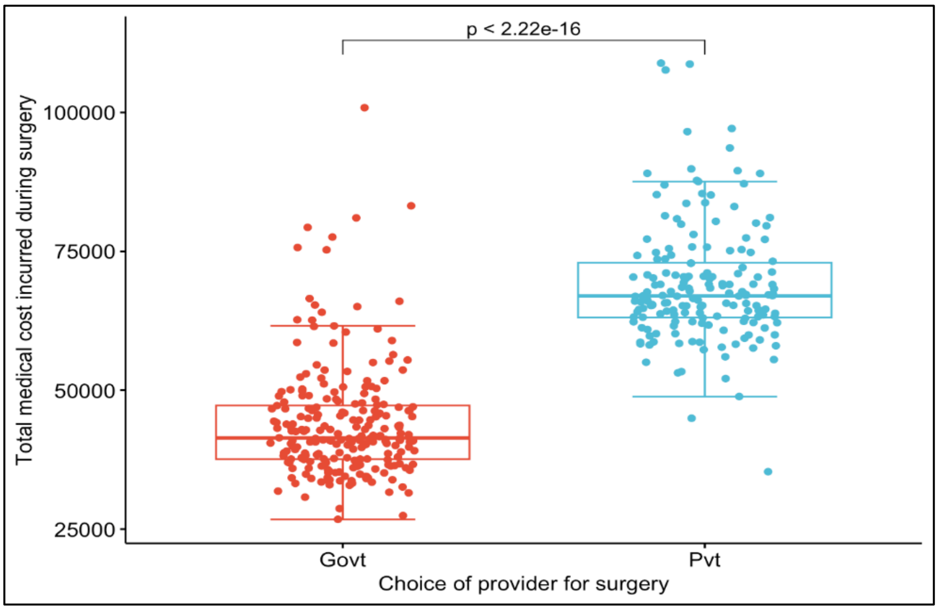


Source: Survey data

The distribution of costs incurred for room and ward facilities during surgery across a choice of healthcare provider is depicted in Figure 6.2G. The p-value from the H test observed across government and private hospitals (2.4e-06) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of room and ward facilities incurred during surgery was significantly different across government and private hospitals. From ANOVA Table 6.7, it can be observed that the mean cost of room and ward facilities incurred during surgery was ₹ 3,576±1,900.

Figure 6.2H

Box-plot depicting total medical cost incurred during surgery across choice of provider



Source: Survey data

The distribution of total medical costs incurred during surgery across the choice of a healthcare provider is depicted in Figure 6.2H. The p-value from the H test observed across government and private hospitals (p<2.22e-16) was less than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of total medical cost incurred during surgery was significantly different across government and private hospitals. From ANOVA Table 6.7, it can be observed that the mean cost of total medical cost incurred during surgery was ₹ 54,769±16,208.

6.3.2.2. Direct Medical Costs Incurred During Radiation

During radiation, a breast cancer patient incurs the following types of costs:

i. Cost of imaging tests: Patients have to undergo imaging tests like ultrasound, X-ray and ECG before receiving radiation.

ii. Cost of biopsy test: Prior to receiving radiation, patients might be asked to take a FNAC biopsy or other type of biopsy in order to assess the stage of cancer post-surgery.

iii. Cost of radiation procedure

iv. Cost of pharmaceutical products and medical consumables.

v. Cost of lab tests: Prior to radiation, several blood tests, like CBC, calcium, sodium, etc, are done in order to determine the health of the patient.

vi. Miscellaneous costs: These include registration fees, consultation fees, nutrition services, physiotherapy services, lymphedema removal charges, and post-radiation check-up charges.

Table 6.8

Distribution of samples based on the medical cost incurred during radiation when the choice of a healthcare provider is government

TNM staging	Mean cost (₹)						
	Mean cost of imaging cost	**Mean cost of Biopsy test**	**Mean cost of radiation procedure**	**Mean cost of pharma and medical consumables**	**Mean cost of lab tests**	**Mean cost of misc. services**	**Mean total medical cost of radiation**
IA & IB	1,375.0	0.0	55,200.0	745.0	1,340.0	870.0	59,530.0
IIA	1,302.1	51.5	61,555.2	860.5	1,377.6	901.5	66,048.6
IIB	571.2	122.7	64,965.7	711.6	1,094.1	728.5	68,194.0
IIIA	521.3	261.5	71,501.3	836.6	933.1	765.8	74,819.9
IIIB	916.3	48.0	80,471.3	746.0	858.3	692.6	83,732.6
IIIC	792.0	183.5	1,01,614	1,017.0	1,457.0	819.0	1,05,882.5
Total	**744.0**	**146.3**	**71,113.4**	**801.5**	**1,095.5**	**771.8**	**74,672.7**

Source: Survey data

The mean cost incurred by respondents who sought radiation treatment in government hospitals is presented in Table 6.8. It can be observed that the mean total medical cost of radiation was ₹ 74,672.7. It can be observed from the Table that the radiation cost incurred was higher for respondents with stage III breast cancer. The cost of radiation procedure contributed the highest to the total mean cost of radiation. The mean cost of the imaging test was ₹ 744, the biopsy test was ₹ 146.3, and the lab test was ₹ 1,095.5. The mean cost of pharmaceutical products and medical consumables was ₹ 801.5, and of miscellaneous services was ₹ 771.8.

Table 6.9

Distribution of samples based on the medical cost incurred during radiation when the choice of a healthcare provider is private

	Mean cost (₹)						
TNM staging	**Mean cost of imaging cost**	**Mean cost of Biopsy test**	**Mean cost of radiation procedure**	**Mean cost of pharma and medical consumables**	**Mean cost of lab tests**	**Mean cost of misc. services**	**Mean total medical cost of radiation**
IA & IB	625.0	550.0	69,812.5	955.0	1,137.5	1722.5	74,802.5
IIA	225.0	440.3	64,334.3	831.2	800.3	1442.5	68,073.7
IIB	243.6	480.0	67,635.3	905.6	892.6	1,523.17	71,680.4
IIIA	300.0	613.1	72,856.8	932.9	959.5	1,648.18	77,310.6
IIIB	533.7	760.0	89,075.0	976.8	953.7	1,832.50	94,131.8
IIIC	764.2	815.7	1,27,271.4	1,128.5	1,131.4	1,768.57	1,32,880
Total	**315.0**	**537.2**	**72,959.2**	**910.4**	**907.1**	**1,568.42**	**77,197.5**

Source: Survey data

The mean cost incurred by respondents who sought radiation treatment in a private hospital is presented in Table 6.9. It can be observed that the mean total medical cost of radiation was ₹ 77,197.5. Stage III breast cancer respondents incurred higher costs for radiation compared to other TNM stages. The mean cost of radiation procedure contributed to almost 95 per cent of the total mean cost of radiation. The mean cost of the imaging test was ₹ 315, the biopsy test was ₹ 537.2, and the lab test was ₹ 907.19. The mean cost of pharmaceutical products and medical consumables was ₹ 910.4, and of miscellaneous services was ₹ 1,568.4.

Table 6.10

ANOVA table representing the different medical cost (₹) incurred during radiation treatment among different choices of healthcare providers

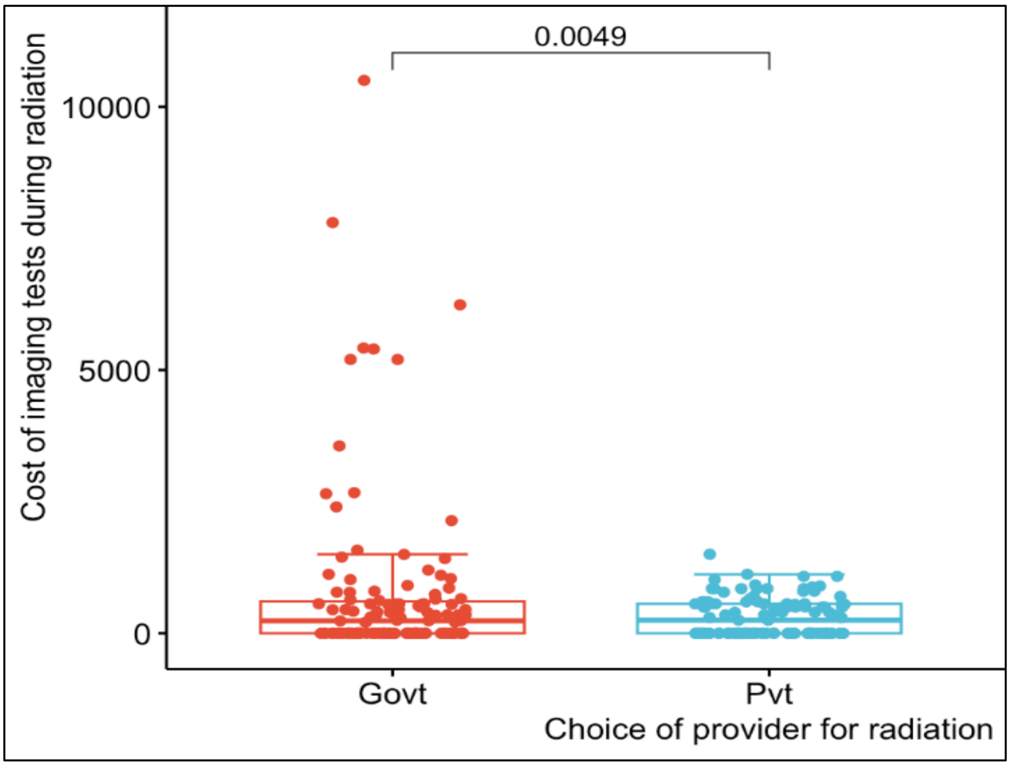
Cost	Choice of provider for radiation	Mean ± SD	Mean ± SD	KS Test	H Test
Cost of biopsy tests during radiation	Govt	207±428	178±639	***	***
	Pvt		542±190	***	
	not applicable		0±0	***	
Cost of imaging tests during radiation	Govt	318±965	749±1621	***	***
	Pvt		318±358	***	
	not applicable		0±0	***	
Cost of lab tests during radiation	Govt	593±757	1,096±1,006	***	***
	Pvt		915±229	***	
	not applicable		0±0	***	
Cost of miscellaneous services during radiation	Govt	682±695	772±364	***	***
	Pvt		1,582±255	***	
	not applicable		0±0	***	
Cost of pharmaceuticals and medical consumables during radiation	Govt	504±509	802±368	***	***
	Pvt		918±363	***	
	not applicable		0±0	***	
Cost of radiation procedure	Govt	42,483±41,536	71,113±34,205	***	***
	Pvt		73,605±1,8790	***	
	not applicable		0±0	***	
Total medical cost incurred during radiation	Govt	44,787±43,275	74,709±34,155	***	***
	Pvt		77,881±19,391	***	
	not applicable		0±0	***	

Source: Survey data

The ANOVA Table determining whether there is a significant difference among various costs incurred during radiation across a choice of a healthcare provider is represented in Table 6.10. The results from the KS test and H test reveal that the values obtained were significant at a 1 per cent level. Hence, it can be concluded that there is a significant difference in costs incurred in government and private hospitals in case of the cost of biopsy tests, imaging tests, lab tests, radiation procedures, room and ward facilities, pharmaceuticals and medical consumables, miscellaneous services, and total medical costs during radiation.

Figure 6.3A

Box-plot depicting costs of imaging tests incurred during radiation across choice of provider

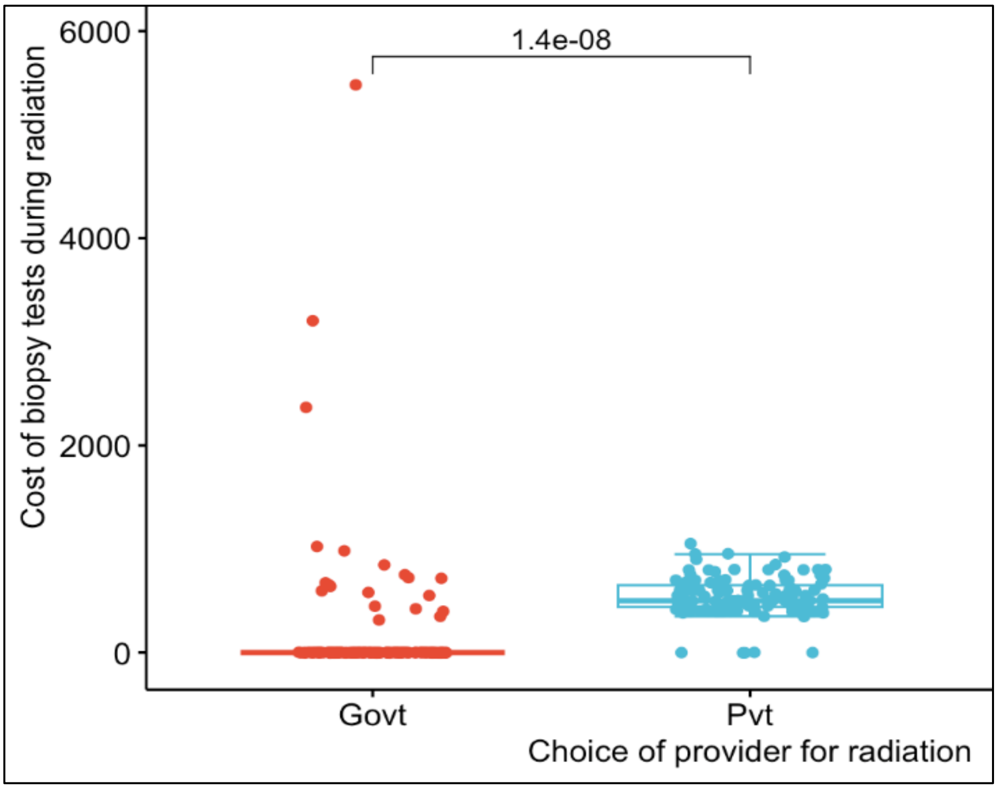


Source: Survey data

The distribution of costs incurred for imaging tests during radiation across a choice of healthcare providers is depicted in Figure 6.3A. The p-value from the H test observed across government and private hospitals (0.004) was less than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of imaging tests incurred during radiation is significantly different across government and private hospitals. From ANOVA Table 6.10, it can be observed that the mean cost of imaging tests incurred during radiation was ₹ 318±965.

Figure 6.3B

Box-plot depicting costs of biopsy tests incurred during radiation across choice of provider

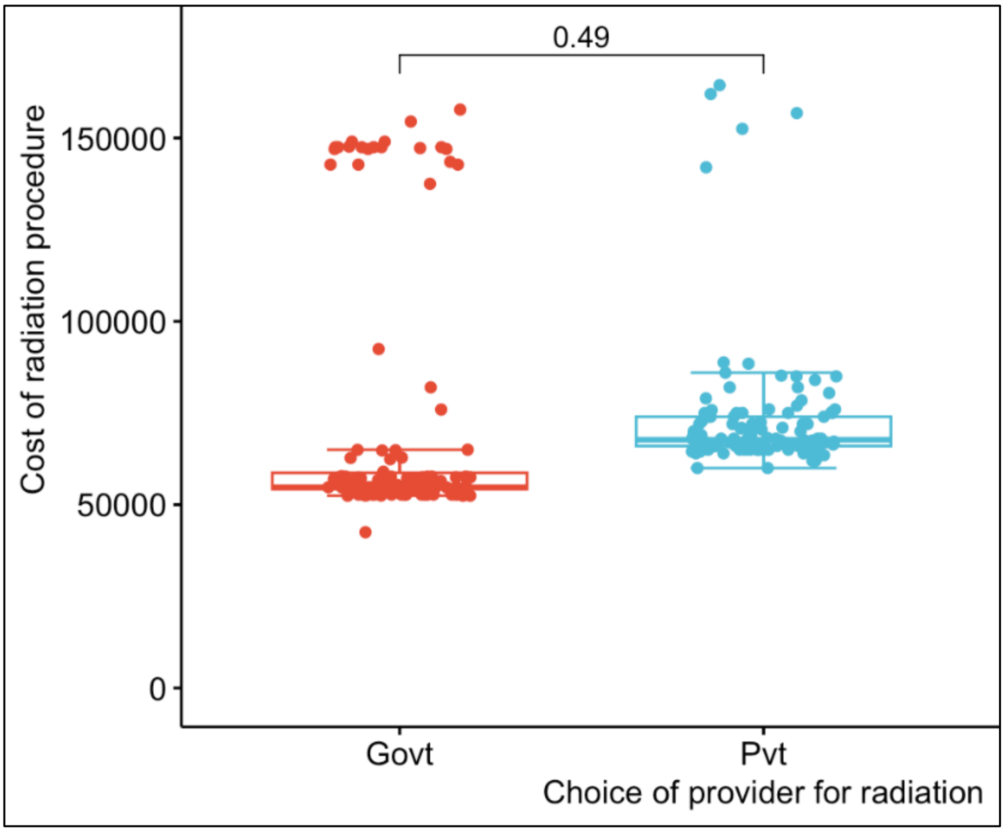


Source: Survey data

The distribution of costs incurred for biopsy tests during radiation across a choice of healthcare provider is depicted in Figure 6.3B. The p-value from the H test observed across government and private hospitals (1.4e-08) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of biopsy tests incurred during radiation is significantly different across government and private hospitals. From ANOVA Table 6.10, it can be observed that the mean cost of biopsy tests incurred during radiation was ₹ 207±428.

Figure 6.3C

Box-plot depicting costs of radiation procedure incurred during radiation across choice of provider

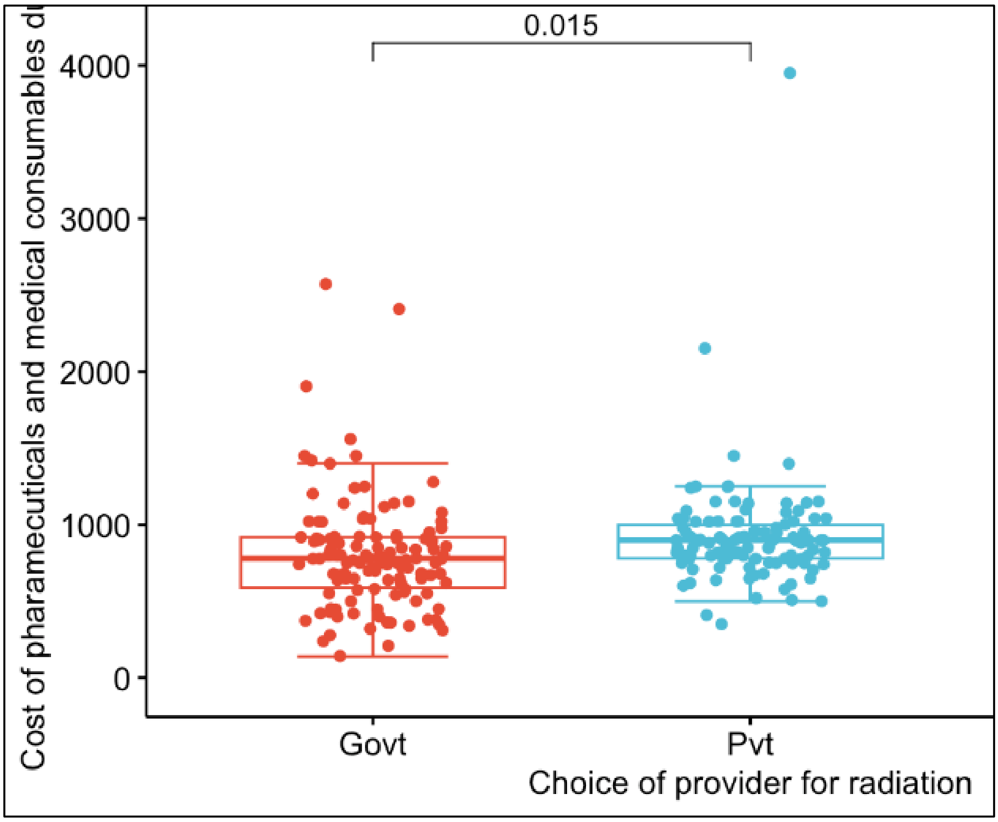


Source: Survey data

The distribution of costs incurred for radiation procedures during radiation across a choice of healthcare provider is depicted in Figure 6.3C. The p-value from the H test observed across government and private hospitals (0.49) was higher than 0.01 and, hence, statistically insignificant at a 1 per cent level. Therefore, we can conclude that the mean cost of radiation procedures incurred during radiation is significantly not different across government and private hospitals. From ANOVA Table 6.10, it can be observed that the mean cost of radiation procedure incurred during radiation was ₹ 42,483±41,536.

Figure 6.3D

Box-plot depicting costs of pharmaceuticals and medical consumables incurred during radiation across choice of provider

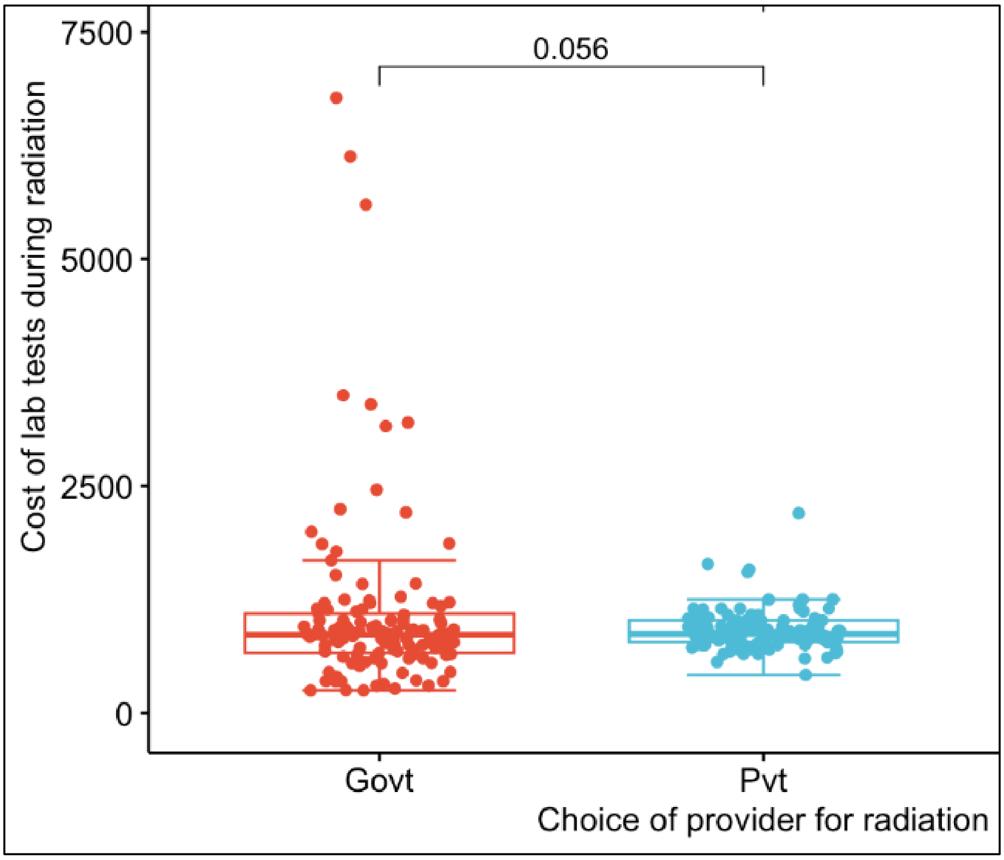


Source: Survey data

The distribution of costs incurred for pharmaceuticals and medical consumables during radiation across a choice of healthcare provider is depicted in Figure 6.3D. The p-value from the H test observed across government and private hospitals (0.015) was lesser than 0.05 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of pharmaceuticals and medical consumables incurred during radiation is significantly different across government and private hospitals. From ANOVA Table 6.10, it can be observed that the mean cost of pharmaceuticals and medical consumables incurred during radiation was ₹ 504±509.

Figure 6.3E

Box-plot depicting costs of lab tests incurred during radiation across choice of provider

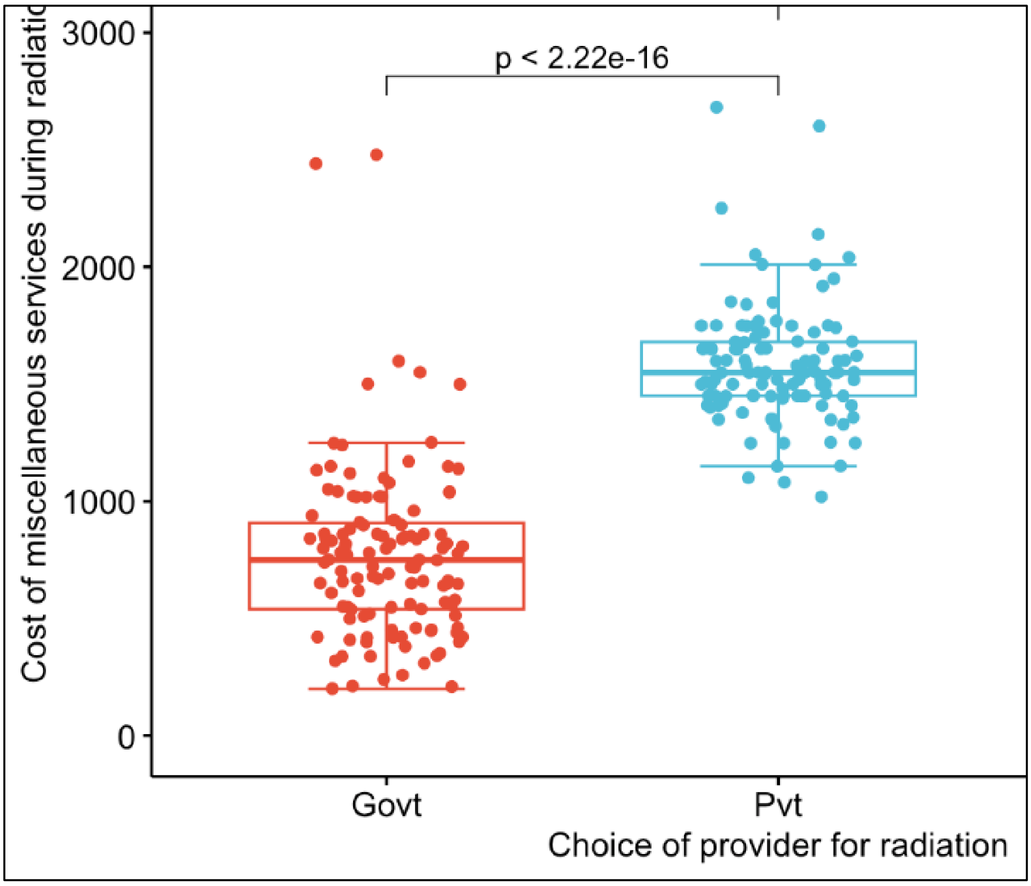


Source: Survey data

The distribution of costs incurred for lab tests during radiation across a choice of healthcare provider is depicted in Figure 6.3E. The p-value from the H test observed across government and private hospitals (0.05) was higher than 0.01 and, hence, statistically insignificant at a 1 per cent level. Therefore, we can conclude that the mean cost of lab tests incurred during radiation is significantly not different across government and private hospitals. From ANOVA Table 6.10, it can be observed that the mean cost of lab tests incurred during radiation was ₹ 593±757.

Figure 6.3F

Box-plot depicting costs of miscellaneous services incurred during radiation across choice of provider

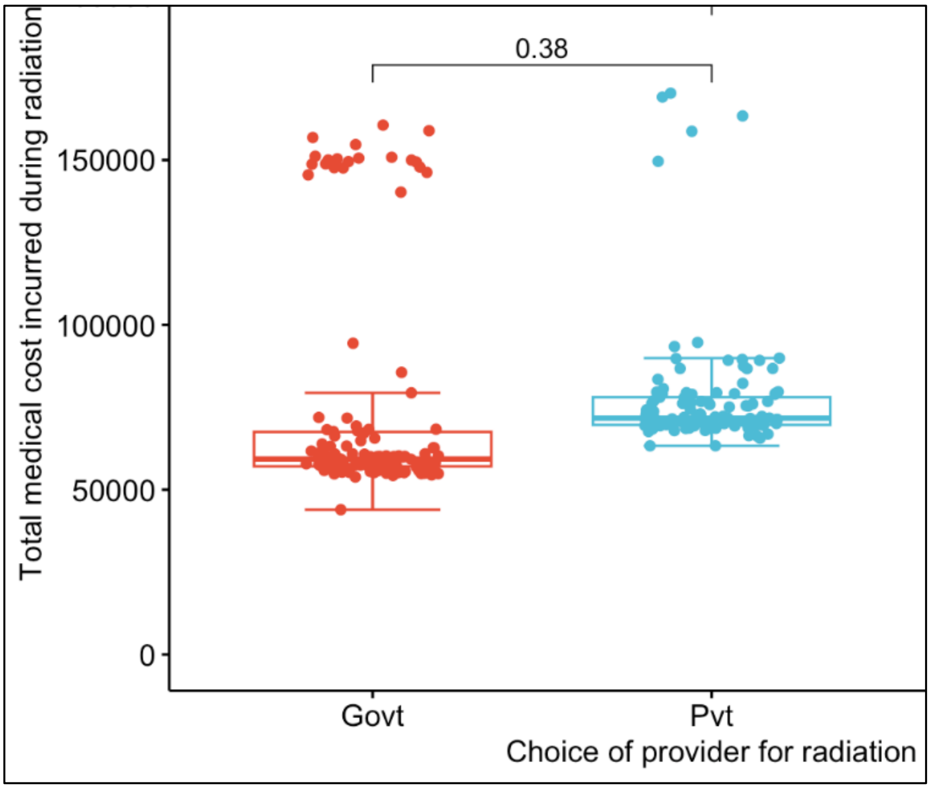


Source: Survey data

The distribution of costs incurred for miscellaneous services during radiation across a choice of healthcare provider is depicted in Figure 6.3F. The p-value from the H test observed across government and private hospitals ($p<2.22e-16$) was less than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of miscellaneous services incurred during radiation is significantly different across government and private hospitals. From ANOVA Table 6.10, it can be observed that the mean cost of miscellaneous services incurred during radiation was ₹ 682±695.

Figure 6.3G

Box-plot depicting total medical cost incurred during radiation across choice of provider



Source: Survey data

The distribution of total medical costs incurred during radiation across a choice of healthcare provider is depicted in Figure 6.3G. The p-value from the H test observed across government and private hospitals (0.38) was higher than 0.01 and, hence, statistically insignificant at a 1 per cent level. Therefore, we can conclude that the mean total medical cost incurred during radiation is significantly not different across government and private hospitals. From ANOVA Table 6.10, it can be observed that the mean total medical cost incurred during radiation was ₹ 44,787±43,275.

6.3.2.3. Direct Medical Costs Incurred During Chemotherapy

During chemotherapy, a breast cancer patient incurs the following types of costs:

i. Cost of imaging tests: Patients have to undergo imaging tests like ultrasound, X-ray and ECG before receiving chemotherapy.

ii. Cost of biopsy test: Before receiving chemotherapy, patients sometimes might be asked to take a FNAC biopsy or other type of biopsy in order to assess the stage of cancer post/pre-surgery.

iii. Cost of chemotherapy drugs, other pharmaceutical products and medical consumables.

iv. Cost of lab tests: Before chemotherapy, several blood tests, like CBC, calcium, sodium, etc, are done in order to determine the health of the patient.

v. Miscellaneous costs: These include costs for registration, consultation, nutrition services, physiotherapy services, lymphedema removal charges and post-chemotherapy check-up charges.

Table 6.11

Distribution of samples based on the medical cost incurred during chemotherapy when the choice of a healthcare provider is government

	Mean cost (₹)					
TNM staging	**Mean cost of imaging test**	**Mean cost of biopsy test**	**Mean cost of chemo drugs and pharma products**	**Mean cost of lab test**	**Mean cost of miscellaneous services**	**Total medical cost of chemo**
IA & IB	968.12	201.87	21,718.75	2,735.62	1,278.12	26,902.5
II A	1,509.62	403.43	28,713.23	4,449.63	1,733.22	36,809.1
II B	1,126.30	357.82	31,668.11	5,641.59	1,713.98	40,507.8
III A	2,284.11	780.44	36,543.70	6,897.79	2,059.08	48,565.1
III B	1,762.85	742.85	37,105.14	6,931.78	1,884.64	48,427.2
III C	2,148.75	933.75	41,333.75	8,003.75	2,327.50	54,747.5
Total	**1,509.07**	**473.30**	**31,322.56**	**5,360.23**	**1,775.50**	**40,440.6**

Source: Survey data

The mean cost incurred by respondents who sought chemotherapy treatment in government hospitals is presented in Table 6.11. It can be observed that the mean total medical cost of chemotherapy was ₹ 40,440.6. It can be observed from the Table that the chemotherapy cost incurred was higher for respondents with stage III breast cancer. The cost of chemotherapy drugs, other pharmaceutical products, and medical consumables was ₹ 31,322.5, which contributed the highest to the total medical cost of chemotherapy. The mean cost of the imaging test was ₹ 1,509.7, the biopsy test was ₹ 473.3, and the lab test was ₹ 5,360.2. The mean cost of miscellaneous services was ₹ 1,775.5.

Table 6.12

Distribution of samples based on the medical cost incurred during chemotherapy when the choice of a healthcare provider is private

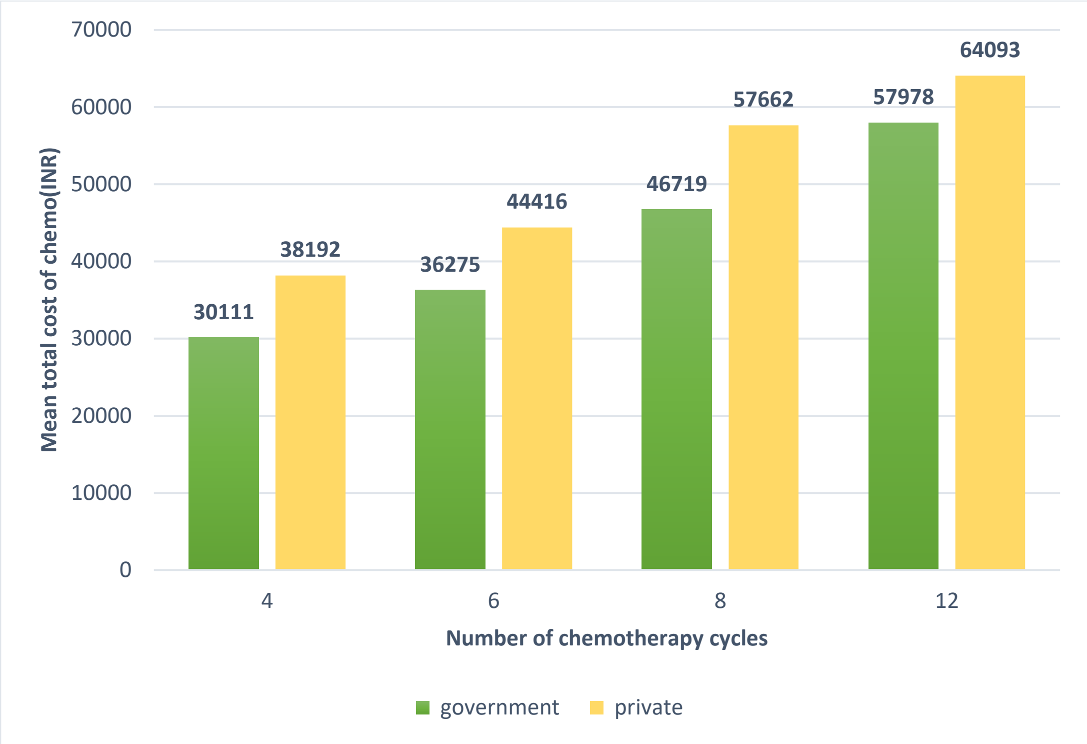
TNM stage	Mean cost (₹)					
	Mean cost of imaging test	**Mean cost of biopsy test**	**Mean cost of chemo drugs and pharma products**	**Mean cost of lab test**	**Mean cost of miscellaneous services**	**Total medical cost of chemo**
IA and IB	965.00	383.75	23,641.25	3,775.0	4,405.62	33,170.6
II A	1,392.80	655.60	28,428.60	5,056.0	5,429.14	40,962.2
II B	1,809.55	616.66	31,163.88	4,985.0	5,329.33	43,904.4
III A	3,279.16	1,138.33	38,099.12	5,985.4	6,040.41	54,542.4
III B	3,351.11	1,658.88	36,548.33	6,221.1	6,478.88	54,258.3
III C	3,481.11	1,435.55	46,825.55	5,598.8	4,762.22	62,103.3
Total	**2,106.21**	**829.92**	**32,513.39**	**5,234.2**	**5,469.11**	**46,152.8**

Source: Survey data

The mean cost incurred by respondents who sought chemotherapy treatment in a private hospital is presented in Table 6.12. It can be observed that the mean total medical cost of chemotherapy was ₹ 46,152.8. Respondents with stage III breast cancer incurred higher chemotherapy costs. The cost of chemotherapy drugs, other pharmaceutical products, and medical consumables was ₹ 32,513.3, which contributed the highest to the total medical cost of chemotherapy. The mean cost of the imaging test was ₹ 21,06.2, the biopsy test was ₹ 829.9, and the lab test was ₹ 5,234.2. The mean cost of miscellaneous services was ₹ 5,469.1.

Figure 6.4

Mean total medical cost of chemotherapy according to the number of chemotherapy cycles received across choice of healthcare provider



Source: Survey data

The mean total cost of chemotherapy on the basis of the number of chemotherapy cycles received by the respondents is illustrated in Figure 6.4. For four-cycle chemotherapy, the mean total medical cost in a government hospital was around ₹ 30,111, while in a private hospital, it was ₹ 38,192. A six-cycle chemotherapy will cost around ₹ 36,275 in a government hospital and ₹ 44,416 in a private hospital. An eight-cycle chemotherapy will cost around ₹ 46,719 in a government hospital and around ₹ 57,662 in a private hospital. Twelve-cycle chemotherapy is usually given to stage III breast cancer patients. It will cost around ₹ 57,978 in a government hospital and around ₹ 64,093 in a private hospital.

Table 6.13:

ANOVA table representing the different medical costs (₹) incurred during chemotherapy treatment among different healthcare providers

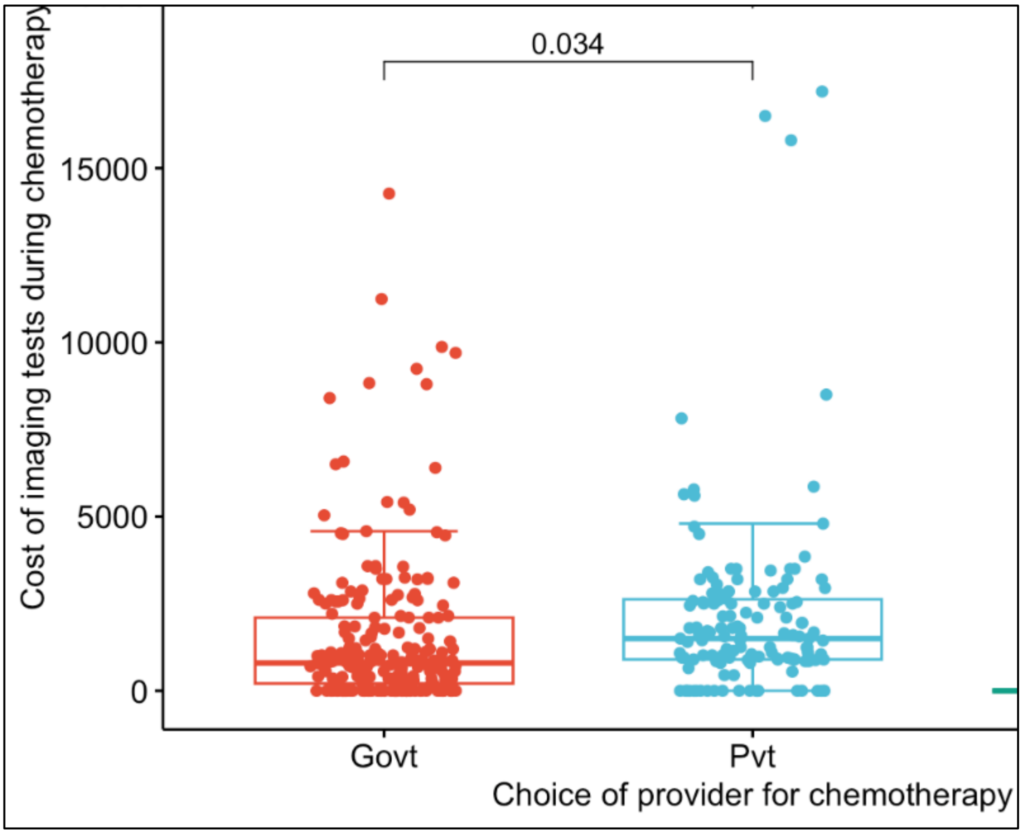
Cost	Choice of provider for chemotherapy	Mean ± SD	Mean ± SD	KS Test	H Test
Cost of biopsy tests during chemotherapy	Govt	544±717	482±723	***	***
	Pvt		836±699	***	
	not applicable		0±0	***	
Cost of imaging tests during chemotherapy	Govt	1,550±2,321	1,537±2,190	***	***
	Pvt		2,122±2,668	***	
	not applicable		0±0	***	
Cost of lab tests during chemotherapy	Govt	4,741±2,582	5,459±2,346	***	***
	Pvt		5,273±1,346	***	
	not applicable		0±0	***	
Cost of miscellaneous services during chemotherapy	Govt	2,840±2,483	1,808±1,453	***	***
	Pvt		5,510±1,779	***	
	not applicable		0±0	***	
Cost of pharmaceuticals and medical consumables during chemotherapy	Govt	2,8360±13,485	31,900±9,626	***	***
	Pvt		32,754±8,017	***	
	not applicable		0±0	***	
Total medical cost incurred during chemotherapy	Govt	38,035±18,196	41,186±13,013	***	***
	Pvt		46,495±10,323	***	
	not applicable		0±0	***	

Source: Survey data

The ANOVA Table determining whether there is a significant difference among various costs incurred during chemotherapy across choice of healthcare provider is represented in Table 6.13. The results from the KS test and H test reveal that the values obtained were significant at a 1 per cent level. Hence, it can be concluded that there is a significant difference in costs incurred in government and private hospitals in the case of the cost of biopsy tests, imaging tests, lab tests, pharmaceuticals and medical consumables, miscellaneous services, and total medical costs during chemotherapy.

Figure 6.5A:

Box-plot depicting costs of imaging tests incurred during chemotherapy across choice of provider for chemotherapy

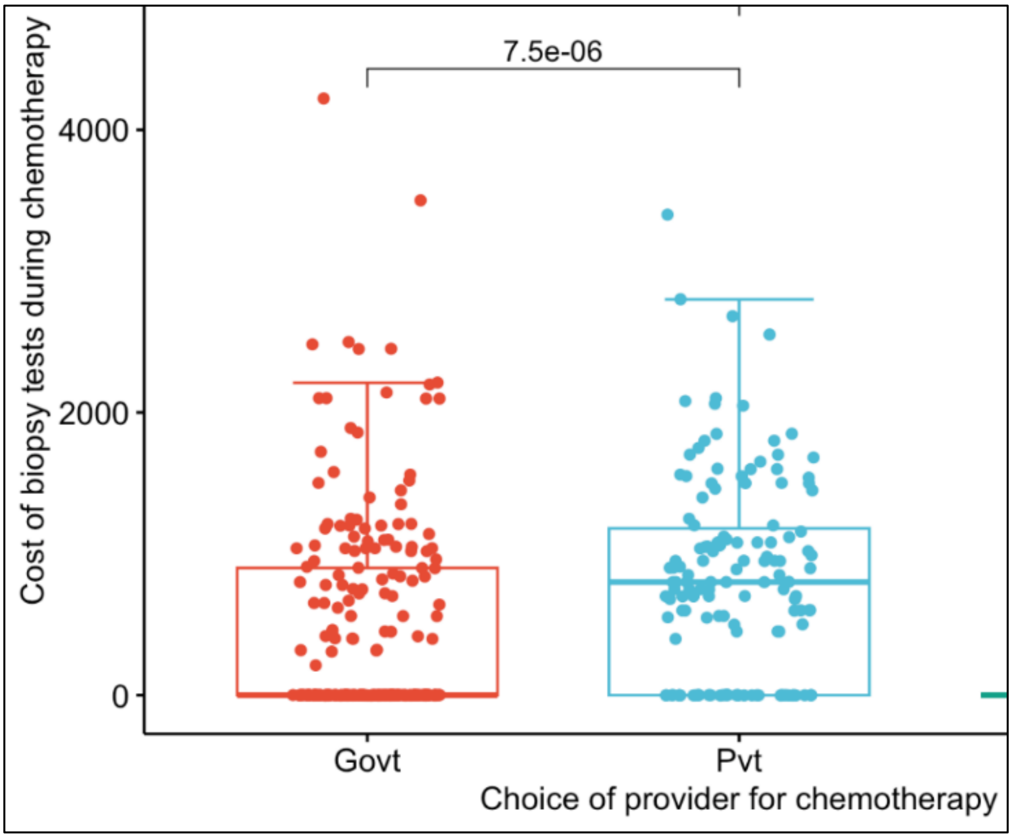


Source: Survey data

The distribution of costs incurred for imaging tests during chemotherapy across a choice of healthcare providers is depicted in Figure 6.5A. The p-value from the H test observed across government and private hospitals (0.03) was lesser than 0.05 and, hence, statistically significant at a 5 per cent level. Therefore, we can conclude that the mean cost of imaging tests incurred during chemotherapy is significantly different across government and private hospitals. From ANOVA Table 6.13, it can be observed that the mean cost of imaging tests incurred during chemotherapy was ₹ 1,550±2,321.

Figure 6.5B:

Box-plot depicting costs of biopsy tests incurred during chemotherapy across choice of provider

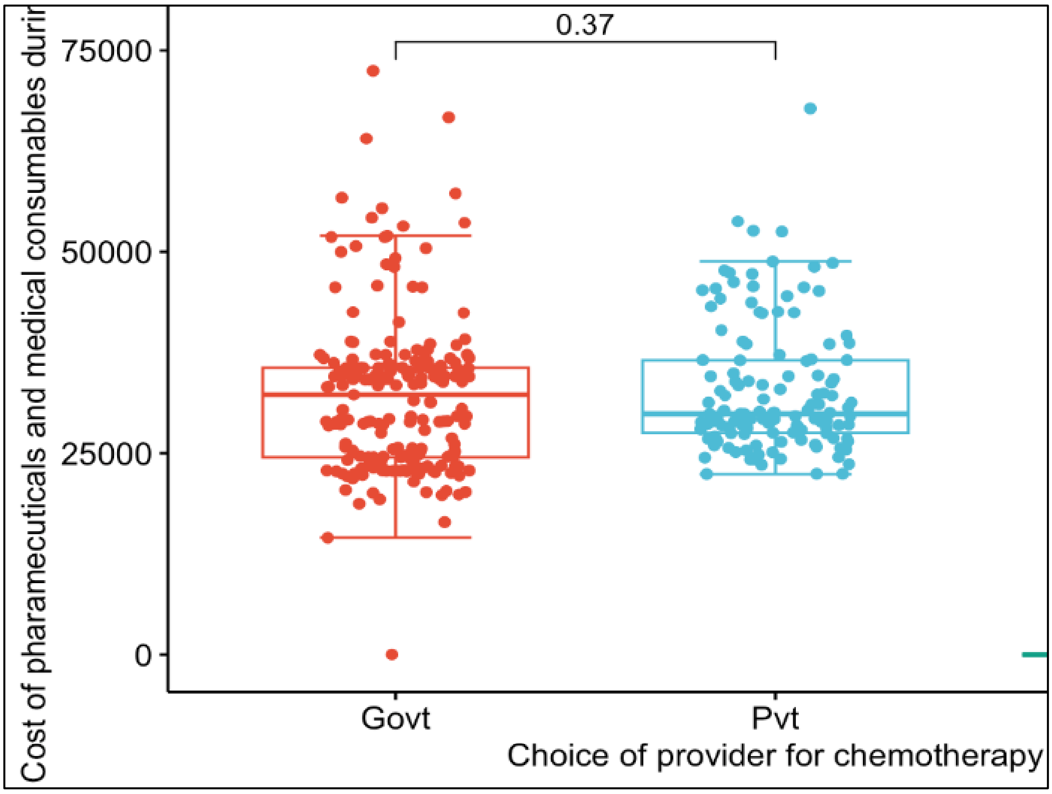


Source: Survey data

The distribution of costs incurred for biopsy tests during chemotherapy across a choice of healthcare providers is depicted in Figure 6.5A. The p-value from the H test observed across government and private hospitals (7.5e-06) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of biopsy tests incurred during chemotherapy is significantly different across government and private hospitals. From ANOVA Table 6.13, it can be observed that the mean cost of biopsy tests incurred during chemotherapy was ₹ 544±717.

Figure 6.5C

Box-plot depicting costs of pharmaceuticals and medical consumables incurred during chemotherapy across choice of provider

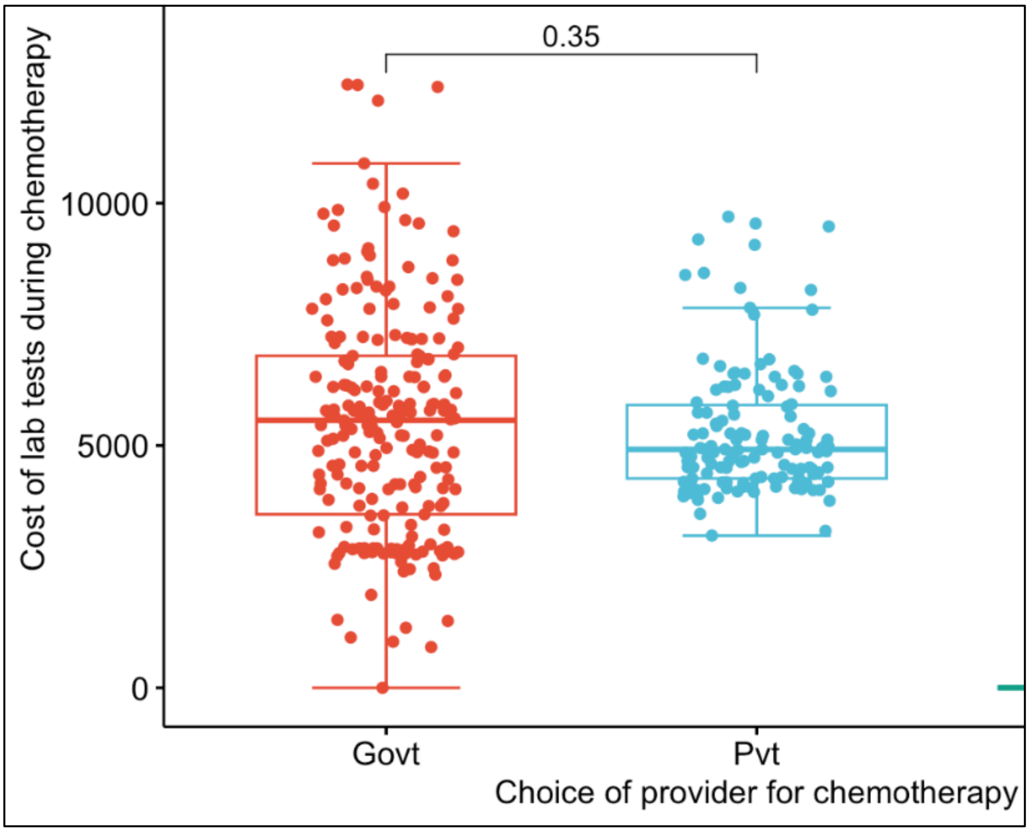


Source: Survey data

The distribution of costs incurred for pharmaceuticals and medical consumables during chemotherapy across choice of healthcare provider is depicted in Figure 6.5C. The p-value from the H test observed across government and private hospitals (0.37) was higher than 0.01 and, hence, statistically insignificant at a 1 per cent level. Therefore, we can conclude that the mean cost of pharmaceuticals and medical consumables incurred during chemotherapy are significantly not different across government and private hospitals. From ANOVA Table 6.13, it can be observed that the mean cost of pharmaceuticals and medical consumables incurred during chemotherapy was ₹ 28,360±13,485.

Figure 6.5D

Box-plot depicting costs of lab tests incurred during chemotherapy across choice of provider

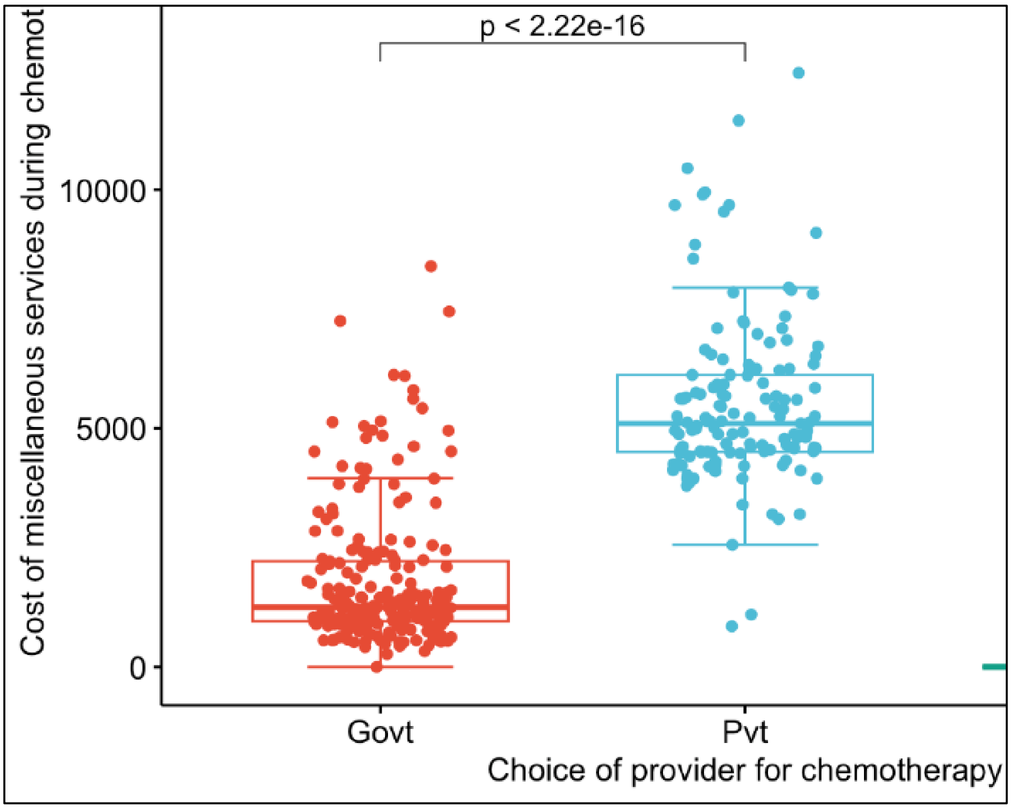


Source: Survey data

The distribution of costs incurred for lab tests during chemotherapy across choice of healthcare provider is depicted in Figure 6.5D. The p-value from the H test observed across government and private hospitals (0.35) was higher than 0.01 and, hence, statistically insignificant at a 1 per cent level. Therefore, we can conclude that the mean cost of lab tests incurred during chemotherapy is significantly not different across government and private hospitals. From ANOVA Table 6.13, it can be observed that the mean cost of lab tests incurred during chemotherapy was ₹ 47,41±2,582.

Figure 6.5E

Box-plot depicting costs of miscellaneous services incurred during chemotherapy across choice of provider

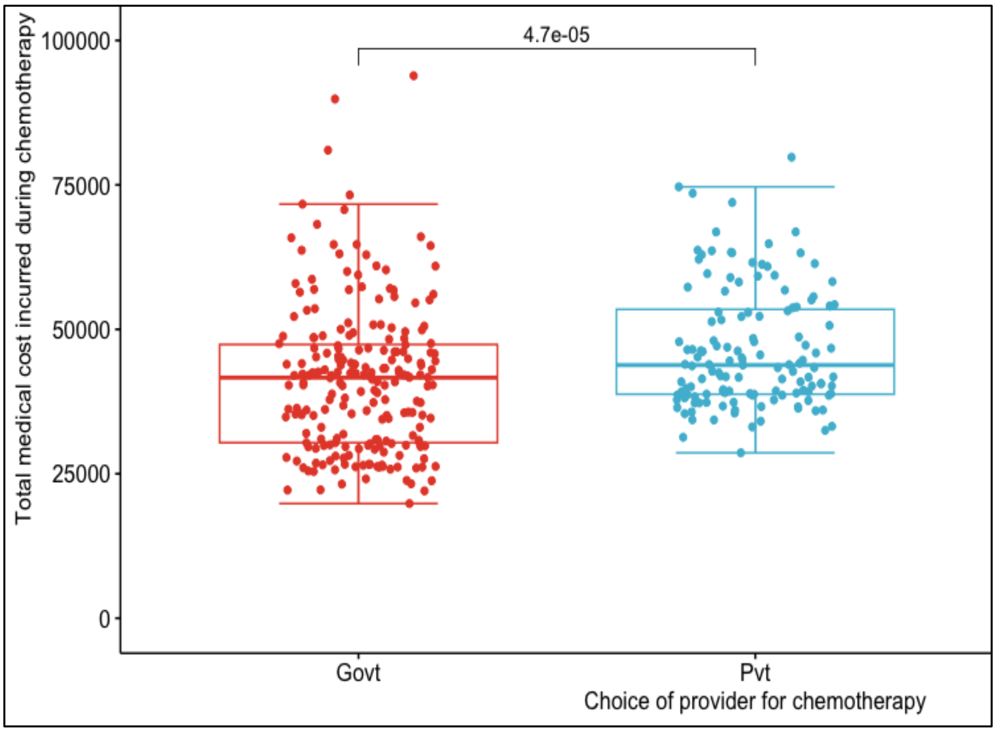


Source: Survey data

The distribution of costs incurred for miscellaneous services during chemotherapy across a choice of healthcare provider is depicted in Figure 6.5E. The p-value from the H test observed across government and private hospitals (p<2.22e-16) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of miscellaneous services incurred during chemotherapy is significantly different across government and private hospitals. From ANOVA Table 6.13, it can be observed that the mean cost of miscellaneous services incurred during chemotherapy was ₹ 2,840±2,483.

Figure 6.5F

Box-plot depicting total medical cost incurred during chemotherapy across choice of provider



Source: Survey data

The distribution of total medical costs incurred during chemotherapy across a choice of healthcare provider is depicted in Figure 6.5F. The p-value from the H test observed across government and private hospitals (2.9e-05) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean total medical costs incurred during chemotherapy are significantly different across government and private hospitals. From ANOVA Table 6.13, it can be observed that the mean total medical costs incurred during chemotherapy was ₹ 38,035±18,196.

6.3.2.4. Direct Medical Costs Incurred During Targeted Therapy

During targeted therapy, a breast cancer patient incurs the following types of costs:

i. Cost of imaging tests: Patients have to undergo imaging tests like ultrasound, X-ray and ECG before receiving targeted therapy.

ii. Cost of targeted therapy drugs, other pharmaceutical products and medical consumables.

iii. Cost of lab tests: Before targeted therapy, several blood tests, like CBC, calcium, sodium, etc, are done in order to determine the health of the patient.

iv. Miscellaneous costs: These include costs for registration, consultation, nutrition services, physiotherapy services, lymphedema removal charges and post-targeted therapy check-up charges.

Table 6.14

Distribution of samples based on the medical cost incurred during targeted therapy when the choice of a healthcare provider is government

	Mean cost (₹)				
TNM staging	**Mean cost of targeted therapy drugs and other pharma products**	**Mean cost of lab test**	**Mean cost of imaging test**	**Mean cost of miscellaneous services**	**Mean total medical cost of targeted therapy**
IA & IB	81,920.0	550.0	400.0	220.0	83,090.0
II A	1,84,150.6	1,358.5	2,124.0	1,181.9	1,88,815.1
II B	2,21,600.8	1,584.7	1,000.2	741.9	2,24,927.8
III A	1,83,875.5	2,247.5	998.7	1,338.7	1,88,460.5
III B	2,26,495.1	2,650.0	1,553.3	1,230.0	2,31,928.5
III C	1,38,285.0	910.0	750.0	770.0	1,40,715.0
Total	**1,99,220.4**	**1,659.5**	**1,423.2**	**1,012.0**	**2,03,315.2**

Source: Survey data

The medical costs incurred by respondents seeking targeted therapy in a government hospital are presented in Table 6.14. The mean total medical cost of targeted therapy was ₹ 2,53,018.6. The highest contributor to the total medical cost was the cost of targeted therapy drugs, pharmaceutical products and medical consumables. The mean cost of the lab test was ₹ 1659.5, the imaging test was ₹ 1,423.2, and the miscellaneous services were ₹ 1,012.

Table 6.15

Distribution of sample based on medical cost incurred during targeted therapy when the choice of healthcare provider is private

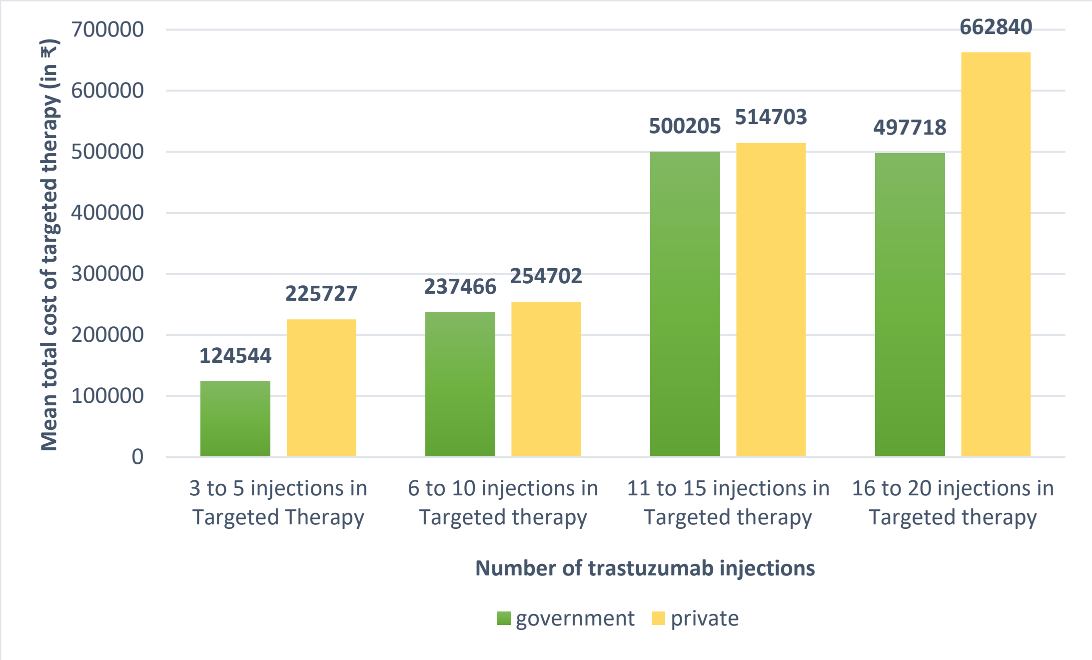
	Mean cost (₹)				
TNM staging	**Mean cost of targeted therapy drugs and other pharma products**	**Mean cost of lab test**	**Mean cost of imaging test**	**Mean cost of miscellaneous services**	**Mean total medical cost of targeted therapy**
IA & IB	6,02,650.0	9,210.0	3,200.0	7,050.0	6,22,110.0
II A	4,13,155.1	4,014.1	2,193.3	3,906.6	4,23,269.3
II B	5,02,880.0	7,088.0	2,376.0	5,711.0	5,18,055.0
III A	5,70,176.2	5,260.0	4,395.0	5,412.5	5,85,243.7
III B	2,50,505.0	1,070.0	820.0	1,730.0	2,54,125.0
III C	3,41,500.0	3,450.0	1,560.0	2,850.0	3,49,360.0
Total	**4,47,925.0**	**4,778.0**	**2,487.2**	**4,417.8**	**4,59,608.0**

Source: Survey data

The medical costs incurred by respondents seeking targeted therapy in a private hospital are presented in Table 6.15. The mean total medical cost of targeted therapy was ₹ 4,59,608. The mean cost of targeted therapy drugs, pharmaceutical products and medical consumables was ₹ 44,7925 and was the highest contributor to total medical costs. The mean cost of the lab test was ₹ 4,778, the imaging test was ₹ 2,487.2, and the miscellaneous services were ₹ 4,417.8.

Figure 6.6

Mean total medical cost (₹) of targeted therapy according to the number of trastuzumab injections received across choice of healthcare provider



Source: Survey data

The mean total cost of targeted therapy based on the number of trastuzumab injections received by respondents is illustrated in Figure 6.6. For three to five injections of trastuzumab, the mean total cost of targeted therapy was ₹ 1,24,544 in a government hospital, while it was ₹ 2,25,727 in a private hospital. The mean total cost of targeted therapy with six to ten trastuzumab injections was 2,37,466 in a government hospital and ₹ 2,54,702 in a private hospital. Targeted therapy with eleven to fifteen trastuzumab injections costs around ₹ 5,00,205 in a government hospital and ₹ 5,14,703 in a private hospital. For sixteen to twenty injections of trastuzumab, the mean total cost of targeted therapy was ₹ 4,97,718 in a government hospital and ₹ 6,62,840 in a private hospital.

Table 6.16

ANOVA Table representing the different medical costs (₹) incurred during targeted therapy treatment for breast cancer among different healthcare providers

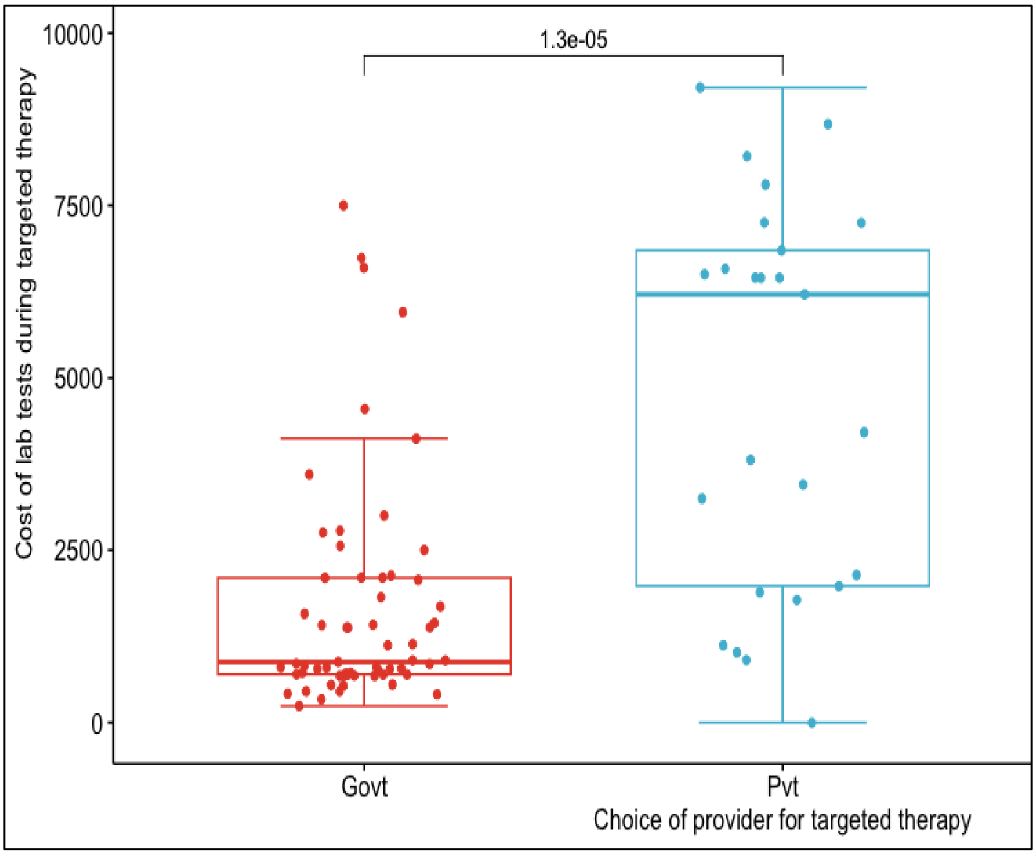
Cost	Choice of provider for targeted therapy	Mean ± SD	Mean ± SD	KS Test	H Test
Cost of imaging tests during targeted therapy	Govt	376±1,387	14,23±2,658	***	***
	Pvt		2,487±2,234	***	
	not applicable		0±0	***	
Cost of lab tests during targeted therapy	Govt	555±1,560	1,660±1,641	***	***
	Pvt		4,778±2,826	***	
	not applicable		0±0	***	
Cost of miscellaneous services during targeted therapy	Govt	433±1,355	1,012±1,113	***	***
	Pvt		4,418±2,754	***	
	not applicable		0±0	***	
Cost of pharmaceuticals and medical consumables during targeted therapy	Govt	58,696±1,46,894	2,01,024±1,51,576	***	***
	Pvt		4,43,925±2,23,932	***	
	not applicable		0±0	***	
Total medical cost incurred during targeted therapy	Govt	60,060±1,50,296	2,05,119±1,53,377	***	***
	Pvt		4,55,608±2,30,369	***	
	not applicable		0±0	***	

Source: Survey data

The variation between groups classified on the basis of respondents' choice of provider for targeted treatment of breast cancer is presented in Table 6.16. It can be observed that there is significant variation between groups with regard to the cost of lab tests, imaging tests, targeted therapy drugs, pharmaceutical products and consumables, miscellaneous services, and the total medical cost of targeted therapy at a 1 per cent level of significance.

Figure 6.7A

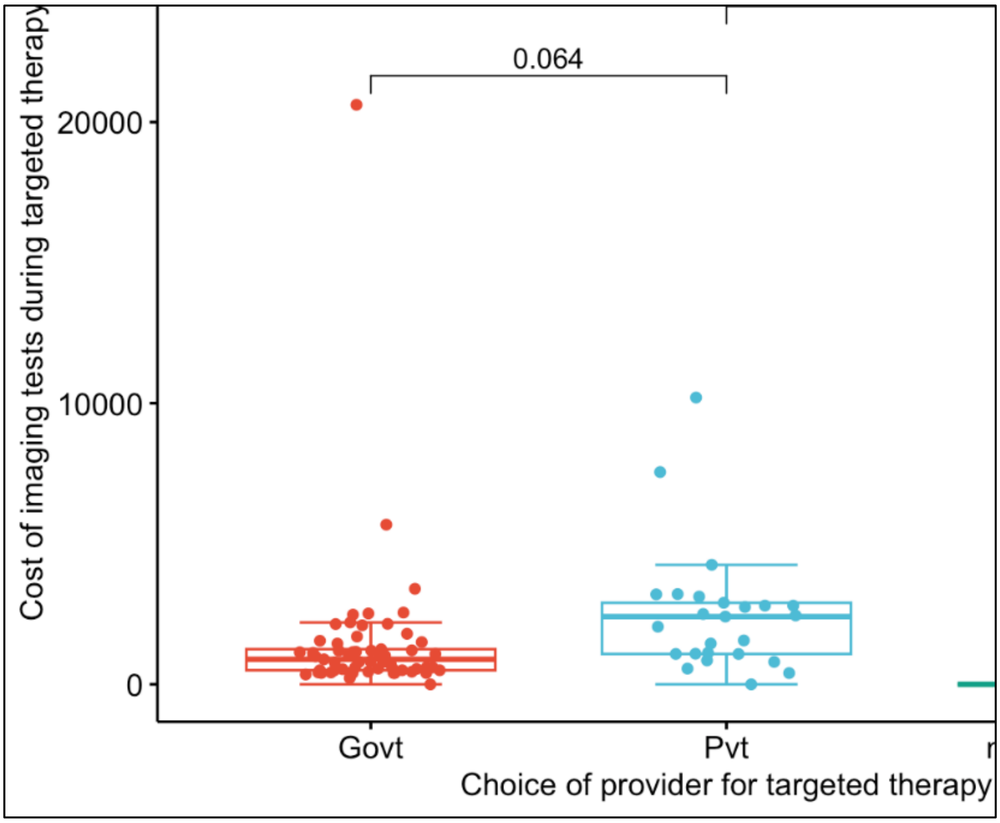
Box plot depicting costs of lab tests incurred during targeted therapy across choice of provider



Source: Survey data

The distribution of costs incurred for lab tests during targeted therapy across choice of healthcare provider is depicted in Figure 6.7A. The p-value from the H test observed across government and private hospitals (1.3e-05) was lower than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of lab tests incurred during targeted therapy is significantly different across government and private hospitals. From ANOVA Table 6.16, it can be observed that the mean cost of lab tests incurred during targeted therapy was ₹ 555±1,560.

Figure 6.7B
Box-plot depicting costs of imaging tests incurred during targeted therapy across choice of provider

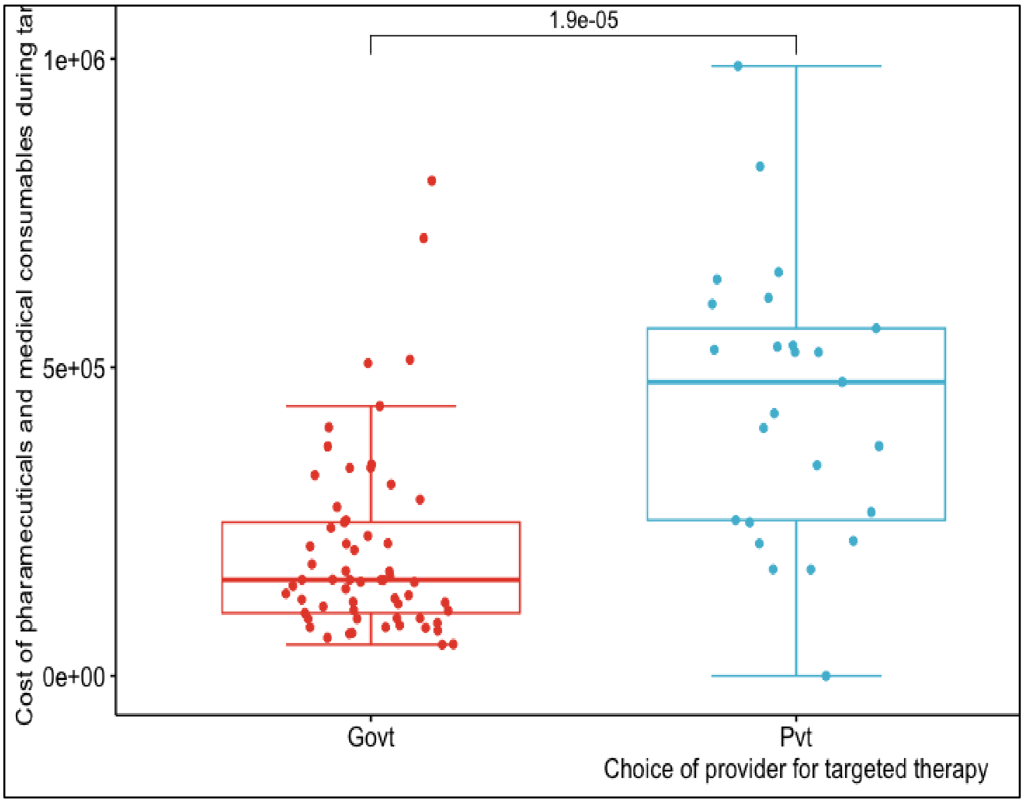


Source: Survey data

The distribution of costs incurred for imaging tests during targeted therapy across choice of healthcare provider is depicted in Figure 6.7B. The p-value from the H test observed across government and private hospitals (0.06) was higher than 0.01 and, hence, statistically insignificant at the 1 per cent level. Therefore, we can conclude that the mean cost of imaging tests incurred during targeted therapy is significantly not different across government and private hospitals. From ANOVA Table 6.16, it can be observed that the mean cost of imaging tests incurred during targeted therapy was ₹ 376±1,387.

Figure 6.7C

Box-plot depicting costs of pharmaceuticals and medical consumables incurred during targeted therapy across choice of provider

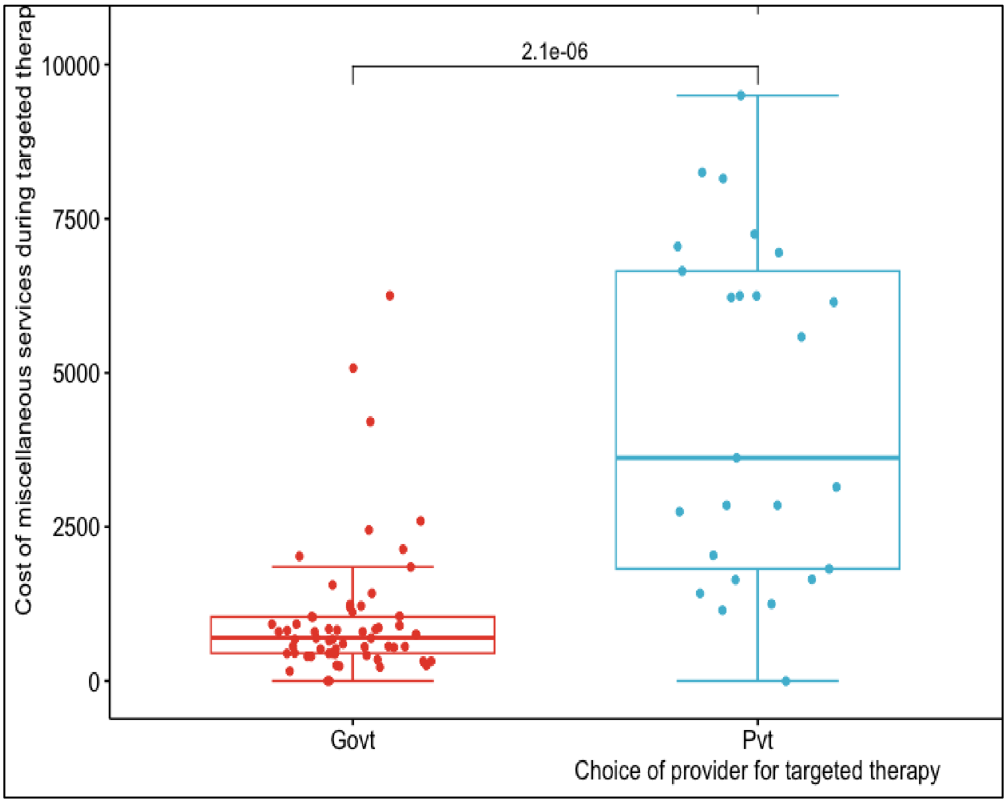


Source: Survey data

The distribution of costs incurred for pharmaceuticals and medical consumables during targeted therapy across choice of healthcare provider is depicted in Figure 6.7C. The p-value from the H test observed across government and private hospitals (1.9e-05) was lower than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of pharmaceuticals and medical consumables incurred during targeted therapy is significantly different across government and private hospitals. From ANOVA Table 6.16, it can be observed that the mean cost of pharmaceuticals and medical consumables incurred during targeted therapy was ₹ 58,696±1,46,894.

Figure 6.7D

Box-plot depicting costs of miscellaneous services incurred during targeted therapy across choice of provider

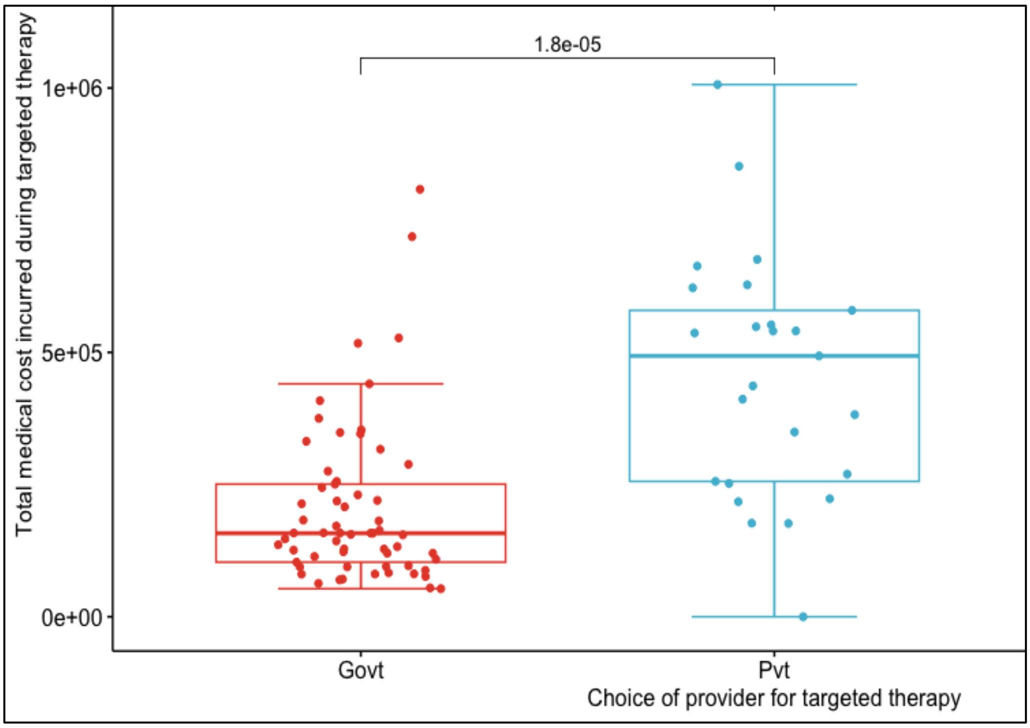


Source: Survey data

The distribution of costs incurred for miscellaneous services during targeted therapy across choice of healthcare provider is depicted in Figure 6.7D. The p-value from the H test observed across government and private hospitals (2.1e-06) was lower than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of miscellaneous services incurred during targeted therapy is significantly different across government and private hospitals. From ANOVA Table 6.16, it can be observed that the mean cost of miscellaneous services incurred during targeted therapy was ₹ 433±1,355.

Figure 6.7E

Box-plot depicting total medical costs incurred during targeted therapy across choice of provider



Source: Survey data

The distribution of total medical costs incurred during targeted therapy across choice of healthcare provider is depicted in Figure 6.7E. The p-value from the H test observed across government and private hospitals (1.8e-05) was lower than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean total medical costs incurred during targeted therapy are significantly different across government and private hospitals. From ANOVA Table 6.16, it can be observed that the mean total medical costs incurred during targeted therapy was ₹ 60,060±1,50,296.

6.3.2.5. Total Medical Costs Incurred During Breast Cancer Treatment

The total medical cost of breast cancer treatment has the following components:

i. Total cost of surgery

ii. Total cost of radiation

iii. Total cost of chemotherapy

iv. Total cost of targeted therapy

The total medical cost incurred for breast cancer treatment is calculated by summing up the above components. As observed from the Tables above, there is variation in medical costs across different healthcare providers. In this section, the total medical cost incurred by respondents is analysed in detail.

Table 6.17

Distribution of sample based on the total medical cost of treatment incurred in different healthcare providers across the TNM stage of respondents

TNM staging	Mean total medical cost of treatment (₹)		
	Treatment completely taken in a government hospital	Treatment completely taken in a private hospital	Treatment taken in both government and private hospital
IA & IB	88,797.1	1,46,598.6	1,14,246.6
II A	1,82,276.7	2,70,421.6	1,86,923.2
II B	2,11,425.9	2,34,010.2	2,58,823.4
III A	2,50,755.0	3,05,543.9	2,61,037.7
III B	2,74,637.6	2,80,123.1	1,87,760.0
III C	2,75,771.7	3,40,362.0	2,40,629.8
Total	**1,98,064.4**	**2,53,174.8**	**2,19,381.7**

Source: Survey data

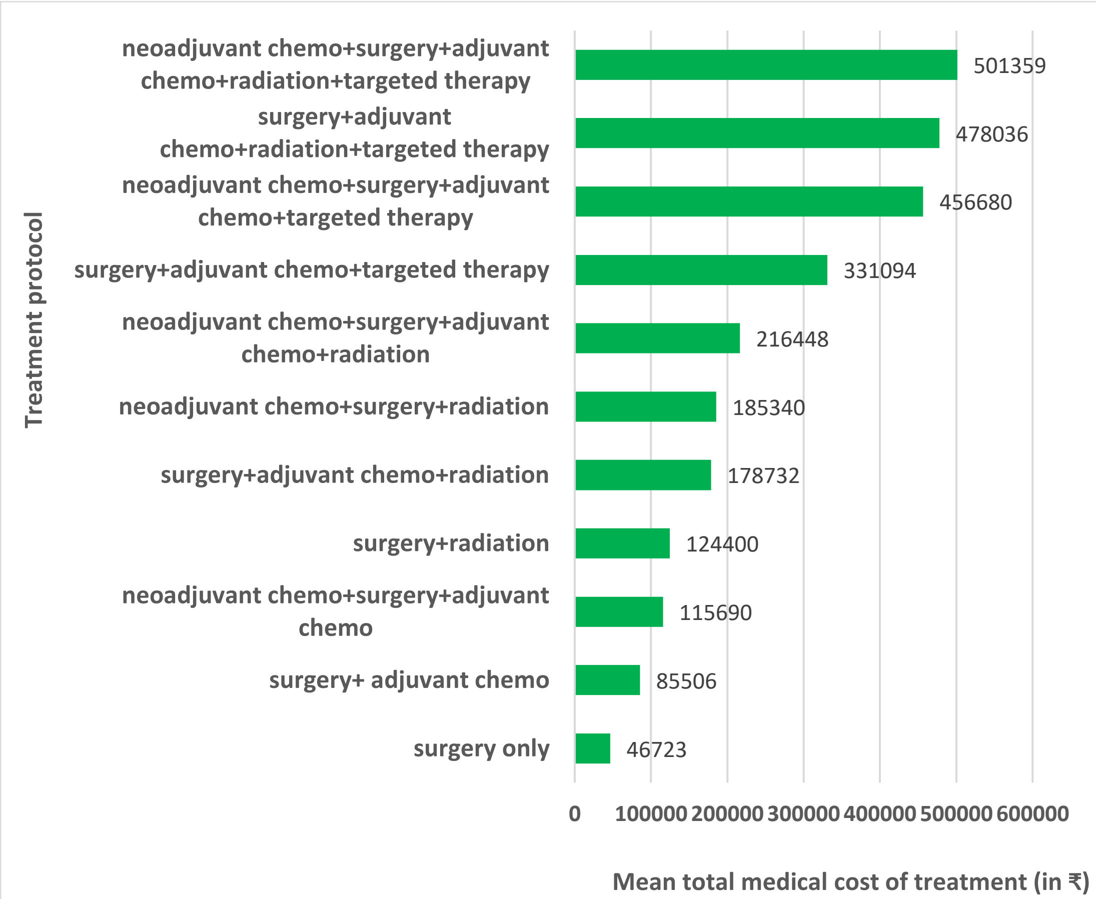
The mean total medical cost incurred by respondents during treatment in different healthcare providers is presented in Table 6.17. It can be observed that stage I breast cancer respondents who took treatment from only a government hospital incurred a mean total medical cost of ₹ 88,797.1, while those respondents who took treatment from only a private hospital incurred ₹ 1,46,598.6, and those who took treatment from both government and private hospitals incurred ₹ 1,14,246.6.

Stage II breast cancer respondents who took treatment from only a government hospital incurred on an average a mean total medical cost of ₹ 1,96,850.5, while those who took treatment from private hospitals incurred ₹ 2,69,776.5, and those who took treatment from both government and private hospitals incurred ₹ 2,22,873.

Across all healthcare providers, stage III breast cancer respondents incurred higher costs compared to stage I and stage II breast cancer respondents. Stage III breast cancer respondents who took treatment from only a government hospital incurred on an average a mean total medical cost of ₹ 2,67,054.3, while those who took treatment from private hospitals incurred ₹ 3,08,676, and those who took treatment from both government and private hospitals incurred ₹ 2,29,808.6.

Figure 6.8

Distribution of sample according to mean total treatment medical cost (₹) across treatment protocol when the treatment was completely taken in a government hospital

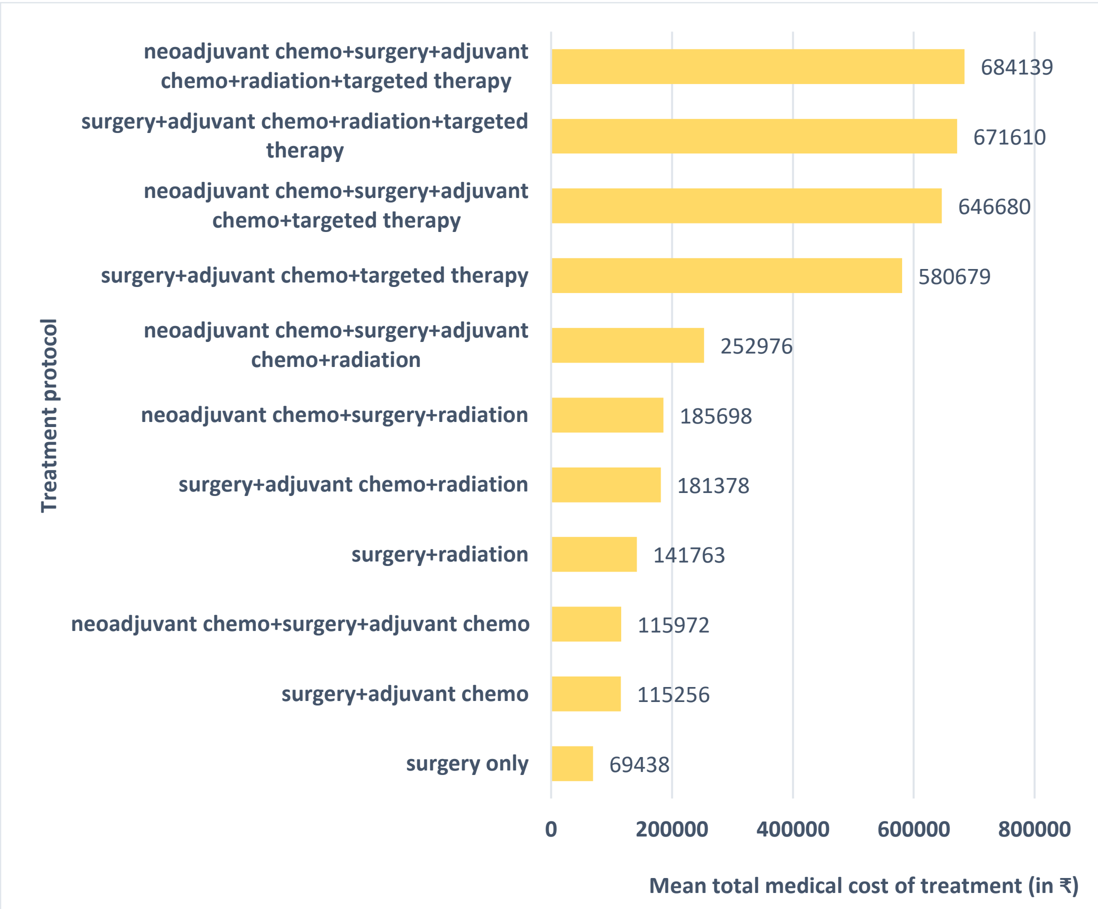


Source: Survey data

The mean total medical cost for treatment on the basis of treatment protocol incurred by respondents who took complete treatment in a government hospital is illustrated in Figure 6.8. It can be observed that the highest mean total medical cost, ₹ 5,01,359, was incurred for the treatment protocol- neoadjuvant chemotherapy followed by surgery, then adjuvant chemotherapy, then radiation and targeted therapy. The lowest mean total medical cost was incurred for the treatment protocol with surgery only. Treatment protocols with targeted therapy resulted in a higher total medical cost compared to other treatment protocols.

Figure 6.9

Distribution of sample according to mean total treatment medical cost (₹) across treatment protocol when the treatment was completely taken in a private hospital



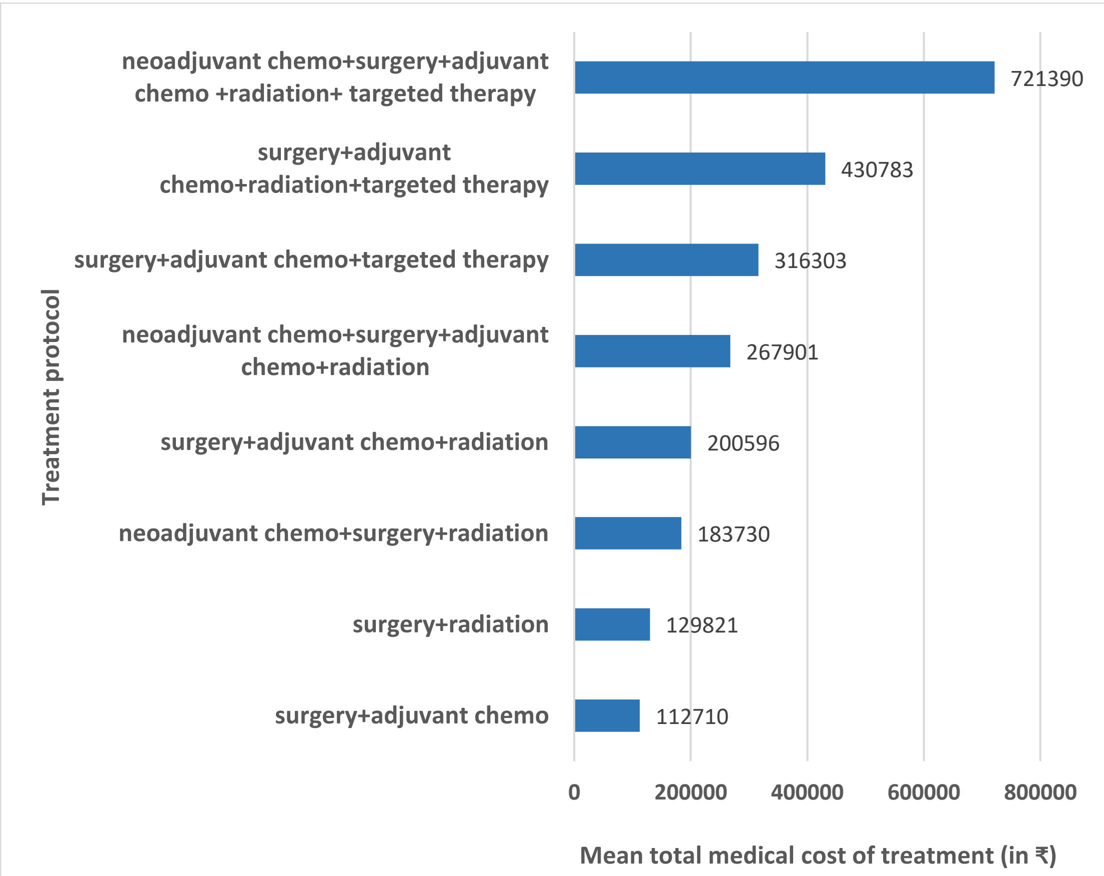
Source: Survey data

The mean total medical cost for treatment on the basis of treatment protocol incurred by respondents who took complete treatment in a private hospital is illustrated in Figure 6.9. Treatment protocol, which had neoadjuvant chemotherapy followed by surgery, then adjuvant chemotherapy, then radiation and targeted therapy, had the highest mean total medical cost, i.e., ₹ 6,84,139. Treatment protocol with only surgery had the lowest mean total medical cost.

During the interviews, it was observed that some respondents took treatment in both government and private hospitals, and hence, the medical costs for treatment were analysed separately for surgery, chemotherapy, radiation and targeted therapy. The observed pattern was that after surgery, some respondents sought treatment in other hospitals due to high medical costs or due to the long distance from their place of residence.

Figure 6.10

Distribution of sample according to mean total treatment medical cost (₹) across treatment protocol when the treatment was taken in both government and private hospitals



Source: Survey data

The mean total medical cost for treatment on the basis of treatment protocol incurred by respondents who took breast cancer treatment in both government and private hospitals is illustrated in Figure 6.10. The treatment protocol, which had surgery and adjuvant chemotherapy only, was observed to have the lowest mean total medical cost of treatment, ₹ 1,12,710. The highest mean medical cost was observed for the treatment protocol had neoadjuvant chemotherapy followed by surgery, then adjuvant chemotherapy, then radiation and targeted therapy.

6.3.3. Direct Medical Cost Incurred During the Follow-Up Stage

Breast cancer patients, after completing the treatment protocol, have to be monitored on a regular basis. According to the American Society of Clinical Oncology (ASCO) Guidelines, the standard approach for monitoring patients is a physical exam and a review of symptoms anywhere from every three to six months for the first two to three years, then every six months until year five, and annually thereafter.

Breast cancer patients are given hormone therapy treatments to help keep the breast cancer under control and to help relieve symptoms from it. Hormone therapy is given up to ten years post their treatment. The most common hormone therapy drugs are tamoxifen, toremifene and aromatase inhibitors such as anastrozole, letrozole, or exemestane.

Regular screening is done in order to check whether the cancer has recurred. Mammograms are done about 6 to 12 months after surgery, and radiation is completed, and then at least every year after that. Pelvic exams are recommended every year because hormone therapy drugs can increase the risk of endometrial cancer. Bone health will also be monitored if the patient is having an aromatase inhibitor. Other tests, such as blood tests, are also done during follow-up. Cancer treatments can also have side effects. Some might only last for a few days or weeks, and some side effects might not even show up until years after you have finished treatment. Hence, doctors recommend regular follow-ups in order to monitor these side effects. Rehabilitation techniques, like physical and occupational therapy, are recommended to patients after treatment. This can reduce pain, fatigue, and weakness.

The medical costs incurred during follow-up are calculated on an annual basis. Breast cancer patients incur the following medical costs during their follow-up stage:

i. Cost of imaging tests: Patients have to undergo imaging tests like mammograms, ultrasounds and other scans as a part of the screening process.

ii. Cost of pharmaceutical products and medical consumables: Drugs like tamoxifen, letrozole and other hormone therapy drugs are prescribed to patients.

iii. Cost of lab tests: Blood tests like CBC, calcium, sodium, and bone density tests are done to determine the health of the patient.

iv. Cost of biopsy test: Patients might be asked to take a FNAC biopsy or other type of biopsy in order to check whether tumour cells are present.

v. Miscellaneous costs: These include costs for consultation, breast prosthesis, nutrition services, physiotherapy services, lymphedema removal charges and rehabilitation services.

Table 6.18

Distribution of sample based on the total medical cost incurred in the follow-up stage across the TNM stage of respondents when the choice of a healthcare provider is government

TNM staging	Mean annual cost (₹)					
	Annual cost of imaging test	Annual cost of biopsy test	Annual cost of pharma and medical products	Annual cost of lab tests	Annual cost of miscellaneous services	Annual total medical cost of follow-up
IA & IB	1,301.41	1,002.0	1,334.9	941.7	1,092.9	5,673.1
II A	1,498.6	1,040.3	1,402.8	979.5	1,119.1	6,040.4
II B	1,407.2	975.2	1,486.1	959.5	1,172.3	6,000.6
III A	1,824.7	1,283.8	1,604.6	1,199.2	1,412.5	7,324.9
III B	1,883.5	1,097.8	1,305.7	1,127.1	1,232.1	6,646.4
III C	1,647.2	1,119.0	1,445.2	1,159.0	1,220.0	6,590.7
Total	**1,519.1**	**1,057.1**	**1,441.7**	**1,015.7**	**1,182.6**	**6,216.4**

Source: Survey data

The mean medical cost incurred during the follow-up stage when the respondents went to a government hospital is presented in Table 6.18. It can be observed that the mean annual follow-up medical cost across all stages was ₹ 6,216.4. The mean annual cost of the imaging test was ₹ 1,519.1, the biopsy test was ₹ 1,057.1, and the lab test was ₹ 1,015.7. Pharmaceutical products and medical consumables, on average, cost around ₹ 1,441.7 annually. The mean cost of miscellaneous services was around ₹ 11,82.6 annually.

Table 6.19

Distribution of sample based on the total medical cost incurred in the follow-up stage across the TNM stage of respondents when the choice of a healthcare provider is private

TNM staging	Mean annual cost (₹)					
	Annual cost of imaging test	Annual cost of biopsy test	Annual cost of pharma and medical products	Annual cost of lab tests	Annual cost of miscellaneous services	Annual total medical cost of follow-up
IA & IB	3,339.4	1,230.0	1,899.1	1,157.2	1,970.5	9,596.3
II A	3,421.8	1,345.0	1,918.8	1,266.5	2,160.0	10,112.2
II B	3,375.6	1,185.6	1,888.4	1,162.3	2,083.0	9,695.2
III A	3,665.0	1,410.0	2,004.3	1,353.1	2,305.8	10,738.3
III B	3,595.5	1,374.4	1,966.6	1,251.1	2,060.0	10,247.7
III C	3,973.3	1,415.0	2,076.6	1,423.3	2,430.0	11,318.3
Total	**3,467.3**	**1,299.1**	**1,929.6**	**1,241.6**	**2,142.5**	**10,080.2**

Source: Survey data

The mean medical cost incurred during the follow-up stage when the respondents went to a private hospital is presented in Table 6.19. The mean annual follow-up medical cost across all stages was ₹ 10,080.2. The mean annual cost of the imaging test was ₹ 3,467.3, the biopsy test was ₹ 1,299.1, and the lab tests were ₹ 1,241.6. Pharmaceutical products and medical consumables, on average, cost around ₹ 1,929.6 annually, and miscellaneous services cost around ₹ 2,142.5 annually.

Table 6.20

ANOVA table representing the different medical costs (₹) incurred during the follow-up stage among different healthcare providers

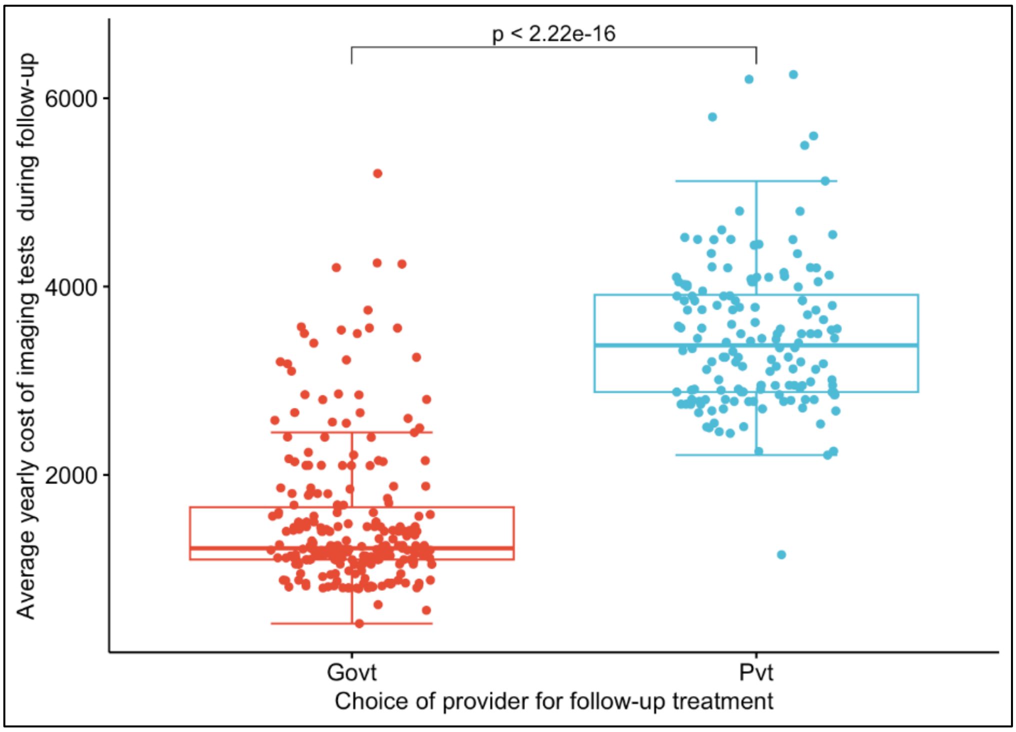
Cost	Choice of provider for follow-up treatment	Mean ± SD	Mean ± SD	KS Test	H Test
Average yearly cost of biopsy tests during follow-up	Govt	1,152±462	1,057±495	***	***
	Pvt		1,299±359	***	
Average yearly cost of imaging tests during follow-up	Govt	2,279±1,223	1,519±764	***	***
	Pvt		3,467±778	***	
Average yearly cost of lab tests during follow-up	Govt	1,104±424	1,016±451	***	***
	Pvt		1,242±335	***	
Average yearly cost of miscellaneous services during follow-up	Govt	1,557±623	1,183±406	***	***
	Pvt		2,142±419	***	
Average yearly cost of pharmaceuticals and medical consumables during follow-up	Govt	1,632±576	1,442±630	***	***
	Pvt		1,930±292	***	
Total average medical cost incurred per year during follow-up	Govt	7,723±2,836	6,216±2,342	***	***
	Pvt		10,080±1,713	***	

Source: Survey data

The ANOVA Table determining whether there is a significant difference among various average yearly costs incurred during the follow-up stage across choice of healthcare provider is represented in Table 6.20. The results from the KS test and H test reveal that the values obtained were significant at a 1 per cent level. Hence, it can be concluded that there is a significant difference in average yearly costs incurred in government and private hospitals in the case of the cost of biopsy tests, imaging tests, lab tests, pharmaceuticals and medical consumables, miscellaneous services, and total medical costs during the follow-up stage.

Figure 6.11A

Box-plot depicting average yearly costs of imaging tests incurred during follow-up across choice of provider

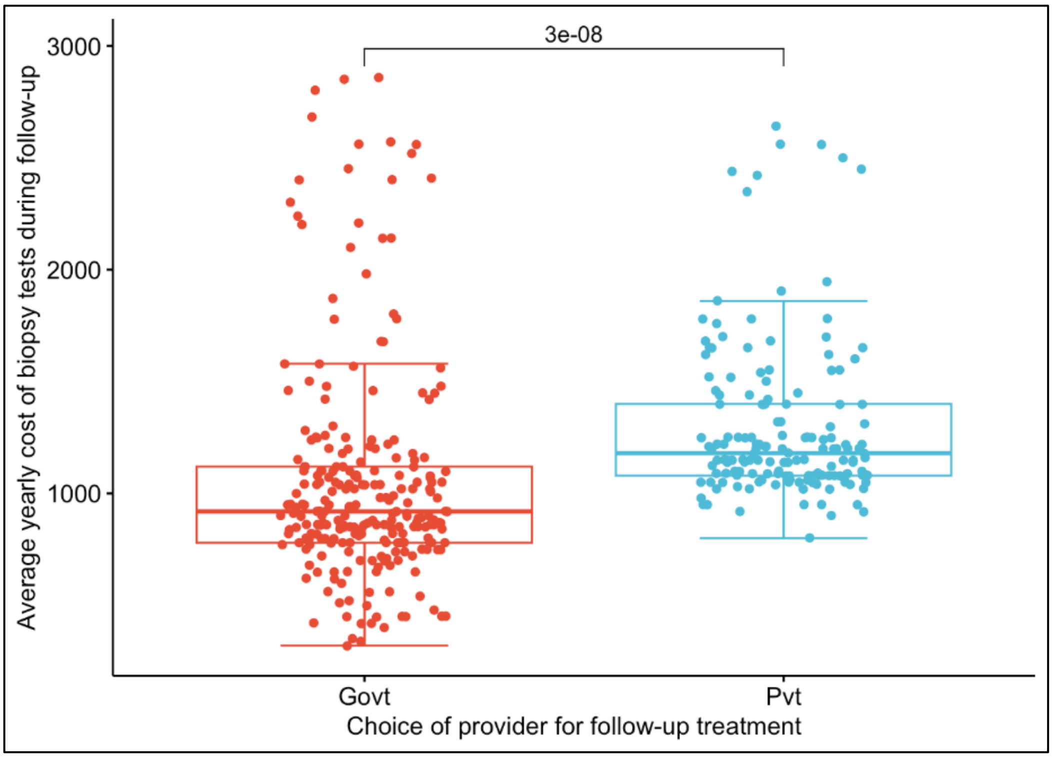


Source: Survey data

The distribution of average yearly costs incurred for imaging tests during the follow-up stage across a choice of a healthcare provider is depicted in Figure 6.11A. The p-value from the H test observed across government and private hospitals (p<2.22e-16) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the average yearly cost of imaging tests incurred during the follow-up stage is significantly different across government and private hospitals. From ANOVA Table 6.20, it can be observed that the mean yearly cost of imaging tests incurred during follow-up was ₹ 2,279±1,223.

Figure 6.11B:

Box-plot depicting average yearly costs of biopsy tests incurred during follow-up across choice of provider

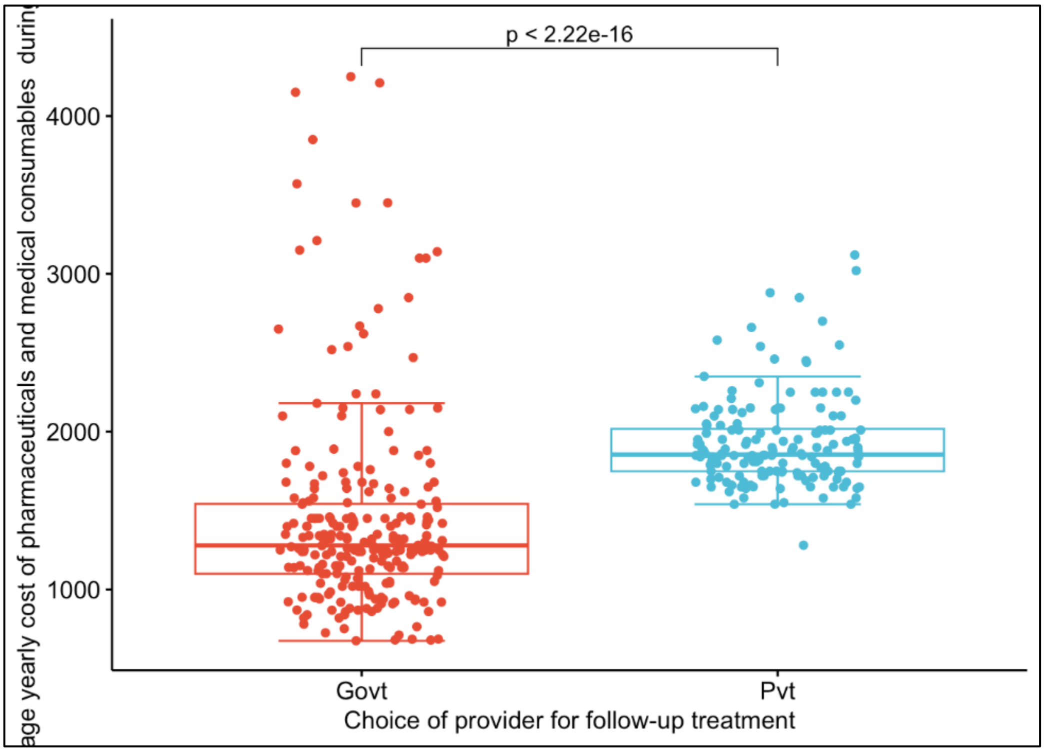


Source: Survey data

The distribution of average yearly costs incurred for biopsy tests during the follow-up stage across a choice of a healthcare provider is depicted in Figure 6.11B. The p-value from the H test observed across government and private hospitals (3e-08) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the average yearly cost of biopsy tests incurred during the follow-up stage is significantly different across government and private hospitals. From ANOVA Table 6.20, it can be observed that the mean yearly cost of biopsy tests incurred during follow-up was ₹ 1,152±462.

Figure 6.11C

Box-plot depicting average yearly costs of pharmaceuticals and medical consumables tests incurred during follow-up across choice of provider

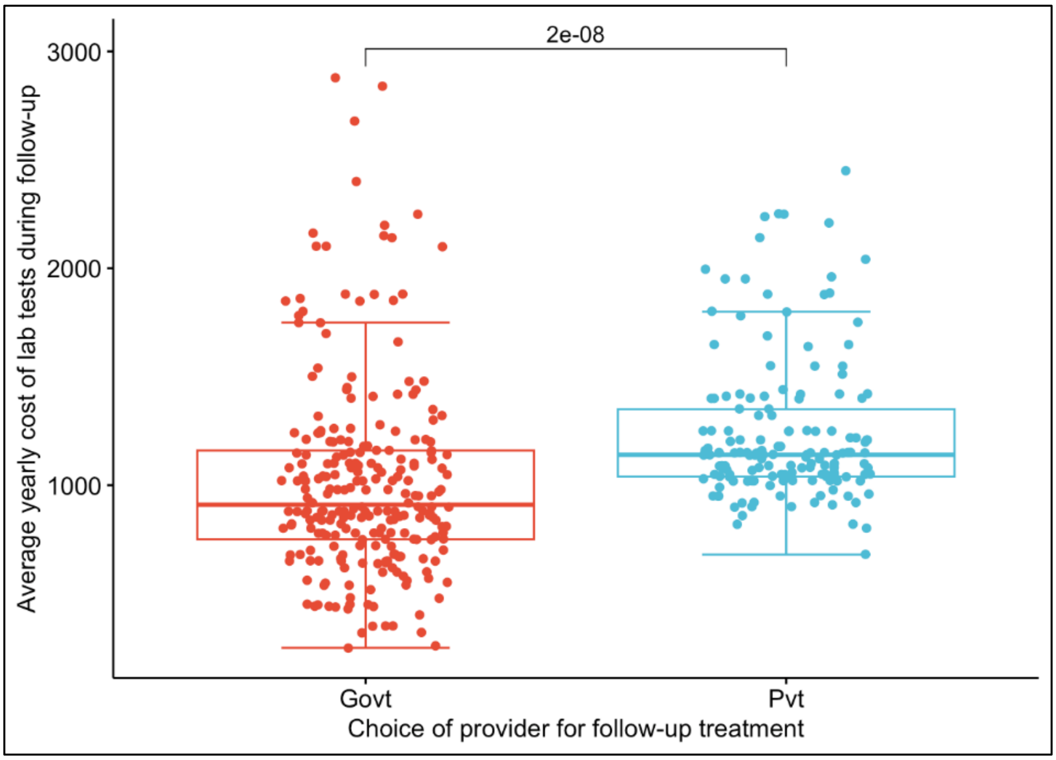


Source: Survey data

The distribution of average yearly costs incurred for pharmaceuticals and medical consumables tests during the follow-up stage across a choice of a healthcare provider is depicted in Figure 6.11C. The p-value from the H test observed across government and private hospitals ($p<2.22e-16$) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the average yearly cost of pharmaceuticals and medical consumables tests incurred during the follow-up stage is significantly different across government and private hospitals. From ANOVA Table 6.20, it can be observed that the mean yearly cost of pharmaceuticals and medical consumables tests incurred during follow-up was ₹ 1,632±576.

Figure 6.11D

Box-plot depicting average yearly costs of lab tests incurred during follow-up across choice of provider

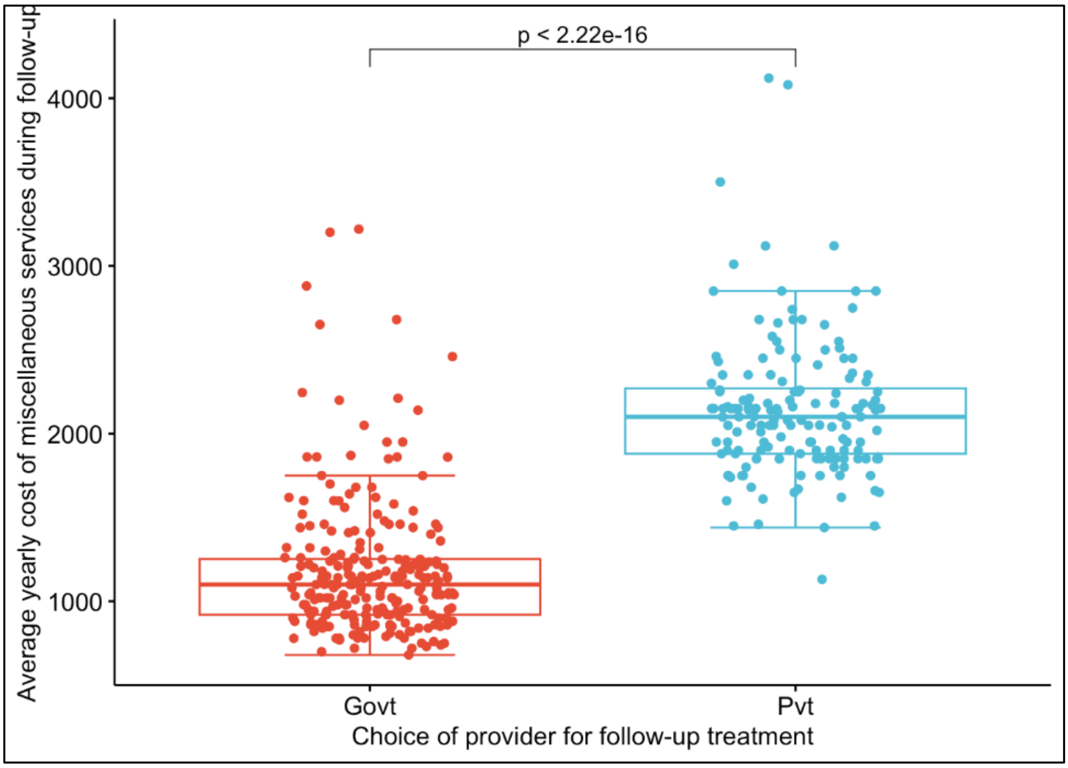


Source: Survey data

The distribution of average yearly costs incurred for lab tests during the follow-up stage across a choice of healthcare provider is depicted in Figure 6.11D. The p-value from the H test observed across government and private hospitals (2e-08) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the average yearly cost of lab tests incurred during the follow-up stage is significantly different across government and private hospitals. From ANOVA Table 6.20, it can be observed that the mean yearly cost of lab tests incurred during follow-up was ₹ 1,104±424.

Figure 6.11E

Box plot depicting average yearly costs of miscellaneous services incurred during follow-up across choice of provider

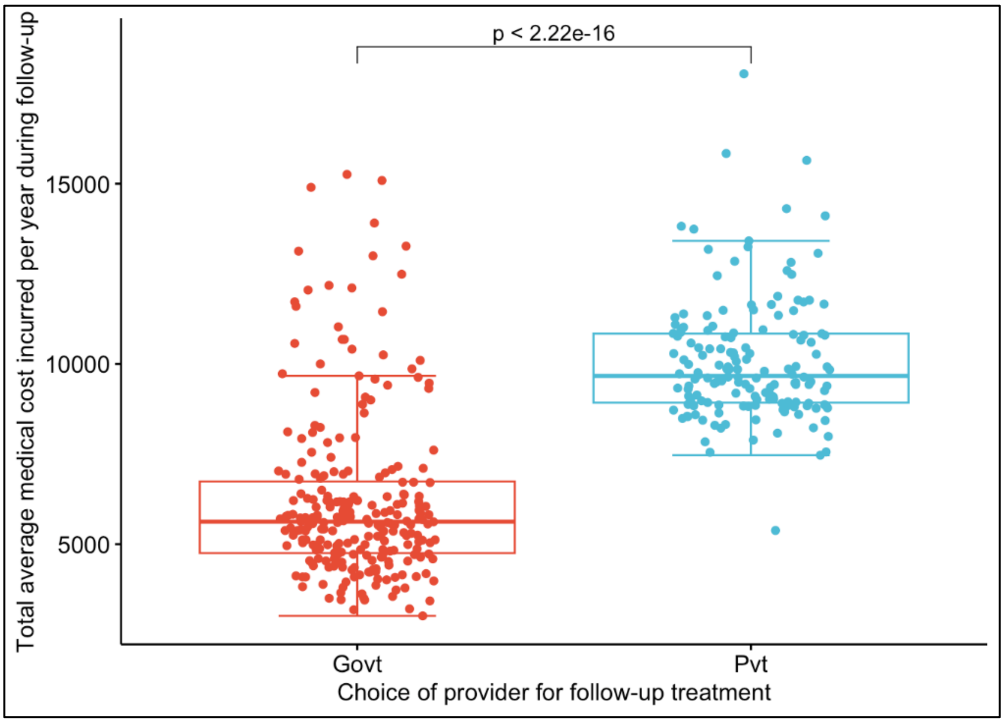


Source: Survey data

The distribution of average yearly costs incurred for miscellaneous services during the follow-up stage across a choice of healthcare provider is depicted in Figure 6.11E. The p-value from the H test observed across government and private hospitals ($p<2.22e-16$) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the average yearly cost of miscellaneous services incurred during the follow-up stage is significantly different across government and private hospitals. From ANOVA Table 6.20, it can be observed that the mean yearly cost of miscellaneous services incurred during follow-up was ₹ 1,557±623.

Figure 6.11F

Box plot depicting total average medical costs incurred per year during follow-up across choice of provider



Source: Survey data

The distribution of total average medical costs incurred per year during the follow-up stage across a choice of healthcare provider is depicted in Figure 6.11F. The p-value from the H test observed across government and private hospitals (p<2.22e-16) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the total average medical costs incurred per year during the follow-up stage are significantly different across government and private hospitals. From ANOVA Table 6.20, it can be observed that the total average medical costs incurred per year during follow-up was ₹ 7,723±2,836.

6.4. Direct Non-Medical Costs Incurred by Breast Cancer Patients

The direct non-medical costs refer to the expenses paid by patients to visit and use the services of medical institutions. Direct non-medical costs include transportation costs, expenditure on food consumption and lodging and relocation costs. In this section, each of these costs are analysed in detail. The direct non-medical costs incurred during treatment are only analysed in this study. Since it is difficult to estimate direct non-medical costs during the diagnosis and follow-up stages, costs incurred during these stages have not been included in the study.

6.4.1. Transportation Cost Incurred During Treatment of Breast Cancer

The cost of transportation incurred during surgery, radiation, chemotherapy and targeted therapy is analysed in this section. The common modes of transportation observed in this study are private cars, taxis, autos, buses and trains.

Table 6.21

Distribution of sample according to mean transportation costs incurred during treatment of breast cancer across TNM stage

TNM stage	Mean cost of transportation (₹)							
	Surgery		Radiation		Chemotherapy		Targeted Therapy	
	Govt. hospital	Private hospital	Govt. hospital	Private hospital	Govt. hospital	Private hospital	Govt. hospital	Private hospital
IA & IB	2,569.6	5,205.2	8,700.0	6,600.0	1,954.3	10,100	950	25,800
IIA	3,661.8	5,327.5	4,913.1	7,111.2	7,312.5	7,885.8	4,142.8	11,208.3
IIB	3,909.4	5,555.7	5,479.0	6,309.7	6,849.7	8,179.3	3,924.3	88,14.00
IIIA	3,587.9	5,079.3	6,042.2	6,314.5	7,018.2	8,914.5	5,153.7	11,512.5
IIIB	3,242.8	6,955.5	7,462.0	6,031.2	9,050.0	9,977.7	6,305.0	4,825.0
IIIC	2,994.4	3,505.0	6,475.0	8,521.4	8,116.2	5,944.4	1,800.0	14,100.0
Total	**3,515.0**	**5,337.6**	**5,935.3**	**6,658.1**	**6,870.1**	**8,291.4**	**4,276.5**	**10,966.8**

Source: Survey data

The mean transportation costs incurred by respondents during surgery, radiation, chemotherapy, and targeted therapy are presented in Table 6.22. The mean cost of transportation incurred during surgery was ₹ 3,515 for respondents who sought treatment in a government hospital, while it was ₹ 5,337.6 in the case of private hospitals. In the case of radiation, in government hospitals, the mean transportation cost was ₹ 5,935.3, while in private hospitals, it was ₹ 6,658.1. During chemotherapy, respondents who sought treatment in government hospitals incurred a mean transportation cost of ₹6,870.1, and those who went to private hospitals incurred ₹ 8,291.4. The mean cost of transportation incurred during targeted therapy was ₹ 4,276.5 in the case of government hospitals and ₹ 10,966.8 in the case of private hospitals. It can be observed that the mean transportation costs are higher for chemotherapy and targeted therapy when compared to surgery and radiation.

Table 6.22

ANOVA Table representing the transportation cost (₹) incurred during breast cancer treatment among different healthcare providers

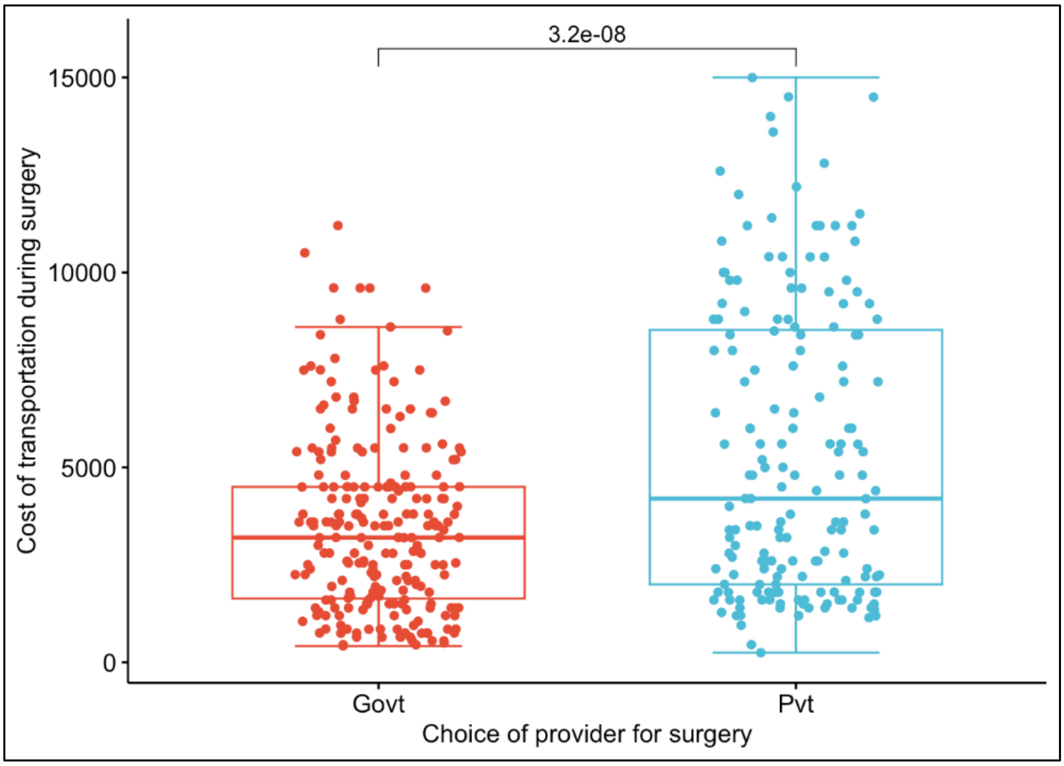
Cost	Choice of provider	Mean ± SD	Mean ± SD	KS Test	H Test
Cost of transportation during surgery	Govt	4,299±3,099	3,515±2,252	***	***
	Pvt		5,338±3,710	***	
Cost of transportation during targeted therapy	Govt	1,338±3,736	4,277±3,779	***	***
	Pvt		10,967±7,378	***	
	not applicable		0±0	***	
Cost of transportation during chemotherapy	Govt	6,592±5,441	6,870±4,821	***	***
	Pvt		8,291±5,686	***	
	not applicable		0±0	***	
Cost of transportation during radiation	Govt	3,693±4,318	5,935±4,569	***	***
	Pvt		6,658±3,077	***	
	not applicable		0±0	***	

Source: Survey data

The variation between groups is classified on the basis of respondents' choice of provider for surgery, radiation, chemotherapy, and targeted therapy, as presented in Table 6.23. It can be observed that there is significant variation between groups with regard to transportation costs incurred during surgery, radiation, chemotherapy, and targeted therapy at a 1 per cent level of significance.

Figure 6.12A

Box plot depicting the transportation costs (₹) incurred during surgery across choice of provider

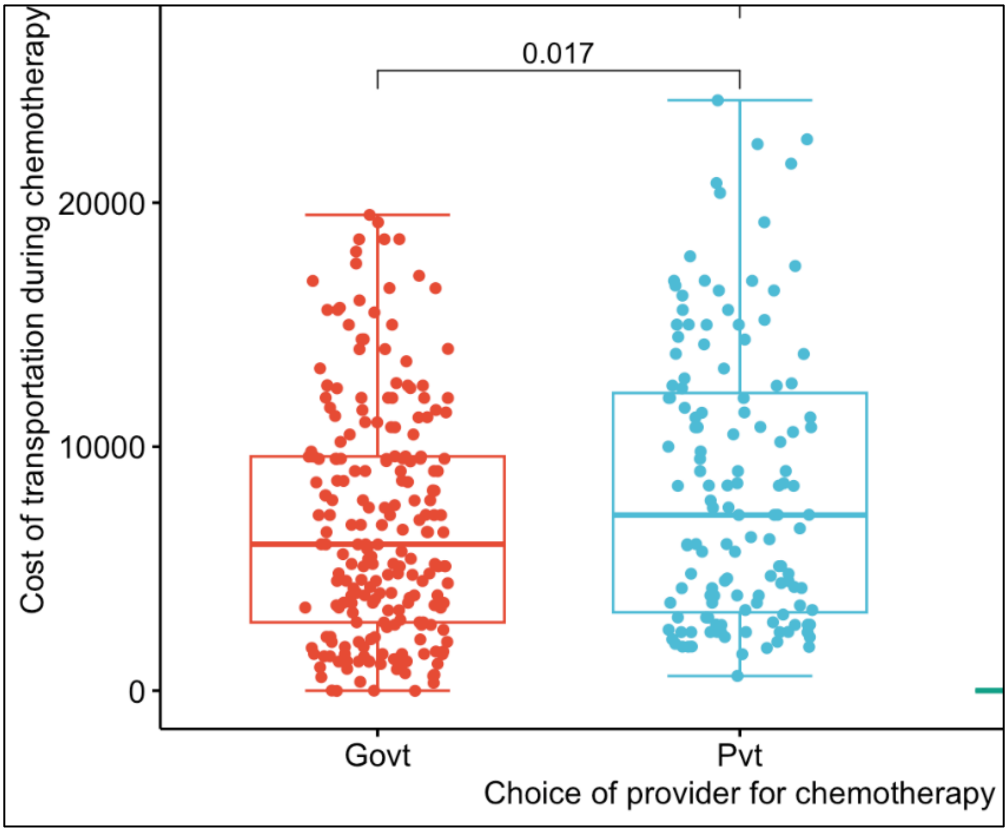


Source: Survey data

The distribution of transportation costs incurred during surgery across a choice of provider is depicted in Figure 6.12A. The p-value from the H test observed across government and private hospitals (3.2e-08) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the transportation costs incurred during surgery are significantly different across government and private hospitals. From ANOVA Table 6.22, it can be observed that the mean transportation costs incurred during surgery were ₹ 4,299±3,099.

Figure 6.12B

Box plot depicting the transportation costs (₹) incurred during chemotherapy across choice of provider

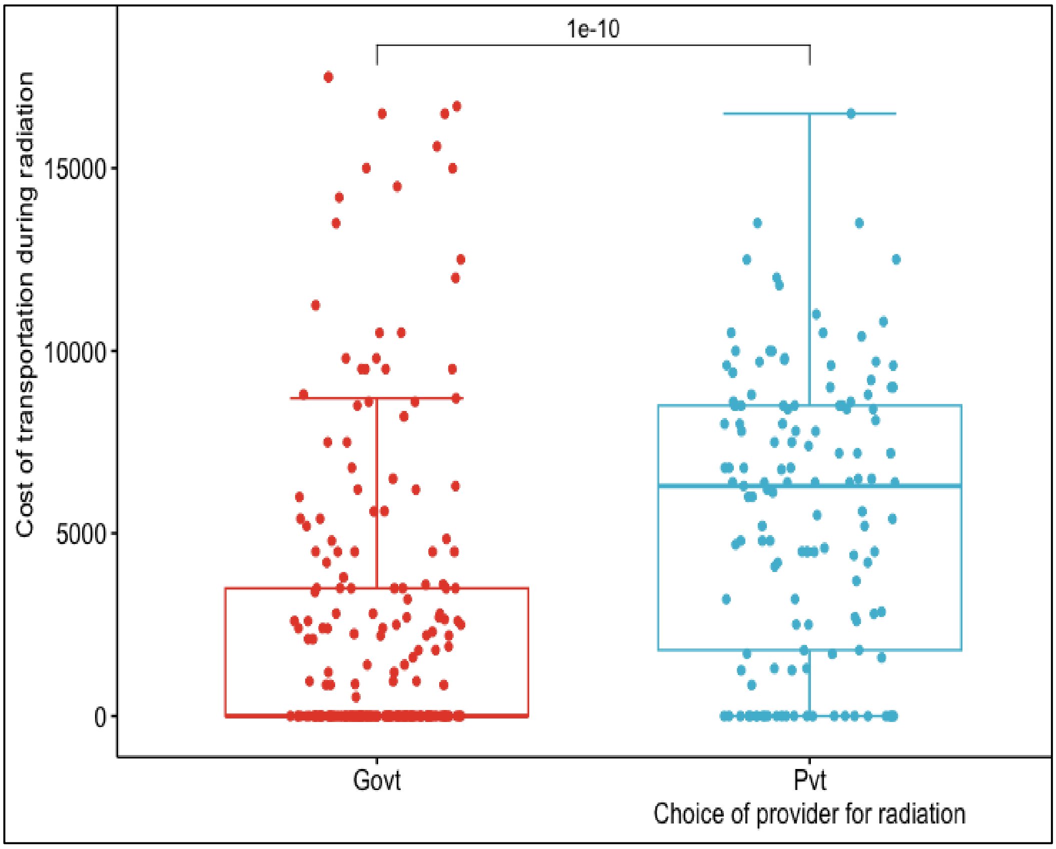


Source: Survey data

The distribution of transportation costs incurred during chemotherapy across a choice of provider is depicted in Figure 6.12B. The p-value from the H test observed across government and private hospitals (0.01) was lesser than 0.05 and, hence, statistically significant at a 5 per cent level. Therefore, we can conclude that the mean transportation costs incurred during chemotherapy are significantly different across government and private hospitals. From ANOVA Table 6.22, it can be observed that the mean transportation costs incurred during chemotherapy were ₹ 6,592±5,441.

Figure 6.12C

Box plot depicting the transportation costs (₹) incurred during radiation across choice of provider

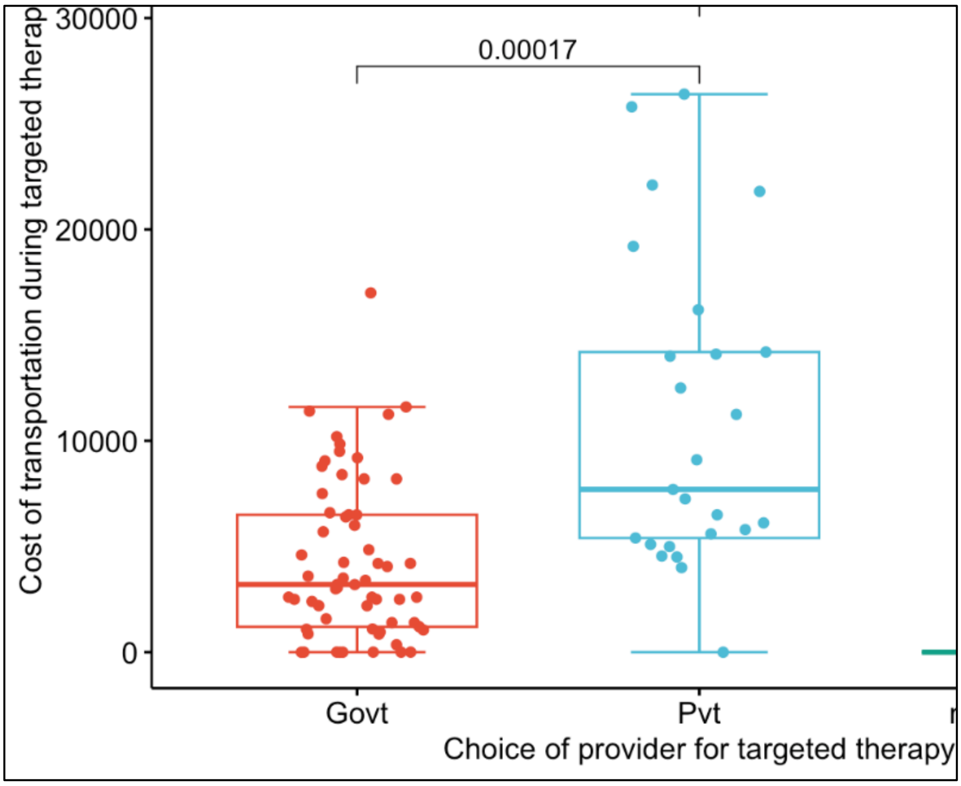


Source: Survey data

The distribution of transportation costs incurred during radiation across a choice of provider is depicted in Figure 6.12C. The p-value from the H test observed across government and private hospitals (1e-10) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean transportation costs incurred during radiation are significantly different across government and private hospitals. From ANOVA Table 6.22, it can be observed that the mean transportation costs incurred during radiation was ₹ 3,693±4,318.

Figure 6.12D

Box plot depicting the transportation costs (₹) incurred during targeted therapy across choice of provider



Source: Survey data

The distribution of transportation costs incurred during targeted therapy across choice of provider is depicted in Figure 6.12D. The p-value from the H test observed across government and private hospitals (0.00) was lesser than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean transportation costs incurred during targeted therapy are significantly different across government and private hospitals. From ANOVA Table 6.22, it can be observed that the mean transportation costs incurred during targeted therapy were ₹ 1,338±3,736.

6.4.2. Food Cost Incurred During Breast Cancer Treatment

The cost of food consumption during surgery, radiation, chemotherapy and targeted therapy is analysed in this section. During surgery, patients and their caregivers usually have to buy three meals from outside their homes. In the case of chemotherapy and targeted therapy, they have to buy two meals from outside their home. For radiation, the number of meals varies depending on whether they have taken lodging or going back to their house.

Table 6.23

Distribution of sample according to mean cost of food consumption during treatment of breast cancer across TNM stage

TNM stage	Mean cost of food (₹)							
	Surgery		Radiation		Chemotherapy		Targeted Therapy	
	Govt. hospital	Private hospital	Govt. hospital	Private hospital	Govt. hospital	Private hospital	Govt. hospital	Private hospital
IA, IB	2,296.9	2,373.6	3,845.0	5,900.0	409.37	634.28	550.00	1,680.0
IIA	2,214.8	2,389.6	5,197.7	5,345.4	1,272.3	1,213.6	620.0	1,515.0
IIB	2,265.0	2,268.5	7,223.2	6,525.8	2,470.1	852.22	775.0	1,764.0
IIIA	2,289.3	2,292.7	5,628.3	6,277.2	1,911.1	1,322.5	1,125.0	4,912.5
IIIB	1,483.5	2,295.5	5,451.3	8,950.0	1,158.5	2,784.4	875.0	1,200.0
IIIC	2,420.0	2,781.2	5,060.0	6,160.7	1,138.7	1,471.1	925.0	1,080.0
Total	**2,214.1**	**2,350.3**	**5,993.1**	**6,280.4**	**1,666.3**	**1,204.3**	**778.6**	**2,072.4**

Source: Survey data

The mean cost of food consumption by respondents during surgery, radiation, chemotherapy, and targeted therapy is presented in Table 6.23. The mean cost of food during surgery was ₹ 2,214.1 for respondents who sought treatment in a government hospital, while it was ₹ 2,350.3 in the case of private hospitals. In the case of radiation, the mean food cost was ₹ 5,993.1 in government hospitals, while in private hospitals, it was ₹ 6,280.4. During chemotherapy, respondents incurred a mean food cost of ₹ 1,666.3 in government hospitals, and those who went to private hospitals incurred ₹ 1,204.3. The mean cost of food consumption during targeted therapy was ₹ 778.6 in the case of government hospitals and ₹ 2,072.4 in the case of private hospitals. The mean food cost was higher during radiation when compared to other modes of treatment. Respondents incurred higher mean food costs in private hospitals than in government hospitals.

Table 6.24

ANOVA Table representing the cost (₹) of food consumption incurred during breast cancer treatment among different healthcare providers

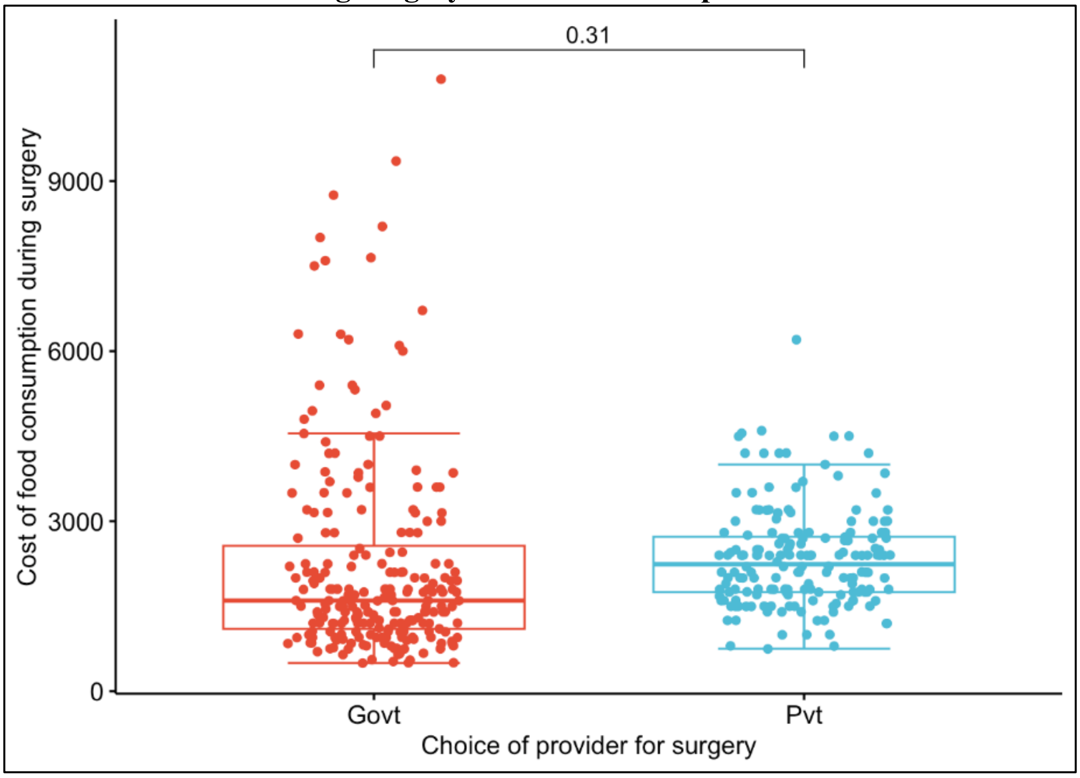
Cost	Choice of provider	Mean ± SD	Mean ± SD	KS Test	H Test
Cost of food consumption during surgery	Govt	2,273±1,457	2,214±1,773	***	***
	Pvt		2,350±877	***	
Cost of food consumption during radiation	Govt	3,587±4,495	5,944±4,798	***	***
	Pvt		6,280±3,845	***	
	not applicable		0±0	***	
Cost of food consumption during chemotherapy	Govt	1,351±3,259	1,666±3,907	***	***
	Pvt		1,204±2,162	***	
	not applicable		0±0	***	
Cost of food consumption during targeted therapy	Govt	257±958	779±720	***	***
	Pvt		2,072±2,925	***	
	not applicable		0±0	***	

Source: Survey data

The variation between groups is classified on the basis of respondents' choice of provider for surgery, radiation, chemotherapy, and targeted therapy, as presented in Table 6.24. It can be observed that there is significant variation between groups with regard to the cost of food consumption incurred during radiation, surgery, chemotherapy and targeted therapy at a 1 per cent level of significance.

Figure 6.13A

Box plot depicting the food costs (₹) incurred during surgery across choice of provider

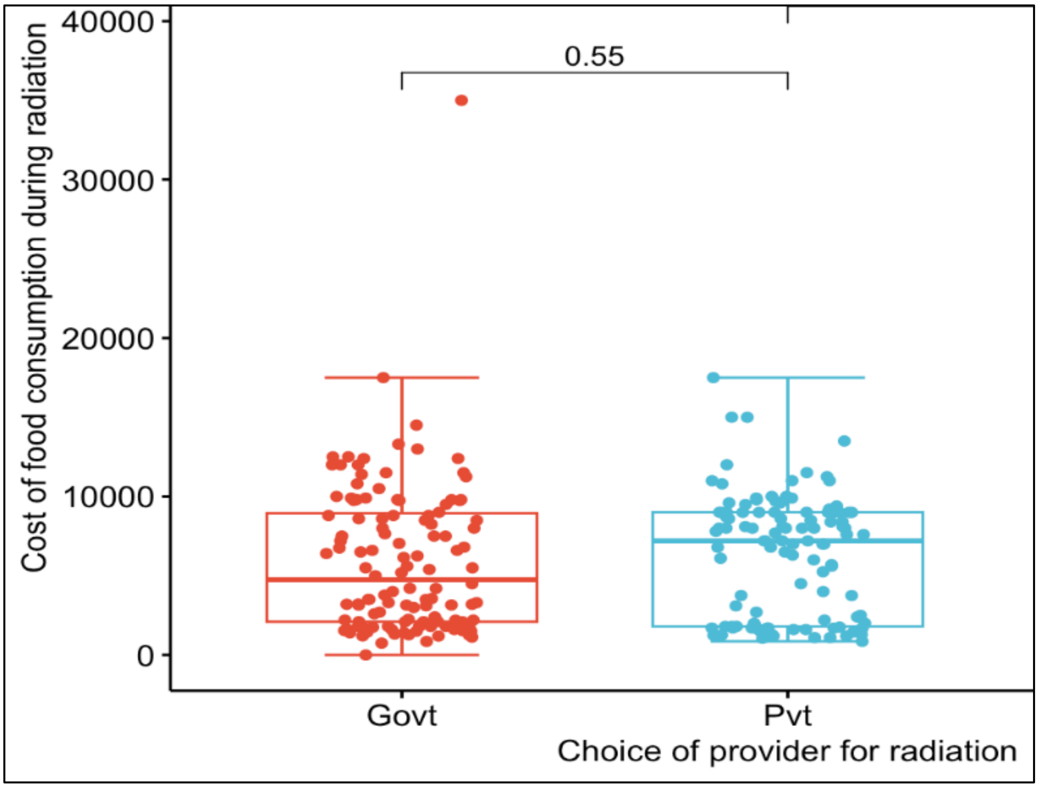


Source: Survey data

The distribution of food costs incurred during surgery across a choice of provider is depicted in Figure 6.13A. The p-value from the H test observed across government and private hospitals (0.31) was higher than 0.01 and, hence, statistically insignificant at a 1 per cent level. Therefore, we can conclude the mean cost of food consumption incurred during surgery is significantly not different across government and private hospitals. From ANOVA Table 6.24, it can be observed that the mean cost of food consumption incurred during surgery was ₹ 2,273±1,457.

Figure 6.13B

Box plot depicting the food costs (₹) incurred during radiation across choice of provider

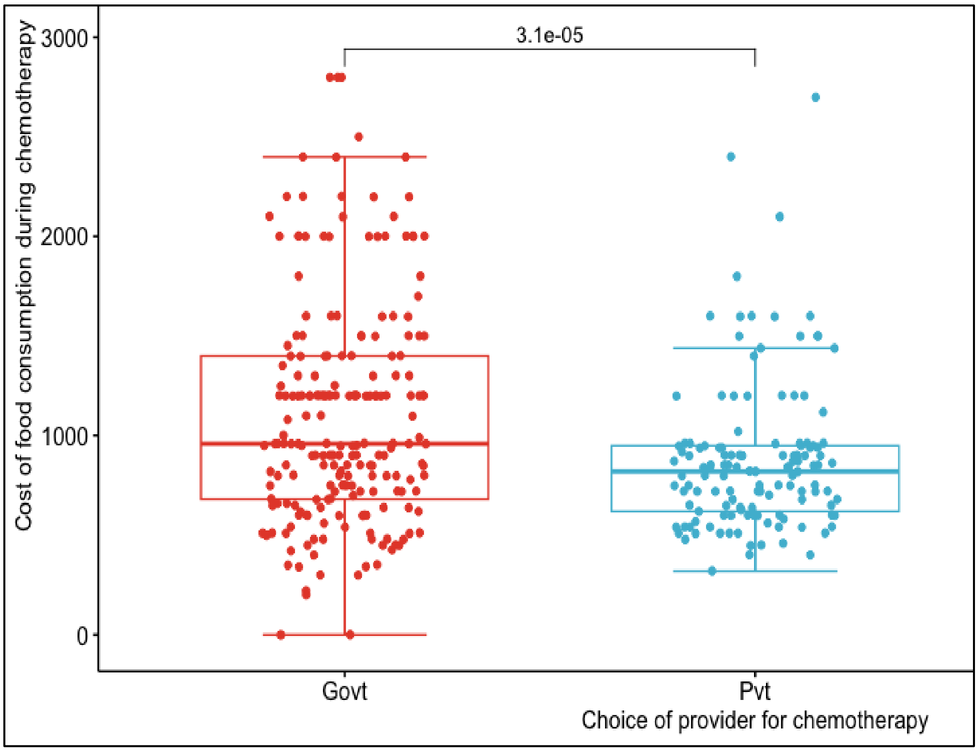


Source: Survey data

The distribution of food costs incurred during radiation across a choice of provider is depicted in Figure 6.13B. The p-value from the H test observed across government and private hospitals (0.55) was higher than 0.01 and, hence, statistically insignificant at a 1 per cent level. Therefore, we can conclude the mean cost of food consumption incurred during radiation is significantly not different across government and private hospitals. From ANOVA Table 6.24, it can be observed that the mean cost of food consumption incurred during radiation was ₹ 3,587±4,495.

Figure 6.13C

Box plot depicting the food costs (₹) incurred during chemotherapy across choice of provider

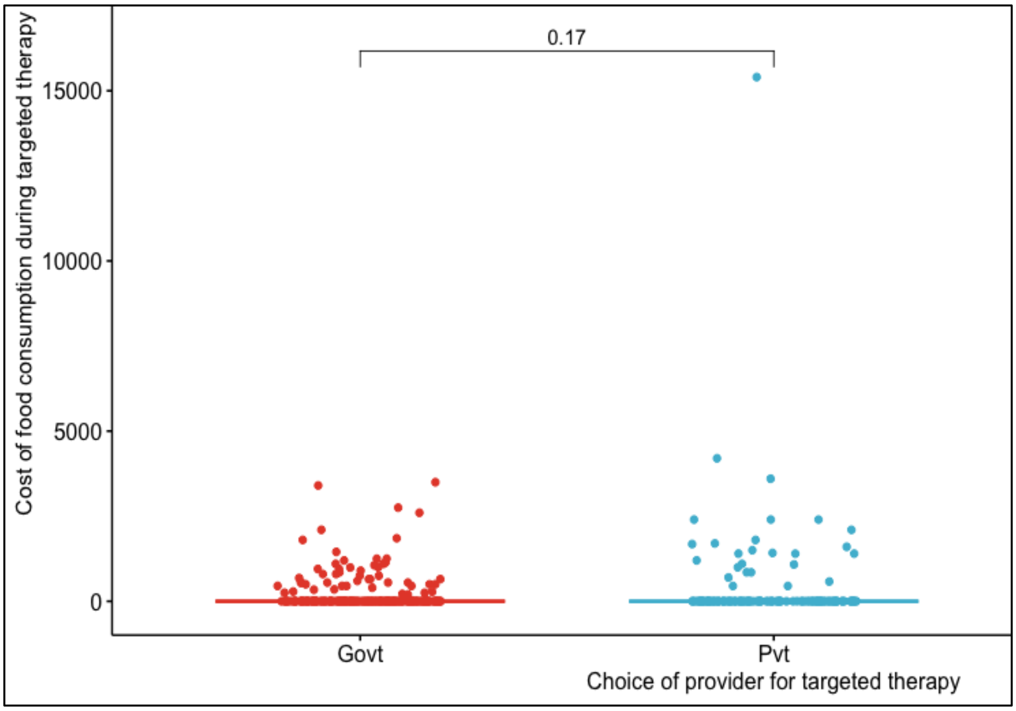


Source: Survey data

The distribution of food costs incurred during chemotherapy across choice of provider is depicted in Figure 6.13C. The p-value from the H test observed across government and private hospitals (3.1e-05) was lower than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of food consumption incurred during chemotherapy is significantly different across government and private hospitals. From ANOVA Table 6.24, it can be observed that the mean cost of food consumption incurred during chemotherapy was ₹ 1,351±3,259.

Figure 6.13D

Box-plot depicting the food costs(₹) incurred during targeted therapy across choice of provider



Source: Survey data

The distribution of food costs incurred during targeted therapy across choice of provider is depicted in Figure 6.13D. The p-value from the H test observed across government and private hospitals (0.17) was higher than 0.01 and, hence, statistically insignificant at a 1 per cent level. Therefore, we can conclude that the mean cost of food consumption incurred during targeted therapy is significantly not different across government and private hospitals. From ANOVA Table 6.24, it can be observed that the mean cost of food consumption incurred during targeted therapy was ₹ 257±958.

6.4.3. Lodging Costs Incurred During Breast Cancer Treatment

The cost of lodging incurred during radiation and chemotherapy is analysed in this section. During radiation, patients usually tend to find accommodation close to the hospital because they have to visit the hospital every day during the radiation cycle. In the case of chemotherapy and targeted therapy, accommodation is taken depending on the distance from the patient's household to the hospital and the mode of transportation used. The accommodation cost incurred during surgery is studied under direct medical expenses in the previous section. In the case of targeted therapy, accommodation is mostly not taken by patients and, hence, not analysed in this section.

Table 6.25

Distribution of sample according to mean cost of lodging during treatment of breast cancer across TNM stage

TNM stage	Mean cost of lodging (₹)			
	Radiation		Chemotherapy	
	Govt hospital	Private hospital	Govt hospital	Private hospital
IA & IB	2,750.0	7,937.5	0.0	0.0
IIA	2,439.4	7,119.3	57.6	521.9
IIB	2,519.2	9,121.9	1,229.8	0.0
IIIA	1,775.4	8,922.7	892.6	633.3
IIIB	1,498.0	12,868.7	0.0	1,950.0
IIIC	904.0	6,528.5	0.0	0.0
Total	**2,029.7**	**8,596.4**	**540.3**	**389.5**

Source: Survey data

The mean cost of lodging incurred by respondents during radiation and chemotherapy is presented in Table 6.25. The mean cost of accommodation during radiation was ₹ 2,029.7 for respondents who sought treatment in a government hospital, while it was ₹ 8,596.4 in the case of private hospitals. During chemotherapy, respondents who sought treatment in government hospitals incurred a mean accommodation cost of ₹ 540.3, and those who went to private hospitals incurred ₹ 389.5. Accommodation costs were higher in the case of radiation when compared to chemotherapy.

Table 6.26

Distribution of samples according to relocation for treatment during treatment for breast cancer across TNM stage

TNM stage	Whether patient relocated for treatment				Total	
	No		Yes			
	N	%	N	%	N	%
IA & IB	52	13.4%	0	0.0%	52	13.0%
IIA	129	33.2%	5	41.7%	134	33.5%
IIB	112	28.9%	4	33.3%	116	29.0%
IIIA	56	14.4%	2	16.7%	58	14.5%
IIIB	22	5.7%	1	8.3%	23	5.8%
IIIC	17	4.4%	0	0.0%	17	4.3%
Total	**388**	**100.0%**	**12**	**100.0%**	**400**	**100.0%**

Source: Survey data

The frequency of breast cancer patients who relocated during treatment is represented in Table 6.26. It can be observed that only twelve respondents (3 per cent of the total number) have relocated for breast cancer treatment. These respondents sought accommodation close to the hospital during the entire course of treatment. Around 97 per cent of the respondents did not relocate for breast cancer treatment.

Table 6.27

ANOVA Table representing the lodging costs(₹) incurred during breast cancer treatment among different healthcare providers

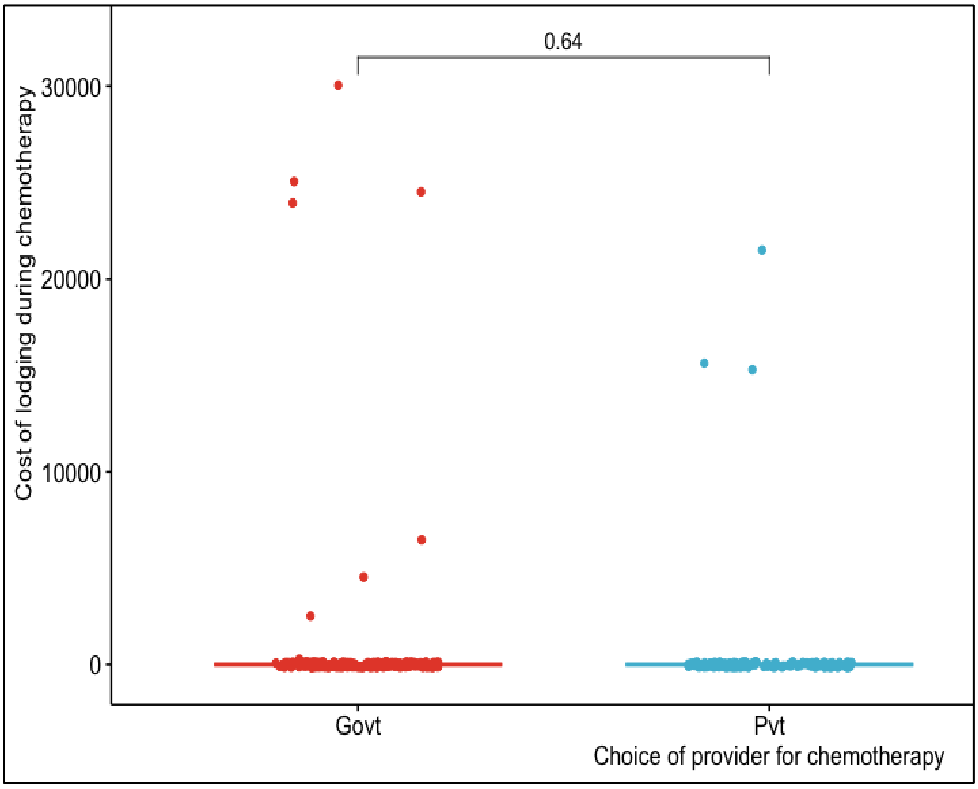
Cost	Choice of provider	Mean ± SD	Mean ± SD	KS Test	H Test
Cost of lodging during radiation	Govt	3,043±5,428	2,013±3,260	***	***
	Pvt		8,596±6,897	***	
	not applicable		0±0		
Cost of lodging during chemotherapy	Govt	452±3,064	540±3,540	***	0.68
	Pvt		387±2,609	***	
	not applicable		0±0	***	

Source: Survey data

The variation between groups classified on the basis of respondents' choice of provider for radiation and chemotherapy is presented in Table 6.27. It can be observed that there is significant variation between groups with regard to the cost of lodging incurred during radiation at a 1 per cent level of significance. There has been no significant variation between groups with regard to the cost of lodging incurred during chemotherapy.

Figure 6.14A

Box plot depicting the lodging costs (₹) incurred during chemotherapy across choice of provider

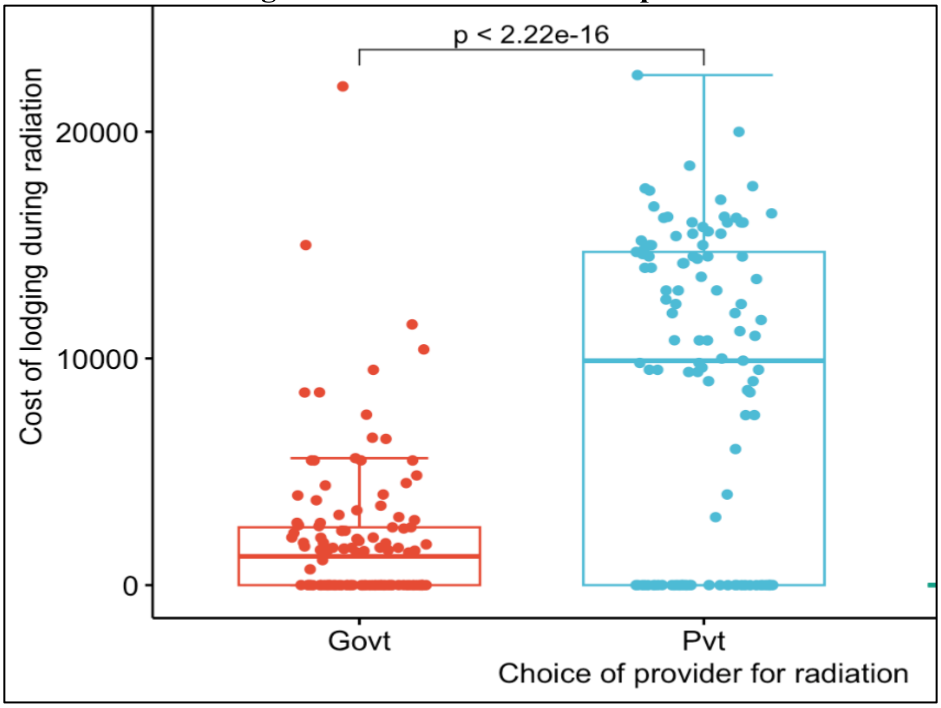


Source: Survey data

The distribution of accommodation costs incurred during chemotherapy across a choice of provider is depicted in Figure 6.14A. The p-value from the H test observed across government and private hospitals (0.64) was higher than 0.01 and, hence, statistically insignificant at the 1 per cent level. Therefore, we can conclude the mean cost of lodging incurred during chemotherapy is significantly not different across government and private hospitals. From ANOVA Table 6.27, it can be observed that the mean cost of accommodation incurred during chemotherapy was ₹ 452±3,064.

Figure 6.14B

Box plot depicting the lodging costs (₹) incurred during radiation across choice of provider



Source: Survey data

The distribution of accommodation costs incurred during radiation across a choice of provider is depicted in Figure 6.14B. The p-value from the H test observed across government and private hospitals (p<2.22e-16) was lower than 0.01 and, hence, statistically significant at a 1 per cent level. Therefore, we can conclude that the mean cost of lodging incurred during radiation is significantly different across government and private hospitals. From ANOVA Table 6.27, it can be observed that the mean cost of accommodation incurred during radiation was ₹ 3,043±5,428.

6.5. Analysing Determinants of Total Medical Cost of Treatment for Breast Cancer

In the following section, the factors affecting the total medical cost of treatment are identified and analysed. Using a multiple regression model, the researcher was able to quantify the direction and degree of association between the variables and the total medical cost of treatment.

In the model used for this study, the dependent variable is the total medical cost of treatment for breast cancer. There are eight independent variables used in the model.

The model of the study is:

$$\mathbf{Y=\beta_0+ \beta_1X_1+ \beta_2X_2+ \beta_3X_3+ \beta_4X_4+ \beta_5X_5+ \beta_6X_6+ \beta_7X_7+ \beta_8X_8+\varepsilon}$$

Where Y=Total medical cost of breast cancer treatment,

X_1= TNM stage of breast cancer,

X_2= Choice of provider for surgery

X_3= Choice of provider for radiation

X_4= Choice of provider for chemotherapy

X_5= Choice of provider for targeted therapy

X_6=Duration of radiation received

X_7=Number of chemotherapy cycles

X_8= Number of trastuzumab injections received during targeted therapy

In order to check whether the above model can be constructed, a variance inflation factor (VIF) was conducted. The VIF results from the model assumptions are given in the Table below.

Table 6.28

Results of initial VIF analysis to determine factors of total medical cost of breast cancer treatment

Term	VIF
TNM stage of breast cancer	7.37
Duration of radiation received	211.07
Number of chemotherapy cycles received	3.17
Number of trastuzumab injections received during targeted therapy	58.06
Choice of provider for surgery	2.96
Choice of provider for radiation	216.72
Choice of provider for chemotherapy	10.10
Choice of provider for targeted therapy	62.21

From Table 6.28, multicollinearity was observed between some independent variables. Hence, a second VIF analysis was conducted, and the results are presented in the Table below.

Table 6.29

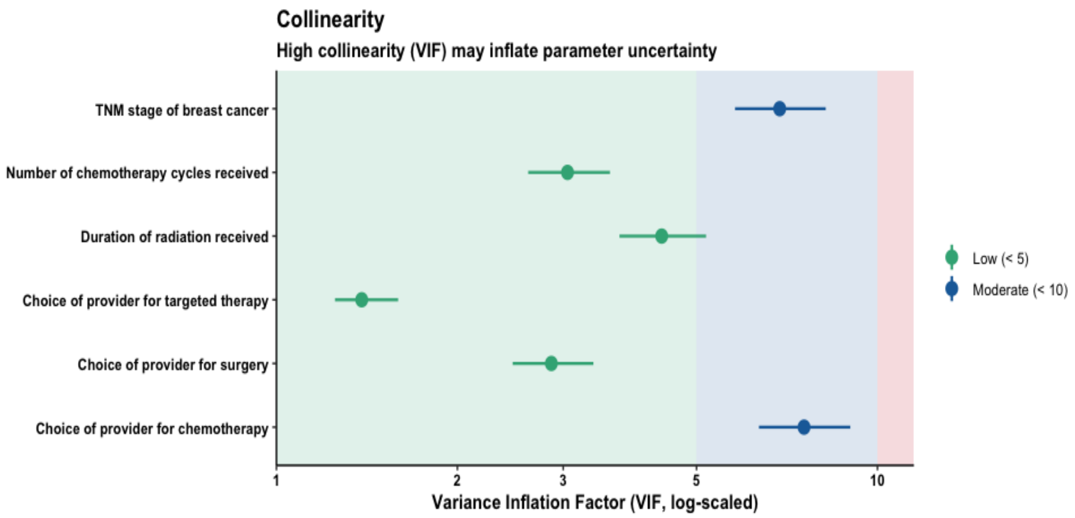
Results of final VIF analysis to determine factors of total medical cost of breast cancer treatment

Term	VIF
TNM stage of breast cancer	6.88
Duration of radiation received	4.37
Number of chemotherapy cycles received	3.05
Choice of provider for surgery	2.87
Choice of provider for chemotherapy	7.55
Choice of provider for targeted therapy	1.39

It can be observed from Table 6.29 that variables like the number of trastuzumab injections received during targeted therapy and the choice of provider for radiation had a very high VIF value. Hence, to avoid multicollinearity issues, these variables have been excluded. Table 5.31 presents the results of the final VIF analysis to determine factors of the total medical cost of treatment.

Figure 6.15

Plot graph representing collinearity values of predictor variables of the total medical cost of treatment



From Figure 6.15, it can be observed that the VIF values of the independent variables are below 10, and hence, there is no significant multicollinearity between the variables.

Model summary	
Tjur's R Square	0.732

Table 6.30

Parameter estimate results of multivariate regression analysis to determine factors of total medical cost of breast cancer treatment

	Variables	Estimate	Statistic	P Value
	(Intercept)	392,986.191	10.228	0.000*
Stage IA and IB	TNM Stage of Breast Cancer: Stage IIA	-13,325.718	-0.763	0.446
	TNM Stage of Breast Cancer: Stage IIB	1,540.759	0.073	0.941
	TNM Stage of Breast Cancer: Stage III A	9,702.805	0.378	0.706
	TNM Stage of Breast Cancer: Stage III B	-17,201.078	-0.543	0.587
	TNM Stage of Breast Cancer: Stage III C	2,069.806	0.055	0.957
Faction over four to six weeks	Duration of Radiation Received 'Faction Over Six to Eight Weeks'	21,420.526	0.625	0.532
	Duration of Radiation Received 'Faction Over Three to Four Weeks'	-33,649.936	-1.244	0.214
	Duration of Radiation Received 'No Radiation'	-103,745.102	-3.640	0.000*
Government	Choice of Provider for Surgery `Private'	29,937.749	2.020	0.044*
Government	Choice of Provider for Chemotherapy `Not Applicable'	-48,079.164	-2.182	0.030*
	Choice of Provider for Chemotherapy 'Private'	7,926.883	0.475	0.635
	Number of Chemotherapy Cycles Received	387.675	0.149	0.881
Government	Choice of Provider for Targeted Therapy `Not Applicable'	-207,395.280	-15.781	0.000*
	Choice of Provider for Targeted Therapy `Private'	253,473.114	10.926	0.000*

**- significant at 5% level*

The TNM stage of breast cancer of the respondent was not a statistically significant determinant of the total medical cost of breast cancer treatment. Through regression analysis, it was observed that respondents with stage IIB, IIIA and IIIC had incurred higher total medical costs, i.e., by 1,540l; 9,702 and 2,069 units, respectively, higher than stage IA and IB breast cancer. This was the same conclusion that was arrived at from a comparison of means analysis (Table 6.17). However, for stage IIA and IIIA, the total medical cost was observed to be 13,325 and 17,201 units, respectively, lower than stage IA and IB breast cancer.

The duration over which radiation factions were taken by the respondent is a statistically significant determinant of the total medical cost of breast cancer treatment. It can be observed through regression analysis that the higher the duration, the higher the total medical cost. Respondents who took radiation factions over four to six weeks incurred higher costs by 33,649 units than those who took over three to four weeks. The total medical cost was higher for respondents who took radiation factions over six to eight weeks by 21,420 units than those who took over four to six weeks. Respondents who did not receive radiation as a part of their treatment incurred a significantly lower total medical cost than those who received radiation.

The choice of provider of surgery was a statistically significant determinant of total medical cost. Respondents who sought surgery in a private hospital had incurred higher medical costs by 29,937 units than those who went to a government hospital. This pattern was observed earlier during the comparison of mean analysis and ANOVA analysis (Tables 6.5, 6.6, and 6.7).

Another statistically significant determinant of the total medical cost of treatment was the choice of provider for chemotherapy. Respondents who sought treatment in a government hospital incurred lower medical costs by 7,926 units than those who sought treatment in a private hospital. Respondents who did not receive chemotherapy as part of their treatment incurred significantly lower medical costs than those who received chemotherapy. This result is similar to the observations in ANOVA analysis (Table 6.13).

Though not statistically significant, as the number of chemotherapy cycles increases, the total medical cost increases by 387 units. This inference is similar to the comparison of the mean cost analysis observed in Figure 6.4.

The choice of provider of targeted therapy was a statistically significant determinant of total medical cost. Respondents who sought targeted therapy in a private hospital incurred a significantly higher medical cost by 2,53,473 units than those who went to a government hospital. Respondents who did not receive targeted therapy as part of their treatment incurred significantly lower medical costs than those who received targeted therapy. This pattern was observed earlier in ANOVA analysis (Table 6.16).

6.6. Conclusion

Every person should have access to quality healthcare. In this chapter, the various types of costs incurred during the diagnosis stage, surgery, radiation, chemotherapy, targeted therapy, and follow-up stage were analysed in detail. It can be concluded from the analysis that the costs incurred during breast cancer treatment are expensive for an ordinary person. The cost of treatment can push patients and their households into impoverishment. Often, due to the high costs, many patients refuse to complete the protocol treatment, which further results in high cases of mortality.

Through the regression analysis, it was observed that respondents incurred higher costs in private hospitals than in government hospitals during breast cancer treatment. The results from ANOVA analysis also reveal that there are significant differences in total medical cost across choice of healthcare provider. From a policy standpoint, this conclusion is important because it shows that there should be efforts to control these vast differences in cost across private and government hospitals.

After analysing the various types of costs of breast cancer treatment and its determinants, the researcher in the next chapter analyses the government schemes, insurance schemes and the sources of finance for treatment.

CHAPTER VII

FINANCIAL BURDEN OF BREAST CANCER

7.1. Introduction

Breast cancer is the leading type of cancer in 80 per cent of the countries and the leading cause of cancer mortality in the majority of the countries. (Bray et al.,2018). Cancer often leads to psychological, economic, and financial consequences, including emotional impact on the quality of life and the need for financial adjustment. Owing to its chronic nature and expensive treatment, out-of-pocket expenditure (OOPE) is the highest for cancer (Sharp et al., 2013; Chang et al.,2013). These financial burdens push the patients and their families into debt or poverty. In India, due to lack of finances, insurance coverage, knowledge and technological assistance, cancer patients and their caregivers, especially those who belong to the lower socioeconomic group, face significant financial struggle. In such cases, a household resorts to distress and alternative ways of financing, which pushes the household into a deeper financial debt (Vashistha et al., 2019).

7.2. Indirect Costs Associated with Breast Cancer Treatment

In cost-of-illness methodology, indirect costs include the monetary value of resources lost due to morbidity and mortality. It mostly includes lost productivity due to premature deaths, missed workdays, and decreased workplace productivity due to morbidity. There are three approaches to measure indirect costs: the human capital approach, the friction cost approach, and the willingness to pay approach. The human capital approach measures the lost production, in terms of lost earnings, of a patient or caregiver. The friction cost approach measures only the production losses during the time it takes to replace a worker, and willingness to pay measures the amount an individual would pay to reduce the probability of illness or mortality. The human capital is the most common approach used to calculate the indirect costs of an illness.

Fu et al. (2011) assessed the incremental indirect costs associated with breast cancer. They observed that in the first year of disease post-diagnosis, breast cancer patients incurred nearly twice the amount of absenteeism-related indirect costs when compared to a matched control group. Zheng et al. (2016) observed that nonelderly women with breast cancer, compared with other people, significantly experienced job incapacity, including reduced productivity at work and home. Grunfeld et al. (2004) observed that 5 per cent of the family caregivers of advanced breast cancer patients in Canada had to quit their jobs or decline advancement, along with a significant decrease in their work hours. Frederix et al. (2019) found that a reduction in productivity due to adverse effects from breast cancer in the Netherlands and Sweden was 68 per cent and 72 per cent, respectively. Indirect costs are critical in lower-middle-income countries because of the growing burden of cancers and issues of resources and affordability (Al-Ziftawi et al.,2021).

For the purpose of this study, the human capital approach is used to measure the indirect costs of breast cancer treatment. Indirect costs are analysed based on missed workdays of the patient and their caregiver, loss of pay and job changes.

7.2.1. Employment-Related Burden Faced by Employed Breast Cancer Patients

Breast cancer treatment takes at least three months to complete. Also, breast cancer patients often take a long time to recover from treatment. This leads to job absenteeism, which further leads to loss of pay, promotion opportunities, and, in some cases, not being able to return to work. In this section, the number of months of work missed, pay loss and return to work after treatment are analysed.

Table 7.1

Distribution of sample based on number of months of work missed by employed respondents across TNM stage

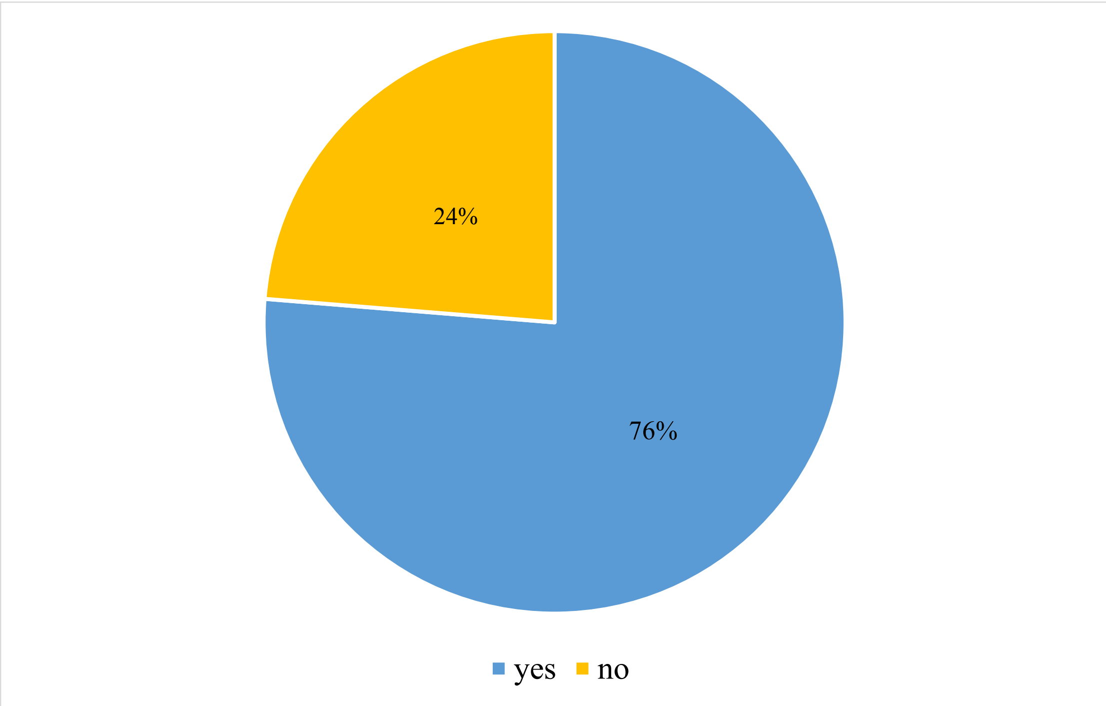
TNM stage	Number of months of work missed by employed patient								Total	
	Not applicable		Less than three months		Between 3 to 6 months		Between 6 to 12 months			
	N	%	N	%	N	%	N	%	N	%
Stage IA and IB	37	12.2%	4	66.7%	7	31.8%	4	5.8%	52	13.0%
Stage IIA	105	34.7%	1	16.7%	6	27.3%	22	31.9%	134	33.5%
Stage IIB	86	28.4%	1	16.7%	3	13.6%	26	37.7%	116	29.0%
Stage IIIA	45	14.9%	0	0.0%	3	13.6%	10	14.5%	58	14.5%
Stage IIIB	19	6.3%	0	0.0%	0	0.0%	4	5.8%	23	5.8%
Stage IIIC	11	3.6%	0	0.0%	3	13.6%	3	4.3%	17	4.3%
Total	**303**	**100.0%**	**6**	**100.0%**	**22**	**100.0%**	**69**	**100.0%**	**400**	**100.0%**

Source: Survey data

The number of months of work missed by employed respondents during treatment is represented in Table 7.1. It can be observed that around 71.1 per cent of employed respondents missed between six to twelve months of work. Only about 6.1 per cent of employed respondents missed less than three months of work. Around 22.6 per cent of employed respondents missed three to six months of work.

Figure 7.1

Distribution of the sample based on whether employed respondents suffered pay loss during breast cancer treatment

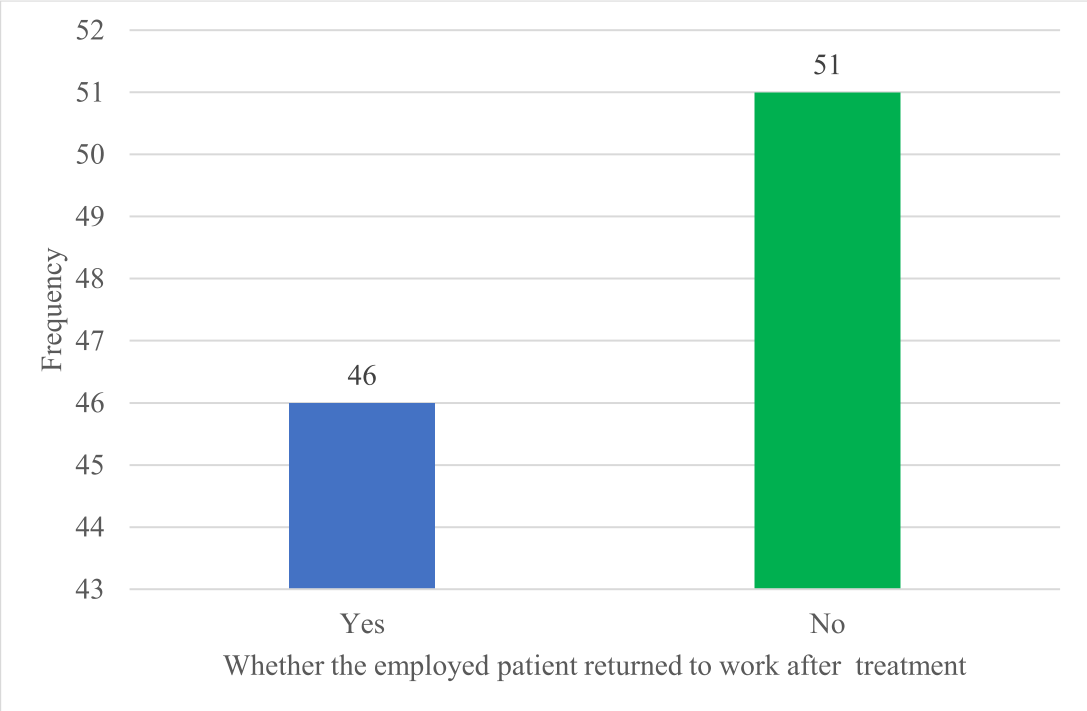


Source: Survey data

From Figure 7.1, it can be observed that 76 per cent of the employed respondents suffered pay loss from work during treatment of breast cancer. Only 24 per cent of the employed respondents did not suffer pay loss during treatment.

Figure 7.2

Distribution of sample based on whether employed respondent returned to work after breast cancer treatment



Source: Survey data

From Figure 7.2, it can be observed that only 46 respondents (47.4%) returned to their work after breast cancer treatment. Around 51 respondents (52.6%) were not able to return to their work post-treatment.

7.2.2. Employed-Related Burden Faced by Employed Primary Caregivers

Primary caregivers of patients face economic consequences during the time of breast cancer treatment. They face the challenge of meeting work demands while pursuing professional goals and caring for their loved ones. Job absenteeism and loss of pay incurred by primary caregivers will lead to financial burdens.

Table 7.2

Distribution of sample based on number of months of work missed by employed primary caregiver of the respondent across TNM stage

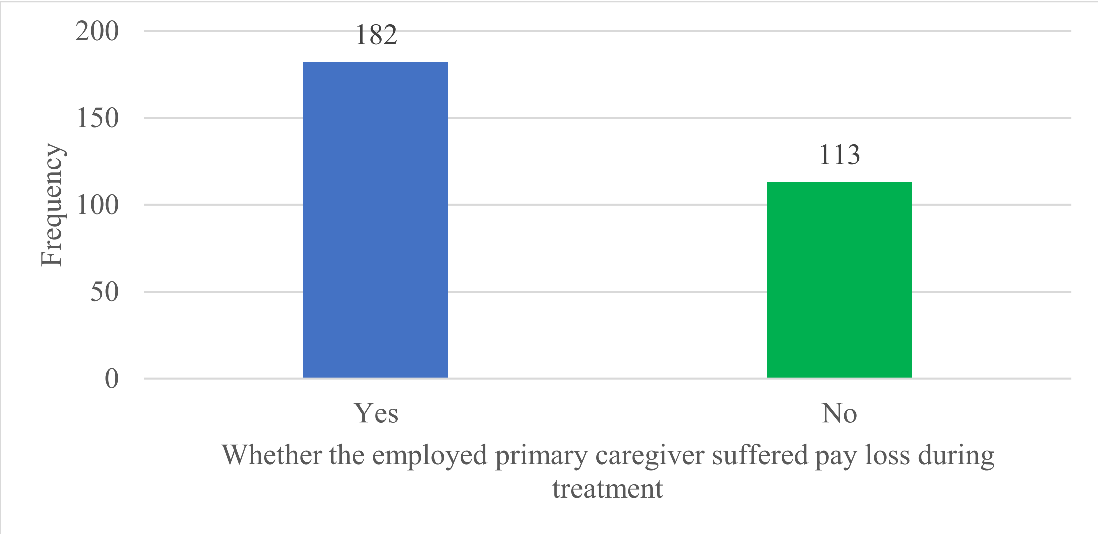
TNM stage of breast cancer	Number of months of work missed by employed primary caregiver								Total	
	Not applicable		Less than one month		Between one to two months		Above two months			
	N	%	N	%	N	%	N	%	N	%
stage IA and IB	14	13.3%	34	27.4%	4	3.1%	0	0.0%	52	13.0%
stage II A	35	33.3%	49	39.5%	42	32.1%	8	20.0%	134	33.5%
stage II B	33	31.4%	22	17.7%	43	32.8%	18	45.0%	116	29.0%
stage IIIA	14	13.3%	9	7.3%	26	19.8%	9	22.5%	58	14.5%
stage III B	6	5.7%	5	4.0%	8	6.1%	4	10.0%	23	5.8%
stage III C	3	2.9%	5	4.0%	8	6.1%	1	2.5%	17	4.3%
Total	**105**	**100.0%**	**124**	**100.0%**	**131**	**100.0%**	**40**	**100.0%**	**400**	**100.0%**

Source: Survey data

The number of months of work missed by employed primary caregivers of respondents during treatment is given in Table 7.2. It can be observed that around 44.4 per cent of employed primary caregivers had missed between one to two months of work, and around 42 per cent missed less than one month of work. Only about 13.5 per cent of employed primary caregivers missed more than two months of work.

Figure 7.3

Distribution of the sample based on whether the employed primary caregiver suffered pay loss during the breast cancer treatment of the respondent



Source: Survey data

From Figure 7.3, it can be observed that 61.6 per cent of employed primary caregivers suffered pay loss, while 38.3 per cent did not suffer pay loss from work.

7.3. Health Schemes and Insurance Schemes Availed During Breast Cancer Treatment

In Kerala, several government health schemes are available which a breast cancer patient can avail during treatment. Along with government schemes, several employee benefit schemes and private health insurance schemes are also available. In this section, the schemes availed by respondents and the amount of money received through these schemes are analysed in detail.

7.3.1. Employee Benefit Schemes Received During Breast Cancer Treatment

Employee benefit schemes refer to schemes that are offered and sponsored by employers. These schemes are either mandated by laws or are provided voluntarily by employers. For the purpose of this study, four schemes were observed during data collection. Only those schemes have been included in this study.

Table 7.3

Distribution of sample according to employee benefit schemes received by respondents during breast cancer treatment

Employee benefit scheme received	Frequency	Percentage (%)
Not applicable	363	90.8%
Employees' State Insurance	19	4.8%
Indian Railway employee benefit	12	3.0%
Central Government Health Scheme	4	1.0%
Employees' Provident Fund scheme	2	0.6%
Total	**400**	**100%**

Source: Survey data

The employee benefit schemes received by respondents are shown in Table 7.3. It can be observed that 4.8 per cent of total respondents received Employees' State Insurance scheme, 3 per cent received Indian Railway employee benefit, 1 per cent received Central Government Health Scheme, and 0.6 % Employees' Provident Fund scheme. Around 91 per cent of the respondents did not receive any employee benefit scheme.

Table 7.4

Distribution of sample based on mean amount of money received through employee benefit scheme during breast cancer treatment

Employee benefit scheme received during treatment	The mean amount received from the employee benefits scheme during treatment (₹)
Employees' State Insurance	1,98,217.3
Indian Railway employee benefit	2,06,434.3
Central Government Health Scheme	2,03,550.0
Employees' Provident Fund scheme	1,07,200.0
Total	**1,96,691.1**

Source: Survey data

The mean amount of money received through the employee benefits scheme for breast cancer treatment is shown in Table 7.4. Through the Employees' State Insurance scheme, the average amount received for breast cancer treatment was ₹ 1,98,217. The average amount received through the Indian Railway employee benefit was ₹

2,06,434; through the Central Government Health Scheme, the average amount received was ₹ 2,03,550, while through the Employees' Provident Fund scheme, it was ₹ 1,07,200.

7.3.2. Government Health Schemes Availed During Breast Cancer Treatment

The Government of India, as well as State Governments, have implemented schemes to assist underprivileged cancer patients. These schemes reduce the financial burden of breast cancer treatment. Though there are several government schemes, only eight schemes have been analysed for the purpose of this study.

Table 7.5

Government health schemes received during breast cancer treatment

Government health scheme	Sample	Percentage (%)
none	164	41.0%
Karunya only	132	33.0%
CHIS only	27	6.8%
Sukuratham only	6	1.5%
CHIS and Karunya	47	11.8%
Karunya and Sukuratham	13	3.3%
CHIS, Karunya and Sukuratham	7	1.8%
AB-PMJAY only	4	1.0%
Total	**400**	**100.0%**

Source: Survey data

The details of government health schemes received by respondents are shown in Table 7.5. It can be observed that 33 per cent of respondents received only the Karunya scheme, 6.8 per cent received only the CHIS scheme, 1.5 per cent received only the Sukuratham scheme and 1 per cent received only the AB-PMJAY scheme. Around 15.1 per cent of respondents received two health schemes, and 1.8 per cent received three health schemes. Around 41 per cent of respondents did not receive any government health scheme.

Table 7.6

Mean amount of money (₹) received through government health schemes

Details of government health schemes received during treatment	Mean amount of money received through government health schemes during treatment (₹)
CHIS only	6,8562.7
Sukuratham only	94,667.16
Karunya only	1,02,418.6
AB-PMJAY only	1,37,871.2
CHIS and Karunya	1,56,916.1
Karunya and Sukuratham	3,30,693.4
CHIS, Karunya and Sukuratham	3,74,107.7
Total	**1,30,435.4**

Source: Survey data

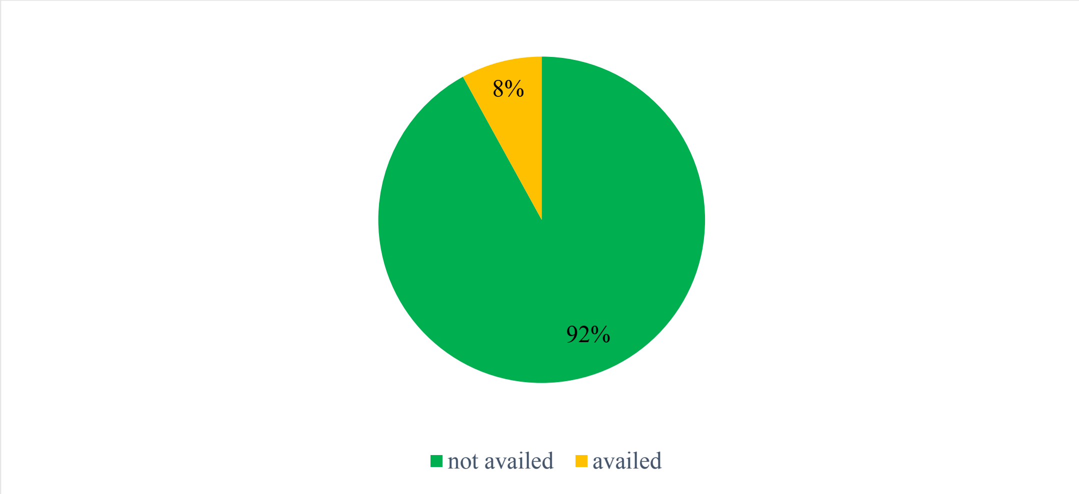
The mean amount of money received through government health schemes for underprivileged patients is shown in Table 7.6. It can be observed that the mean amount of money received through the CHIS scheme is ₹ 68,562, through Sukuratham is ₹ 94,667 and through Karunya is ₹ 1,02,418. The mean amount of money received through AB-PMJAY is ₹ 1,37,871. Through more than one health scheme, the mean amount of money received ranged between ₹ 1,56,916 to ₹ 3,74,107.

7.3.3. Private Health Insurance Schemes Availed During Breast Cancer Treatment

Insurance schemes aid patients to cover expenses during treatment. The limit for covering expenses is determined by the type of scheme availed by the patient. In this section, the private health insurance schemes availed by respondents are analysed in detail.

Figure 7.4

Distribution of samples according to private health insurance availed



Source: Survey data

From Figure 7.4, it can be observed that 368 respondents (92%) did not avail of any private health insurance. Only 32 respondents (8%) availed some type of private health insurance.

Table 7.7

Distribution of sample based on mean amount of money (₹) received through private health insurance across TNM stage of breast cancer

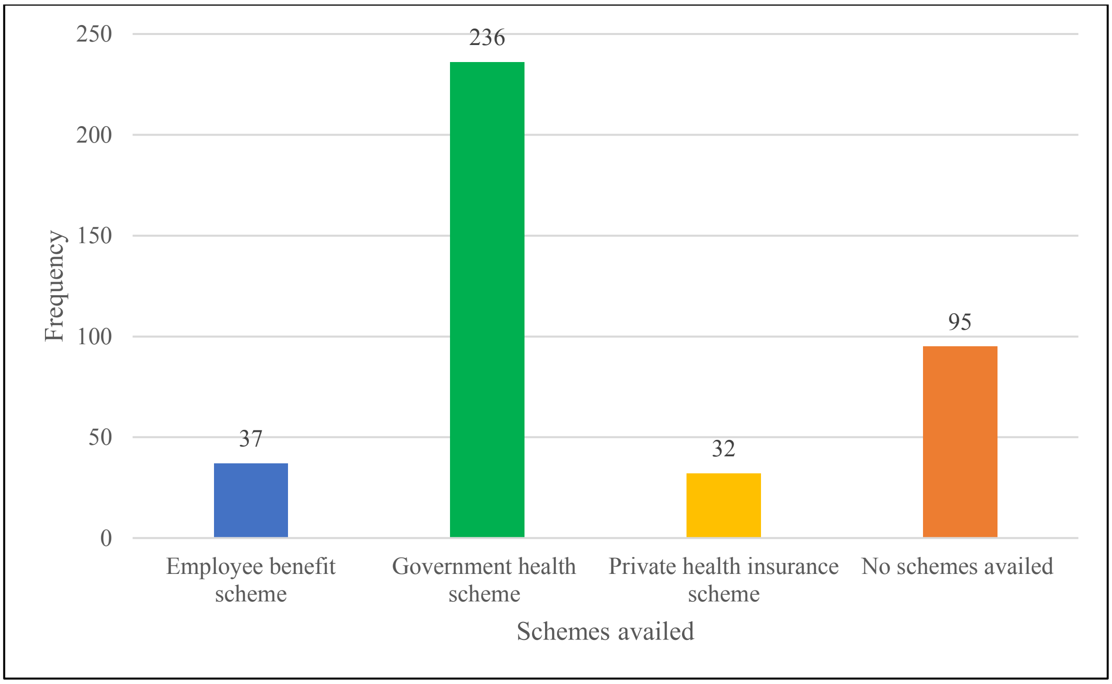
TNM stage	Mean amount of money received through private health insurance scheme during treatment (₹)
Stage I A and I B	73,973.3
Stage II A	1,71,287.6
Stage II B	2,02,262.3
Stage III A	1,73,163.4
Stage III B	2,02,440.0
Stage III C	1,85,658.4
Total	**1,65,667.6**

Source: Survey data

The mean amount of money received through private health insurance schemes is shown in Table 7.7. It can be observed that for stage I breast cancers, the mean amount of money received is ₹ 73,973. For stage II and stage III breast cancers, the mean amount of money received ranged between ₹ 1,71,287 and ₹ 2,02,440. Since the cost of treatment for advanced-stage cancers is higher, the mean amount of money received through private health insurance schemes is also higher.

Figure 7.5

Distribution of samples based on health schemes and insurance schemes received during breast cancer treatment



Source: Survey data

The health scheme and insurance scheme availed by respondents is illustrated in Figure 7.5. It can be observed that 9.2 per cent of respondents availed employee benefit schemes, 59 per cent of respondents availed government health schemes and 8 per cent availed private health insurance scheme. Around 23.7 per cent of respondents did not avail any health or insurance scheme.

7.4. Out-of-pocket Expenditures (OOPE) and Catastrophic Health Expenditures (CHE) Incurred During Breast Cancer Treatment

Treatment of breast cancer is expensive, which leads to high out-of-pocket expenditures by patients and their families. Financial protection through public or private health insurance substantially reduces the amount people pay directly for medical care. Yet, in some countries, the burden of out-of-pocket spending can still create barriers to healthcare access and use. Households that have difficulties paying medical bills may delay or forgo needed health care (Hoffman et al., 2005). On average, across OECD countries, 18 per cent of health spending is paid directly by patients (OECD,2009).

Households face catastrophic health expenditures each year as a result of severe illness or major injury. Countries that have a greater reliance on out-of-pocket health care expenditure tend also to have a higher proportion of households with catastrophic expenditure (OECD,2009). The US Medical Expenditure Panel Survey found that 28 per cent of Americans living in a low-income family were spending more than 10 per cent of their after-tax family income on health services and health insurance premiums in 2004, compared with 10 per cent of Americans in a high-income family (Banthin et al., 2008).

India has one of the highest proportions of household out-of-pocket health expenditures in the world, estimated at 71.1 per cent in 2008-09 (Balarajan et al.,2011). Households' share in health spending is almost more than two-thirds in India, which is around three times the amount of all government expenditure. (WHO,2012). In India, the out-of-pocket expenditures are highest for cancer. Rajpal et al. (2018) found in their study that 36.3 per cent(public healthcare facilities) and 33.7 per cent(private healthcare facilities) of cancer patients in India were spending more than 10 per cent of their annual per capita household expenditure (PCHE). In another study by Jain and Mukherjee (2016), lower-income households in India were reported to be 39.38 times and middle-income households to be 5.79 times more likely to face CHE as compared to higher-income households. This kind of financial burden can be blamed on the low-funded and low-quality health care of the public health system, which forces consumers to seek care from the expensive private sector. Another contributor that causes the financial burden is the lack of protective mechanisms like health insurance. The insurance coverage is limited in India and health expenditures are not covered for approximately 80 per cent of the population (Government of India, NSSO, 2020).

Table 7.8

Distribution of sample based on OOPE incurred by respondents when the choice of healthcare provider is government across TNM stage

TNM stage	OOPE(₹)		
	Mean	Minimum	Maximum
I A and I B	45,363.8	22,107.0	92,256.0
II A	61,130.6	23,463.0	2,48,345.0
II B	84,480.0	24,268.0	5,31,073.0
III A	1,03,628.7	37,426.0	4,01,045.0
III B	1,19,673.5	61,881.0	2,58,860.0
III C	1,14,165.5	65,381.0	2,86,480.0
Total	**76,434.0**	**22,107.0**	**5,31,073.0**

Source: Survey data

The OOPE incurred by respondents whose choice of healthcare provider for treatment and diagnosis was government hospitals is represented in Table 7.8. It can be observed that the least OOPE incurred was for stage I breast cancer, and the highest was for stage III breast cancer. The mean OOPE incurred for stage I breast cancer was ₹ 45,363.8; for stage II, it was ₹ 72,805; and for stage III, it was ₹ 1,12,488.6. The minimum OOPE observed was ₹ 22,107, and the maximum OOPE observed was ₹ 5,31,073.

Table 7.9

Distribution of sample based on OOPE incurred by respondents when the choice of healthcare provider is both government and private across TNM stage

TNM stage	OOPE(₹)		
	Mean	Minimum	Maximum
Stage IA and I B	77,223.3	37,690.0	1,19,060.0
Stage II A	1,25,532.6	48,190.0	2,09,435.0
Stage II B	1,80,008.7	43,787.0	2,60,741.0
Stage III A	1,90,647.3	76,545.0	3,59,840.0
Stage III B	1,74,000.0	1,74,000.0	1,74,000.0
Stage III C	1,70,776.3	96,918.5	2,18,270.0
Total	**1,53,995.3**	**37,690.0**	**3,59,840.0**

Source: Survey data

The OOPE incurred by respondents who took treatment and diagnosis in both government and private hospitals is represented in Table 7.9. It can be observed that as the stage of breast cancer advanced, the OOPE also increased. The mean OOPE incurred for stage I breast cancer was ₹ 77,223.3; for stage II, it was ₹ 1,52,770; and for stage III, it was ₹ 1,78,474.3. The minimum OOPE observed was ₹ 37,690, and the maximum OOPE observed was ₹ 3,59,840.

Table 7.10

Distribution of sample based on OOPE incurred by respondents when the choice of healthcare provider is private across TNM stage

TNM stage	OOPE(₹)		
	Mean	Minimum	Maximum
Stage I A and I B	1,26,048.4	39,650.0	2,04,785.0
Stage II A	2,32,156.6	14,224.0	8,68,445.0
Stage II B	2,60,557.7	59,680.0	8,16,050.0
Stage III A	3,19,975.1	89,375.0	1,07,9250.0
Stage III B	3,28,858.1	1,57,775.0	5,75,790.0
Stage III C	3,11,089.0	81,435.0	7,05,750.0
Total	**2,50,594.6**	**14,224.0**	**1,07,9250.0**

Source: Survey data

The OOPE incurred by respondents who took treatment and diagnosis in only private hospitals is represented in Table 7.10. The OOPE incurred by respondents who had stage III breast cancer was higher when compared to stage I and stage II breast cancer. The mean OOPE incurred for stage I breast cancer was ₹ 1,26,048.4, for stage II was ₹ 2,46,356.5, and for stage III was ₹ 3,19,974. The minimum OOPE observed was ₹ 14,224, and the maximum OOPE observed was ₹ 10,79,250. The OOPE incurred by respondents who sought treatment in private hospitals was higher than the OOPE incurred by respondents who sought treatment in government hospitals.

Table 7.11

Distribution of sample based on CHE experienced across annual income

Annual income of the household	**CHE experienced due to breast cancer treatment**				**Total**	
	yes		**no**			
	N	**%**	**N**	**%**	**N**	**%**
below ₹ 1 lakh	36	22.5%	9	3.8%	45	11.3%
between ₹ 1 lakh to 5 lakhs	118	73.8%	120	50.0%	238	59.5%
between ₹ 5 lakh to 10 lakhs	6	3.8%	88	36.7%	94	23.5%
between ₹ 10 lakhs to ₹ 25 lakhs	0	0.0%	23	9.6%	23	5.8%
Total	**160**	**100.0%**	**240**	**100.0%**	**400**	**100.0%**

Source: Survey data

The catastrophic health expenditure (CHE) experienced by respondents across the annual income of households is represented in Table 7.11. Around 40 per cent of respondents experienced CHE during breast cancer treatment. It can be observed that 22.5 per cent of respondents who experienced CHE had an annual household income below ₹ 1 lakh, and 73.8 per cent of respondents had an annual household income between ₹ 1 lakh and five lakhs. Respondents whose households had an annual income above ₹ 5 lakhs had lower chances of experiencing CHE when compared to respondents whose annual household income was below ₹ 5 lakhs.

7.5. Coping Mechanisms Used to Fund Breast Cancer Treatment

Though there has been economic growth over the past couple of decades, India is still a developing country. High and increasing health care cost is one of the major public health challenges in developing countries. The deficiencies in the public healthcare system, on the one hand, and the lack of a universal health insurance mechanism, on the other, have resulted in higher out-of-pocket (OOP) spending in India (Jayakrishnan et al.,2016). According to India's National Health Accounts, 2013–14, OOP spending accounts for 64.2 per cent of total health spending (MOHFW, 2016). The high out-of-pocket expenditures associated with breast cancer treatment result in a financial burden to the patient and their household.

About 28 per cent to 48 per cent of cancer survivors experience financial toxicity based on monetary measures, and 16 per cent to 73 per cent experience financial toxicity based on subjective measures (Carrera et al., 2018). Previous studies have demonstrated that patients with cancer are at particular risk for financial burden when compared to persons without cancer (Nipp et al., 2016). While the household remains the major source of financing health care, the extent of poverty, impoverishment, and indebtedness due to high out-of-pocket expenditure (OOPE) is on the rise (Roy et al., 2007; Garg et al., 2009).

In such situations, people either use their savings and income or they have to rely upon alternative sources of finance, such as depletion of household assets, borrowings from banks and moneylenders, and contributions from family and friends to cope with the cost of illness (Flores et al.,2008; Leive et al., 2008). Coping strategies aim to avert the economic burden associated with the economic burden of illness on households (Sauerborn et al., 1996).

Research from low and middle-income countries suggests that borrowing from relatives and friends, loans from money lenders and financial institutions, mortgaging assets, selling assets, selling livestock, and selling harvest crops are common forms of distress financing (Mock et al., 2003; Damme et al.,2004). Studies observe that other coping strategies to meet healthcare costs include reducing household food and non-food expenditures and increasing working hours for extra income (Kabir et al., 2000). Income diversification, selling of assets and borrowing money were common practices to meet the direct health care costs, while task reallocation among household members was used for meeting the indirect costs of illness in low-income countries (McIntyre et al., 2006). Coping strategies such as using savings, borrowing, the sale of assets, and transfers finance three-fourths of the cost of inpatient care in rural areas and two-thirds of the cost in urban areas in India (Dilip & Duggal, 2002; Flores et al., 2008).

Table 7.12

Distribution of sample based on whether property lease was used as coping mechanism across annual income

Annual income of the household	Whether the property was leased to fund treatment				Total	
	yes		no			
	N	%	N	%	N	%
below ₹ 1 lakh	5	35.7%	40	10.4%	45	11.3%
between ₹ 1 lakh to ₹ 5 lakhs	8	57.1%	230	59.6%	238	59.5%
between ₹ 5 lakhs to ₹ 10 lakhs	1	7.1%	93	24.1%	94	23.5%
between ₹ 10 lakhs to ₹ 25 lakhs	0	0.0%	23	6.0%	23	5.8%
Total	**14**	**100.0%**	**386**	**100.0%**	**400**	**100.0%**

Source: Survey data

The distribution of the sample based on whether respondents leased properties as part of a coping mechanism in order to fund breast cancer treatment is represented in Table 7.12. It can be observed that only 3.5 per cent of total respondents had leased their property. Out of these respondents, 35.7 per cent had an annual household income below ₹ 1 lakh, 57.1 per cent belonged to the income category between ₹ 1 lakh and ₹ 5 lakhs, and 7.1 per cent belonged to the income category between ₹ 5 lakhs to ₹ 10 lakhs.

Table 7.13

Distribution of the sample based on whether gold was sold as a coping mechanism across the annual income of the household

Annual income of the household	Whether gold was sold to fund treatment				Total	
	yes		no			
	N	%	N	%	N	%
below ₹ 1 lakh	39	17.6%	6	3.4%	45	11.3%
between ₹ 1 lakh to ₹ 5 lakhs	157	71.0%	81	45.3%	238	59.5%
between ₹ 5 lakhs to ₹ 10 lakhs	24	10.9%	70	39.1%	94	23.5%
between ₹ 10 lakhs to ₹ 25 lakhs	1	0.5%	22	12.3%	23	5.8%
Total	**221**	**100.0%**	**179**	**100.0%**	**400**	**100.0%**

Source: Survey data

The distribution of the sample based on whether respondents sold gold as part of a coping mechanism in order to fund breast cancer treatment is represented in Table 7.13. It can be observed that 55.2 per cent of respondents sold gold as a coping mechanism. Around 17.6 per cent of respondents who sold gold belonged to households with an annual income category below ₹ 1 lakh, 71 per cent belonged to an annual income category between ₹ 1 lakh to ₹ 5 lakhs, and 11.4 per cent belonged to an annual income category above ₹ 5 lakhs.

Table 7.14

Distribution of the sample based on whether gold was leased as a coping mechanism across the annual income of the household

Annual income of the household	Whether gold was leased to fund treatment				Total	
	yes		no			
	N	%	N	%	N	%
below ₹ 1 lakh	9	6.2%	36	14.1%	45	11.3%
between ₹ 1 lakh to ₹ 5 lakhs	85	58.6%	153	60.0%	238	59.5%
between ₹ 5 lakhs to ₹ 10 lakhs	46	31.7%	48	18.8%	94	23.5%
between ₹ 10 lakhs to ₹ 25 lakhs	5	3.4%	18	7.1%	23	5.8%
Total	**145**	**100.0%**	**255**	**100.0%**	**400**	**100.0%**

Source: Survey data

The distribution of the sample based on whether respondents leased gold as part of a coping mechanism in order to fund breast cancer treatment is represented in Table 7.14. It can be observed that only 36.2 per cent of total respondents had leased their gold as part of a coping mechanism. Out of these respondents, 6.2 per cent had an annual household income below ₹ 1 lakh, 58.6 per cent belonged to the income category between ₹ 1 lakh and ₹ 5 lakhs, and 35.1 per cent belonged to the income category above ₹ 5 lakhs.

Table 7.15

Distribution of the sample based on whether money was borrowed from friends or relatives as a coping mechanism across the annual income of the household

Annual income of the household	Whether money was borrowed from friends or relatives in order to fund treatment				Total	
	yes		no			
	N	%	N	%	N	%
below ₹ 1 lakh	31	16.5%	14	6.6%	45	11.3%
between ₹ 1 lakh to ₹ 5 lakhs	138	73.4%	100	47.2%	238	59.5%
between ₹ 5 lakhs to ₹ 10 lakhs	18	9.6%	76	35.8%	94	23.5%
between ₹ 10 lakhs to ₹ 25 lakhs	1	0.5%	22	10.4%	23	5.8%
Total	**188**	**100.0%**	**212**	**100.0%**	**400**	**100.0%**

Source: Survey data

The distribution of the sample based on whether respondents borrowed money from friends or relatives as part of a coping mechanism in order to fund breast cancer treatment is represented in Table 7.15. It can be observed that 47 per cent of total respondents had borrowed money from friends or relatives as part of a coping mechanism. Among these, 16.5 per cent of respondents belonged to the annual household income category below ₹ 1 lakh, 73.4 per cent belonged to the income category between ₹ 1 lakh to ₹ 5 lakhs, and 10.1 per cent belonged to the income category above ₹ 5 lakhs.

Table 7.16

Distribution of the sample based on whether a bank loan was used as a coping mechanism across the annual income of the household

Annual income of the household	Whether money was borrowed from a bank in order to fund treatment				Total	
	yes		no			
	N	%	N	%	N	%
below ₹ 1 lakh	17	18.7%	28	9.1%	45	11.3%
between ₹ 1 lakh to ₹ 5 lakhs	71	78.0%	167	54.0%	238	59.5%
between ₹ 5 lakhs to ₹ 10 lakhs	3	3.3%	91	29.4%	94	23.5%
between ₹ 10 lakhs to ₹ 25 lakhs	0	0.0%	23	7.4%	23	5.8%
Total	**91**	**100.0%**	**309**	**100.0%**	**400**	**100.0%**

Source: Survey data

The distribution of the sample based on whether respondents took bank loans as part of a coping mechanism in order to fund breast cancer treatment is represented in Table 7.16. Around 22.7 per cent of total respondents took bank loans as part of a coping mechanism. Out of this, 18.7 per cent belonged to the annual household income category below ₹ 1 lakh, 78 per cent belonged to the income category between ₹ 1 lakh to ₹ 5 lakh, and 3.3 per cent belonged to the income category above ₹ 5 lakhs.

Table 7.17

Distribution of the sample based on whether financial grants from friends or relatives were received across the annual income of the household

Annual income of the household	Whether financial grants were received from relatives or friends in order to fund treatment				Total	
	yes		no			
	N	%	N	%	N	%
below ₹ 1 lakh	17	15.0%	28	9.8%	45	11.3%
between ₹ 1 lakh to ₹ 5 lakhs	78	69.0%	160	55.7%	238	59.5%
between ₹ 5 lakhs to ₹ 10 lakhs	17	15.0%	77	26.8%	94	23.5%
between ₹ 10 lakhs to ₹ 25 lakhs	1	0.9%	22	7.7%	23	5.8%
Total	**113**	**100.0%**	**287**	**100.0%**	**400**	**100.0%**

Source: Survey data

The distribution of the sample based on whether respondents received financial grants from friends or relatives in order to fund breast cancer treatment is represented in Table 7.17. Around 28.2 per cent of total respondents received financial grants. Among these, 15 per cent belonged to the annual household income category below ₹ 1 lakh, 69 per cent belonged to the income category between ₹ 1 lakh to ₹ 5 lakh, and 15.9 per cent belonged to the income category above ₹ 5 lakh.

7.6. Patient experience during breast cancer treatment

Breast cancer patients during the period of treatment face difficulties. The common difficulties encountered are lack of transportation and lodging facilities, lack of cancer hospitals and specialists, lapse in treatment and availing health schemes, and high cost of treatment. The researcher has studied these through a qualitative survey, and the results are presented below.

Table 7.18

Distribution of sample based on difficulties faced by respondents during breast cancer treatment

Difficulties faced by respondents during breast cancer treatment	**Response**					
	Yes		**No**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**
Lack of cancer hospitals around their residence	143	35.8%	257	64.8%	400	100%
Lack of cancer specialists around their residence	169	42.3%	231	57.8%	400	100%
Long distance to cancer hospitals	246	61.5%	154	38.5%	400	100%
Lack of transportation facilities to cancer hospitals	177	44.3%	223	55.8%	400	100%
Lack of lodging facilities in cancer hospitals	122	30.5%	278	69.5%	400	100%
Lack of quality in infrastructural facilities of cancer hospitals	59	14.8%	349	85.3%	400	100%
Lack of quality in treatment in cancer hospitals	48	12.0%	352	88.0%	400	100%
Lack of nursing homes close to their residence	106	26.5%	294	73.5%	400	100%
High cost of medicines and treatment of cancer	325	81.3%	75	18.8%	400	100%
Difficulty in availing health schemes and insurance during treatment	232	58.0%	168	42.0%	400	100%

Source: Survey data

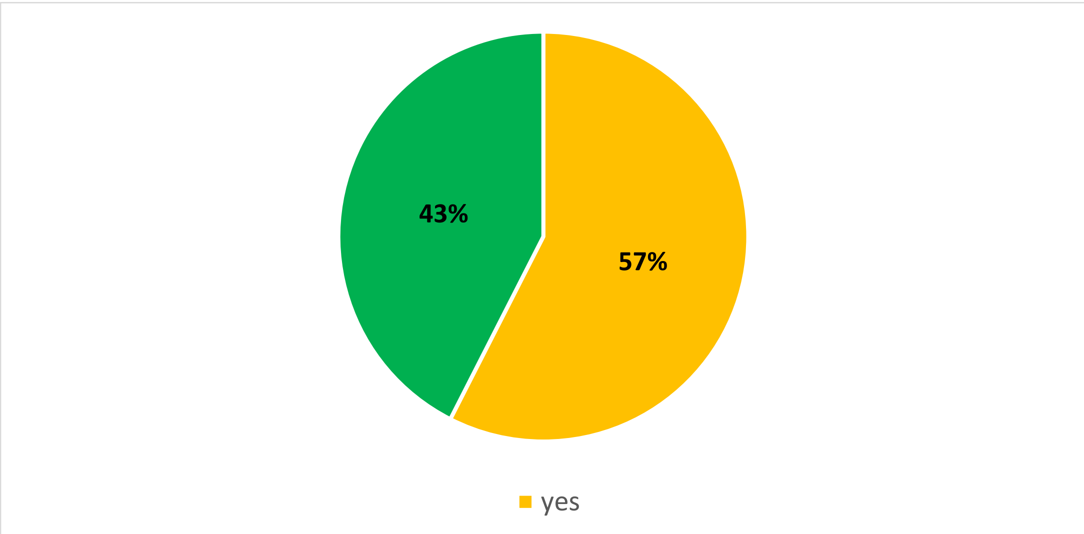
The difficulties faced by respondents during breast cancer treatment are represented in Table 7.18. It can be observed that 35.8 per cent of total respondents felt that there is a lack of cancer hospitals close to their residences, and 42.3 per cent felt there are not enough cancer specialists in hospitals close to their residences. Around 61.5 per cent of total respondents felt that there is a long distance from their residence to the cancer hospitals from where they received treatment, and 44.3 per cent experienced transportation difficulties while commuting to cancer hospitals. Lodging difficulties were experienced by 30.5 per cent of respondents. Around 14.8 per cent and 12 per cent of respondents felt the quality of infrastructural facilities and the quality of treatment in cancer hospitals were not up to the standard, respectively. Almost 27 per cent of respondents felt that there were not enough nursing homes close to their residences. The burden of the high cost of medicines and treatment of breast cancer was experienced by 81.3 per cent of respondents. Around 58 per cent of respondents had difficulty in availing of health and insurance schemes during breast cancer treatment.

7.7. Cancer Pension Scheme

The Government of Kerala had launched a 'Cancer pension scheme' for cancer patients. Pension is given to cancer patients after completion of treatment for supportive care. The patient has to produce a certificate from the concerned doctor to that effect each year and apply to the Government on the basis of this certificate. Patients who are eligible for this scheme get a pension of ₹ 1000 per month on a lifelong basis.

Figure 7.6

Distribution of sample based on whether respondent receives cancer pension



Source: Survey data

The distribution of the sample based on whether they receive cancer pension is depicted in Figure 7.6. It can be observed that almost 57 per cent of respondents received a cancer pension, and 43 per cent of respondents did not receive any cancer pension.

7.8. Factors Affecting the Out-Of-Pocket Expenditure Incurred by Patients During Treatment of Breast Cancer

The determinants of out-of-pocket expenditures of breast cancer treatment are analysed in this section. A multivariate regression analysis was done to determine the predictors of OOPE. In this model, the dependent variable is out-of-pocket expenditures. There are 14 independent variables used in the model.

The model of the study is:

$$\mathbf{Y=\beta_0+ \beta_1U_1+ \beta_2U_2+ \beta_3U_3+ \beta_4U_4+ \beta_5U_5+ \beta_6U_6+ \beta_7U_7+ \beta_8U_8+ \beta_9U_9+ \beta_{10}U_{10}+ \beta_{11}U_{11}+ \beta_{12}U_{12}+ \beta_{13}U_{13}+ \beta_{14}U_{14}+ \beta_{15}U_{15}+ \beta_{16}U_{16}+ \varepsilon}$$

Where Y=Total out-of-pocket expenditure,

U_1= TNM stage of breast cancer,

U_2= Choice of provider for surgery

U_3= Choice of provider for radiation

U_4= Choice of provider for chemotherapy

U_5= Choice of provider for targeted therapy

U_6=Duration of radiation received

U_7=Number of chemotherapy cycles

U_8= Number of trastuzumab injections received during targeted therapy

U_9= Choice of provider for diagnosis

U_{10}= Choice of provider for follow-up

U_{11}=Amount received from employee benefits scheme during treatment

U_{12}= Amount of money received through government health schemes during treatment

U_{13}= Amount of money received through private health insurance scheme during treatment

U_{14}= Amount of money received through private health insurance scheme during treatment

U_{15}= Total medical cost of treatment

U_{16}= Total non-medical cost of treatment

In order to check whether the above model can be constructed, a variance inflation factor (VIF) was conducted. The VIF results from the model assumptions are given in the Table below.

Table 7.19

Results of initial VIF analysis to determine factors of total OOPE

Term	VIF
TNM stage of breast cancer	8.04
Duration of radiation received	230.31
Number of chemotherapy cycles received	3.25
Number of trastuzumab injections received during targeted therapy	14.44
Choice of provider for diagnosis	1.61
Choice of provider for surgery	4.32
Choice of provider for radiation	277.20
Choice of provider for chemotherapy	11.17
Choice of provider for follow-up treatment	5.59
Amount received from employee benefits scheme during treatment	1.41
Amount of money received through government health schemes during treatment	2.75
Amount of money received through private health insurance scheme during treatment	1.50
Total medical cost of treatment	13.37
Total non-medical cost of treatment	1.83

From Table 7.19, it can be observed multicollinearity was observed between some independent variables. Hence, a second VIF analysis was conducted, and the results are presented in the Table below.

Table 7.20

Results of final VIF analysis to determine factors of total OOPE

Term	VIF
TNM stage of breast cancer	6.44
Duration of radiation received	4.44
Number of chemotherapy cycles received	2.05
Choice of provider for diagnosis	1.57
Choice of provider for surgery	3.89
Choice of provider for follow-up treatment	3.84
Amount received from employee benefits scheme during treatment	1.35
Amount of money received through government health schemes during treatment	2.25
Amount of money received through private health insurance scheme during treatment	1.41
Total medical cost of treatment	2.47
Total non-medical cost of treatment	1.73

It was observed that variables like the number of trastuzumab injections received during targeted therapy, choice of provider for radiation, chemotherapy, and targeted therapy exhibited a high correlation. Hence, to avoid multicollinearity issues, these variables have been excluded. Table 7.20 presents the results of the final VIF analysis to determine factors of the total medical cost of treatment.

Table 7.21

ANOVA table of determinants of total OOPE incurred

Variables	Degrees of Freedom	P Value
TNM stage of breast cancer	5	0.00e+00
Duration of radiation received	3	0.00e+00
Number of chemotherapy cycles received	1	9.39e-94
Choice of provider for diagnosis	2	2.13e-321
Choice of provider for surgery	1	0.00e+00
Choice of provider for follow-up treatment	1	7.87e-294
Amount received from employee benefits scheme during treatment	1	2.14e-245
Amount of money received through government health schemes during treatment	1	1.60e-55
Amount of money received through private health insurance scheme during treatment	1	1.05e-35
Total medical cost of treatment	1	0.00e+00
Total non-medical cost of treatment	1	5.84e-209
Residuals	381	NA

Model summary	
R Square	0.97

Table 7.22

Parameter estimate results of multivariate regression analysis to determine factors of total OOPE

	Variables	Estimate	Statistic	P Value
	(Intercept)	15,607.307	9.394	0.000*
TNM stage: Stage IA and IB	TNM Stage of Breast Cancer: Stage IIA	643.656	0.762	0.446
	TNM Stage of Breast Cancer: Stage II B	2,911.965	2.814	0.005*
	TNM Stage of Breast Cancer: Stage III A	4,617.965	3.594	0.000*
	TNM Stage of Breast Cancer: Stage III B	7,661.427	4.779	0.000*
	TNM Stage of Breast Cancer: Stage III C	9,910.815	5.184	0.000*
Faction Over four to six Weeks	Duration of Radiation Received: Faction over Six to Eight Weeks	2,155.140	1.243	0.215
	Duration of Radiation Received: Faction over Three to Four Weeks	2,065.446	1.503	0.134
	Duration of Radiation Received: No Radiation	2,553.799	1.764	0.078
Both government and private	Choice of Provider for Diagnosis: Government	-1,532.275	-2.528	0.012*
	Choice of Provider for Diagnosis: Private	-235.683	-0.421	0.674
Government	Choice of Provider for Surgery: Private	2,624.638	3.011	0.003*
Government	Choice of Provider for Follow-Up Treatment: Private	11,307.500	12.861	0.000*
	Number Of Chemotherapy Cycles Received	187.470	1.743	0.082
	Amount Received from Employee Benefits Scheme During Treatment	-1.002	-299.067	0.000*
	Amount of Money Received Through Government Health Schemes During Treatment	-1.003	-311.764	0.000*
	Amount of Money Received Through Private Health Insurance Scheme During Treatment	-1.002	-246.588	0.000*
	Total Medical Cost of Treatment	1.007	481.450	0.000*
	Total Non-Medical Cost of Treatment	1.008	65.286	0.000*

**: significant at 5 % level*

The TNM stage of breast cancer is a statistically significant determinant of OOPE. It can be observed that as the TNM stage advances, the OOPE also increases. Through regression analysis, it was observed that patients with stage IIA and IIB have a higher chance of incurring higher OOPE by 643 and 2912 units, respectively, than stage IA and IB breast cancer. The probability of OOPE for patients with stage IIIA, IIIB and IIIC cancers were higher by 4618, 7661 and 9911 units, respectively, than stage IA and IB cancer.

The duration over which radiation factions are taken is another determinant of total OOPE. The parameter estimates of this determinant are not statistically significant. It can be observed that patients who receive factions over six to eight weeks and over three to four weeks have a chance of incurring higher OOPE (by 2155 and 2065 units, respectively) than patients who receive factions over four to six weeks. Patients who did not receive radiation had a probability of incurring higher OOPE than those who received radiation.

The choice of provider for diagnosis is a statistically significant determinant of OOPE. From the regression analysis, it was observed that patients who went to government hospitals only had a chance of incurring lower OOPE by 1532 units than those who went to both government and private hospitals. Patients who went to private hospitals only for diagnosis also had a chance to incur lower OOPE than those who went to both government and private hospitals. The choice of healthcare provider during surgery was another statistically significant determinant of OOPE. It was observed that patients who sought surgery in a private hospital had a probability of incurring higher OOPE by 2624 units than those who went to a government hospital. Another significantly significant determinant of OOPE was the choice of provider during follow-up. The parameter estimates reveal that those patients who went to a private hospital incurred a higher OOPE by 11307 units than those who went to a government hospital.

The number of chemotherapy cycles received by the patient is another determinant of OOPE. It can be observed that as the number of chemotherapy cycles increases, the OOPE also increases. The amount of money received through employee benefit schemes, government health schemes, and private health insurance schemes during treatment is an important statistically significant determinant of OOPE. A patient who receives money through these schemes has a probability of incurring lower OOPE than those who do not receive any money through schemes. The total medical and non-medical costs of treatment are also statistically significant determinants of OOPE. The higher the total medical and non-medical cost of treatment, the probability of incurring a higher OOPE also increases.

7.9. Determinants of Economic Burden Experienced by Patients and Their Households Due to Treatment of Breast Cancer

The economic burden experienced by breast cancer patients during treatment causes a burden on them and their households. In this section, using a multinomial logistic regression model, an attempt is made to identify the prominent factors that determine the economic burden experienced by patients.

The model of the study is:

$$\mathbf{Y = \beta_0 + \beta_1 Z_1 + \beta_2 Z_2 + \beta_3 Z_3 + \beta_4 Z_4 + \beta_5 Z_5 + \beta_6 Z_6 + \beta_7 Z_7 + \beta_8 Z_8 + \beta_9 Z_9 + \beta_{10} Z_{10} + \beta_{11} Z_{11} + \beta_{12} Z_{12} + \beta_{13} Z_{13} + \beta_{14} Z_{14} + \beta_{15} Z_{15} + \beta_{16} Z_{16} + \beta_{17} Z_{17} + \beta_{18} Z_{18} + \varepsilon}$$

Where Y= Economic Burden

Z_1= Marital status

Z_2= Annual income of the household

Z_3= Number of employed members in the household

Z_4= TNM stage of breast cancer

Z_5= Whether patient relocated for treatment

Z_6= Whether the employed patient suffered pay loss due to treatment

Z_7= Whether the employed patient returned to work after treatment

Z_8= Amount received from employee benefits scheme during treatment

Z_9= Amount of money received through government health schemes during treatment

Z_{10}= Amount of money received through private health insurance scheme during treatment

Z_{11}= Whether property was leased to fund treatment

Z_{12}= Whether gold was sold to fund treatment

Z_{13}= Whether gold was leased to fund treatment

Z_{14}= Whether money was borrowed from friends or relatives in order to fund treatment

Z_{15}= Whether money was borrowed from a bank in order to fund treatment

Z_{16}= Whether financial grants were received from relatives of friends in order to fund treatment

Z_{17}= Out-of-pocket expenditure

In order to check whether the above model can be constructed, a variance inflation factor (VIF) was conducted. The VIF results from the model assumptions are given in the Table below.

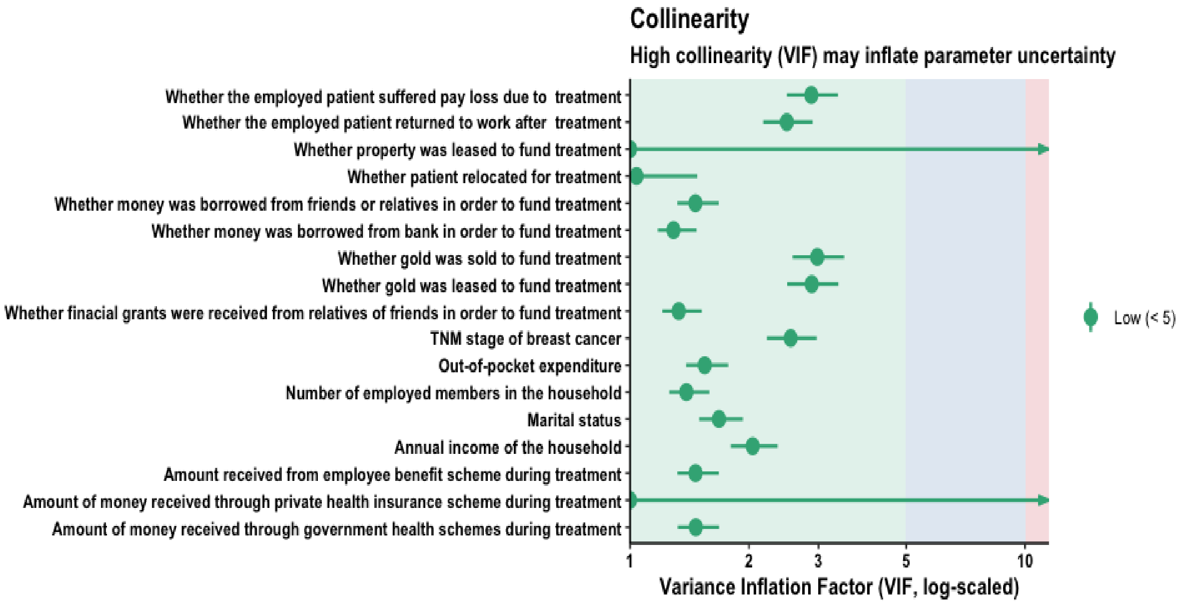
Table 7.23

Results of VIF analysis to determine factors of economic burden

Term	VIF
Marital status	1.68
Annual income of the household	2.04
Number of employed members in the household	1.39
TNM stage of breast cancer	2.55
Whether patient relocated for treatment	1.04
Whether the employed patient suffered pay loss due to treatment	2.88
Whether the employed patient returned to work after treatment	2.49
Amount received from employee benefits scheme during treatment	1.46
Amount of money received through government health schemes during treatment	1.47
Amount of money received through private health insurance scheme during treatment	1.00
Whether property was leased to fund treatment	1.00
Whether gold was sold to fund treatment	2.98
Whether gold was leased to fund treatment	2.89
Whether money was borrowed from friends or relatives in order to fund treatment	1.46
Whether money was borrowed from a bank in order to fund treatment	1.29
Whether financial grants were received from relatives of friends in order to fund treatment	1.33
Out-of-pocket expenditure	1.55

Figure 7.7

Plot graph representing collinearity values of predictor variables of the economic burden



From Table 7.23 and Figure 7.7, it can be observed that the VIF values of the independent variables are below five, and hence, there is no significant multicollinearity between the variables.

Table 7.24

Results of AIC and BIC analysis to determine the selection of a model for factors of the economic burden

Model	AIC	BIC	Removing Variable
I Model	228.3884	336.1579	
II Model	227.8138	331.5919	Whether the employed patient returned to work after treatment
III Model	223.5867	315.3903	Marital status
IV Model	229.5482	317.3604	Whether money was borrowed from friends or relatives in order to fund treatment
V Model	226.6752	306.5045	Whether the employed patient suffered pay loss due to treatment
VI Model	227.2307	303.0685	Number of employed members in the household
VII Model	227.1821	299.0285	Whether gold was leased to fund treatment
VIII Model	227.0147	294.8696	Out-of-pocket expenditure
IX Model	228.3021	292.1655	Whether financial grants were received from relatives of friends in order to fund treatment

The results of AIC and BIC analysis predict that the ninth model is more reliable for regression analysis to determine the factors for economic burden. From Table 7.24, it can be observed that the values of AIC and BIC are decreasing with successive models. Hence, the final model is used for analysing the predictors.

Model summary	
R Square	**0.68**

Table 7.25

Parameter estimate results of multinomial regression analysis to determine factors of economic burden

Variables	**OR**	**Estimate**	**Statistic**	**P Value**
(Intercept)	0.077	-2.566	-2.969	0.003*
Annual Income of The Household: Between ₹ 1 Lakh to ₹ 5 Lakhs	0.294	-1.225	-2.354	0.019*
Annual Income of The Household: Between ₹ 10 Lakhs to ₹ 25 Lakhs	0.010	-20.922	-0.007	0.994
Annual Income of The Household: Between ₹ 5 Lakhs to ₹ 10 Lakhs	0.027	-3.620	-4.099	0.000*
Annual Income of The Household: Below ₹ 1 lakh	0			
TNM Stage of Breast Cancer: Stage II A	3.329	1.203	1.721	0.085
TNM Stage of Breast Cancer: Stage II B	1.765	0.568	0.774	0.439
TNM Stage of Breast Cancer: Stage III A	3.512	1.256	1.566	0.117
TNM Stage of Breast Cancer: Stage III B	3.931	1.369	1.494	0.135
TNM Stage of Breast Cancer: Stage III C	38.752	3.657	3.110	0.002*
TNM Stage of Breast Cancer: Stage IA and IB	0			
Patient Relocated for Treatment: Yes	21.061	3.047	1.446	0.148
Patient Relocated for Treatment: No	0			
Amount of money received through Employee Benefit Scheme during treatment	1.000	0.000	0.102	0.919
Amount Of Money Received Through Government Health Schemes During Treatment	1.000	0.000	0.829	0.407
Amount of Money Received Through Private Health Insurance Scheme During Treatment	1.000	0.000	-0.010	0.992
Property Was Leased to Fund Treatment: Yes	651,456,384.630	20.295	0.006	0.995

Variables	OR	Estimate	Statistic	P Value
Property Was Leased to Fund Treatment: No	0			
Gold Was Sold to Fund Treatment: Yes	11.615	2.452	5.014	0.000*
Gold Was Sold to Fund Treatment: No	0			
Money Was Borrowed from Bank in Order to Fund Treatment: Yes	75.808	4.328	5.627	0.000*
Money Was Borrowed from the Bank in Order to Fund Treatment: No	0			

**: significant at 5 % level*

The annual income of the household is a statistically significant predictor of economic burden. It was observed that the higher the annual income of the household, the lower the probability of economic burden. The odds of economic burden being experienced by patients who belong to households with annual income below ₹ 1 lakh is higher by 0.2 times than those who belong to households with annual income between ₹ 1 lakh to ₹ 5 lakh. Patients who belong to households with annual incomes higher than ₹ 5 lakhs had a very low probability of experiencing economic burden.

The TNM stage of breast cancer is an important predictor of economic burden. It can be observed that as the TNM stage advances, the probability of experiencing economic burden also increases. Patients who had stage IIA and IIB breast cancer had a higher probability, by 3.3 times and 1.7 times, respectively, of experiencing economic burden than patients with stage IA and IB breast cancer. The odds of experiencing economic burden were 3.5 times higher for stage IIIA patients and 3.9 times higher for stage IIIB patients than stage IA and IB. Stage IIIC had the highest probability of experiencing economic burden, i.e., 38.7 times higher than stage IA and IB.

Patients who relocate for treatment have a 21.06 times higher probability of experiencing economic burden than patients who do not relocate for treatment.

The amount of money received through employee benefit schemes, government health schemes and private health insurance schemes was found to have no association with the economic burden. The odds ratio for these predictors was one, which indicated no relation with the dependent variable.

Patients who leased their property to fund the treatment of breast cancer had the highest probability of experiencing economic burden. The odds of experiencing economic burden were 651,456,384 times more than those patients who did not lease property to fund treatment.

Another statistically significant predictor of economic burden was whether gold was sold to fund treatment. Patients who sold gold had a probability of experiencing an economic burden 11.61 times higher than those patients who did not sell gold.

Money borrowed from banks to fund treatment was a statistically significant predictor of economic burden. It was observed that patients who borrowed money from the banks had a probability of experiencing an economic burden 75.8 times higher than those patients who did not borrow money from the banks.

7.10. Conclusion

The indirect costs associated with the treatment of breast cancer are high. Patients and their caregivers suffer pay loss during the duration of treatment. The treatment of cancer is so exhausting that it sometimes results in patients resigning from their jobs. Thus, breast cancer not only causes physical strain but also causes financial strain.

The high out-of-pocket expenditure associated with the treatment of cancer pushes patients and their households into financial distress. They resort to various coping mechanisms, like selling assets and borrowing money. There are several government health schemes which provide financial aid to patients undergoing treatment. These schemes only cover the direct medical cost of treatment and not the non-medical cost and indirect costs.

Through multivariate regression analysis, it was observed that the most significant predictors of out-of-pocket expenditures were the TNM stage of breast cancer, choice of provider for healthcare, the amount received through government health schemes and insurance schemes, and total cost of treatment. A multinomial logistic regression was performed in order to assess the determinants of catastrophic health expenditure. The important determinants were the annual income of the household, the TNM stage of cancer and the coping mechanisms used to fund treatment. These results are helpful in formulating government health schemes that will reduce the burden of treatment costs on breast cancer patients and their households.

CHAPTER VIII

SUMMARY OF FINDINGS AND POLICY RECOMMENDATIONS

8.1 Introduction

Breast cancer incidence has been increasing steadily globally. It is the leading type of cancer in 80 per cent of the countries and the leading cause of cancer mortality in the majority of the countries (Bray et al, 2018). Cancer is such a disease that has a high disease burden accompanied by a high economic burden. Though the Indian healthcare sector has been rapidly growing over the years, the treatment of cancer is still expensive for most Indian families. Breast cancer has an impact not only physically and psychologically but also financially on the patient and their families.

Breast cancer is the most common type of cancer among females in India. The economic burden associated with breast cancer treatment can force patients and households to acute misery and even insolvency. There have been significant improvements in cancer treatment, but the health care costs have also been increasing simultaneously. Poor health financing mechanisms and heavy reliance on out-of-pocket (OOP) healthcare payments compel several breast cancer patients to resort to distressed means for treatment financing. Many families resort to more than one coping mechanism to overcome financial distress.

The purpose of this study is to understand the degree of financial hardship and the impact of cancer costs on breast cancer patients and their households. This study aims to fill the gaps identified in the empirical literature review. The objectives of the study are as follows:

1. To explore the extent and dimensions of cancer in India, with a special focus on breast cancer.

2. To identify and analyse the socioeconomic dimensions of breast cancer patients and examine the direct and indirect costs associated with breast cancer in households in Kerala.

3. To analyse the health schemes provided by the government and other organisations for breast cancer treatment and the financial coping mechanisms used by the households to fund breast cancer.

4. To identify and analyse the determinants of the economic burden of breast cancer in Kerala.

The economic burden associated with breast cancer is analysed using cost-of-illness methodology. The aim of the COI studies is to provide an estimate of how much society spends on a particular disease and identify different cost components. The assessment of costs associated with treatment of breast cancer has become essential for policymakers and healthcare providers.

This study hypothesises that the total cost of breast cancer treatment is not different across government and private hospitals. It also hypothesises that the economic factors and treatment-related factors have no significant effect on the total cost of treatment, out-of-pocket expenditures and catastrophic health expenditures incurred by patients and their households.

For the purpose of the study, primary data collected from the selected patients have been analysed. The sample area for the study was the state of Kerala. In this study, female breast cancer patients who completed the required treatment protocol were interviewed for this study. The sample size for the study was 400. The respondents were interviewed when they visited the hospital for their follow-up. A face-to-face interview was conducted by the interviewer. A retrospective study was conducted. The female breast cancer patients were randomly selected from government and private hospitals across Kerala. Hospitals where complete cancer treatment was available were only selected for the study. Of the 400 respondents, 245 were selected from government cancer hospitals, and 150 were selected from private hospitals.

In this chapter, the major findings mentioned in previous chapters are incorporated. The validation of the hypothesis and the limitations of this study are also discussed in this chapter. It also incorporates the policy recommendations and areas of future research.

8.2 Cancer at a National and State Level

In a developing country like India, with a population of more than 1.3 billion, cancer is one of the leading causes of mortality. According to the GLOBOCAN Report 2020, the incidence rates of cancer increased with increasing levels of HDI. Globally, the highest incidence rate was observed for breast cancer. In India, over the years, the incidence of breast cancer surpassed cervical cancer. Breast cancer has emerged as the leading cancer site among females in India.

After analysing the 36 PBC₹ and 236 HBC₹ under the NCRP (2012-2016), it was observed that the distribution of cancer was heterogeneous across different states in India. The highest incidence crude rate per 100000 population among males was in Aizawl district (206.2), followed by Kamrup urban (190.5), Thiruvananthapuram district (170.4) and Kollam district (159.4). Among females, the highest incidence of CR per 1,00,000 population was observed in the Aizawl district (174.6), followed by the Thiruvananthapuram district (164.8). The highest crude mortality rate (CMR) per 100000 population among males was in Aizawl district (115.0), followed by Kollam district (84.3). Among females, the highest CMR per 1,00,000 population was observed in the Aizawl district (69.6), followed by Mumbai (61.6). Overall, the southern states of India reported a higher incidence of cancer compared to all other regions.

Breast cancer had the highest number of new cases, incidence rate and death rate. The highest age-adjusted incidence rate for breast cancer (AAR per 1,00,000) was reported in Hyderabad (48.0), and the lowest AAR per1,00,000 was reported in Meghalaya (7.0). It was observed that North-Eastern and South cancer registries have reported higher crude incidence for both male and female populations. While analysing the clinical extent of female breast cancer patients, it was observed that 57 per cent of the cases reported locoregional spread, followed by 29 per cent of cases with localised diseases and 10 per cent of cases with distant metastasis. Multi-modality was the most common choice of treatment for locoregional spread (79.1 per cent), localised spread (74.3 per cent) and distant metastasis (47.4 per cent).

The incidence and prevalence of cancer in Kerala is steadily increasing. According to the NCRP 2012-2016 report, the average crude incidence rate of cancer per 1,00,000 of the population is 164.9 among males and 151.95 among females in Kerala. The incidence and mortality from cancer were much higher in Kerala when compared to other states in India. A secondary data analysis using the National Sample Survey (NSS) 75th round was done by the researcher in order to understand the current scenario of cancer in Kerala. The data of cancer patients between the ages of 18 to 60 years was taken for analysis.

Kerala had the highest percentage of cancer patients among the southern states of India. More than 80 per cent of patients were married. Only 70 per cent of cancer patients had an educational attainment of secondary level and more. Cancer patients in urban sectors had higher levels of educational attainment when compared to their rural counterparts. Also, male cancer patients had comparatively higher levels of educational status than female cancer patients. Almost 73 per cent of male cancer patients were employed, but only 29 per cent of female cancer patients were employed. In rural areas of Kerala, cancer patients availed treatment from government medical institutions more than private, while in urban areas, treatment was availed from private medical institutions more than government. The most common reasons for not availing treatment from government institutions were patients preferring a trusted hospital/doctor and the government medical institution being too far from their residence. Most of the cancer patients in Kerala sought treatment from a hospital in an urban area in the same district as their residence.

The average total medical expenditure incurred by cancer patients in Kerala was ₹ 60,227. Female cancer patients incurred more medical expenditure than male cancer patients for the treatment of cancer. Among males, the average total medical expenditure was ₹ 50,373, and among females, it was ₹ 73,553. The total direct expenditure constituted about 90 per cent of total medical expenditure. The package component was the highest contributor to the total direct expenditure, followed by the cost of medicines. Non-medical expenses were significantly less when compared to medical expenses. They were only 10 per cent of total direct expenditure.

Reimbursement received by patients was significantly lower than the total medical expenditure. On average, cancer patients received only around 10 per cent of the average total medical expenditure as their reimbursement. This results in a high out-of-pocket expenditure. The common sources of finance for cancer treatment were household income and contributions from friends/relatives. Cancer treatment often leads to loss of household income if the cancer patient or their caregiver is employed. On average, the household of a cancer patient in Kerala incurs a loss of ₹ 6,782 during treatment. The mean loss of household income among males was almost double compared to the mean loss of household income among females.

8.3 Socio-Economic Distribution and Disease Profile of Breast Cancer Patients

Socio-economic factors influence the health outcomes of an individual. It also plays a role in the treatment-seeking behaviour of the patient. The primary data was collected from various government and private cancer hospitals in Kerala. A total of 400 female breast cancer patients who completed their treatment were interviewed for the study. While analysing the socio-economic distribution, it was observed that around 41.3 per cent of the respondents belonged to the age group 41 to 50 years, 32.5 per cent belonged to the age group 31 to 40 years, 22.0 per cent belonged to the age group 51 to 60 years and 4.3 per cent of the total respondents belonged to the age group 20 to 35 years. It can be observed that as age increases, the prevalence of advanced-stage breast cancer also increases. Around 41.75 per cent of the respondents had completed secondary education, and 31 per cent had completed primary education. Only 27.25 per cent of the respondents have an educational level of higher secondary and above. Most of the respondents were married, and only 22.8 per cent of respondents were either widowed, divorced or unmarried.

The employment rate among female breast cancer patients was very low. Around 70 per cent of respondents were unemployed. Among employed respondents, 35.5 per cent worked in the unorganised sector, 24 per cent worked in the government sector, 16.5 per cent worked in the private sector, 5 per cent had their own business, and 19 per cent were retired employees. Respondents who worked in the government sector and private companies could avail employee benefit schemes provided by the employer and the government. The annual income of the household was an important factor when making decisions regarding treatment choices. It was observed that 11.3 per cent of the households had an annual income below ₹ one lakh, 59.5 per cent of the households had an annual income between ₹ one lakh and five lakhs, 23.5 per cent of the households had an annual income between ₹ five lakhs to ten lakhs and 5.8 per cent of the households had an annual income above ₹ ten lakhs. Employed members in a household contribute to the annual income of the household. Around 29 per cent of the households had only one employed member, 34.75 per cent had two employed members and 36.25 per cent had three or more employed members. Primary caregivers help a patient to manage their disease both physically and financially. Spouses and children were the most common primary caregivers of the respondents.

The TNM stage of breast cancer determines the treatment protocol taken by the patient. Around 13 per cent of the respondents had stage I breast cancer, 62.5 per cent had stage II breast cancer, and 24.6 per cent had stage III breast cancer. The most common type of treatment protocol received by Stage IA and IB breast cancer patients was surgery only. Among stage II breast cancer patients, surgery followed adjuvant chemotherapy, and surgery followed by adjuvant chemotherapy and radiation was the most common type of treatment protocol. Among stage III breast cancer patients, neoadjuvant chemotherapy followed by surgery, adjuvant chemotherapy and radiation were the most common type of treatment protocol.

Chemotherapy was part of the treatment for 87.8 per cent of respondents. Four-cycle and six-cycle chemotherapy was the most common type of treatment among stage I and stage II breast cancer. Stage III was an advanced type of breast cancer, and respondents who had stage III cancers mostly took eight-cycle and twelve-cycle chemotherapy. Radiation was taken by 59 per cent of the respondents as part of their treatment. The most common mode of radiation was factions given over a time period ranging between three to four weeks, and this was mostly given for stage I and stage II breast cancer. Radiation faction given over four to eight weeks was the common type of treatment among stage III breast cancer. Only 21.2 per cent of the respondents had received targeted therapy as part of their treatment. Most of the respondents who had been given targeted therapy as part of their treatment had received less than ten injections of trastuzumab.

Among stage I breast cancer, the most common type of treatment was either a combination of surgery and chemotherapy or a combination of surgery and radiation. Among stage II breast cancer, it was mostly surgery along with a lower number of chemotherapy cycles and a lower number of radiation factions. Stage III breast cancer respondents had to undergo treatment with a higher number of chemotherapy cycles and radiation factions. For the majority of the respondents, it took between three to twelve months to complete the treatment protocol for breast cancer. The majority of respondents who had stage I breast cancer had completed their treatment in three months. Stage II breast cancer respondents mostly completed their treatment in four to twelve months. It took stage III breast cancer respondents a minimum of six months to complete their treatment. Respondents who received targeted therapy took a longer time to complete their treatment.

The most common choice of healthcare provider for diagnosis of breast cancer was private hospitals. For surgery, as part of breast cancer treatment, 57 per cent of the respondents had gone to a government hospital, and 43 per cent of the respondents had gone to a private hospital. Among patients who received radiation as part of their treatment, around 51.1 per cent of the respondents had gone to a government hospital for radiation, and 48.9 per cent of the respondents had gone to a private hospital. Among patients who received radiation as part of their treatment, around 61.5 per cent of the respondents had gone to a government hospital for radiation, and 38.5 per cent of the respondents had gone to a private hospital. Most patients who received targeted therapy as part of treatment had gone to a government hospital for targeted therapy. For follow-up after their treatment, around 61 per cent of the respondents went to a government hospital for follow-up and 39 per cent of the respondents went to a hospital.

In the case of surgery and chemotherapy, the majority of the respondents had gone to a government healthcare institution. There was little difference in the preference for government or private healthcare institutions in the case of radiation. The majority of the respondents who received Trastuzumab injections as a part of targeted therapy preferred to go to a government healthcare institution due to the high cost of injections.

8.4 Economic Cost of Breast Cancer

Cancer and its treatment result in the loss of economic resources and opportunities for patients, their families, and society overall. The economic costs associated with cancer also pose a financial risk for households. Households mitigate the adverse circumstances of one of their family members having cancer by using various coping mechanisms. The time spent by caregivers taking care of cancer patients also has an economic impact.

8.4.1 Direct Medical Cost Incurred by Breast Cancer Patients

Breast cancer patients incur direct medical costs during diagnosis, treatment, and follow-up stages.

a) During the diagnosis stage, respondents who had stage III cancers incurred higher costs compared to stage I and stage II cancers. Respondents who went to private healthcare centres for all tests during the diagnosis stage incurred the highest mean cost for diagnosis. The mean total cost of diagnostic tests incurred by respondents who went to government healthcare institutions was ₹ 20,949.74, while those who went to private healthcare institutions incurred ₹ 32,122.88. Those respondents who went to both private and government health centres for diagnosis incurred a mean total cost of ₹ 27,758.95. The cost of imaging tests contributed the highest to the total cost of diagnosis, while lab tests contributed the least. From the ANOVA analysis, it can be concluded that there was a significant difference in costs across the three groups of healthcare providers: government, private, and both government and private cases of cost of biopsy tests, imaging tests, lab tests, miscellaneous tests and total medical costs incurred during diagnosis stage at 1 per cent level of significance.

b) Treatment of breast cancer: This includes surgery, radiation, chemotherapy and targeted therapy.

i. Surgery: Respondents who had surgery in a government hospital incurred lower total medical costs than those who went to a private hospital. In a government hospital, the mean total medical cost of surgery was ₹ 44,037.2, whereas the mean total medical cost of surgery was ₹ 68,993.6 in a private hospital. The mean cost of total medical cost incurred during surgery was ₹ 54,769±16,208 across both types of healthcare providers. The surgical procedure cost contributed the highest to the total medical costs incurred during surgery. The cost of imaging tests contributed the least to total medical costs. From the ANOVA analysis, it can be concluded that there was a significant difference in costs incurred in government and private hospitals in case of cost of biopsy tests, imaging tests, lab tests, surgical procedures, room and ward facilities, pharmaceuticals and medical consumables, miscellaneous services, and total medical costs during surgery at 1 per cent level of significance.

ii. Radiation: The total medical cost incurred for radiation in a private hospital was only slightly higher than the total medical costs incurred in a government hospital. Respondents who went to a government hospital for radiation incurred a mean total medical cost of ₹ 74,672.7, while those who went to a private hospital incurred ₹ 77,197.5. Stage III breast cancer respondents incurred higher costs for radiation compared to other TNM stages. The cost of radiation procedure contributed to almost 95 per cent of the total medical cost incurred during radiation. From the ANOVA analysis, it can be concluded that there was a significant difference in costs incurred in government and private hospitals in the case of cost of biopsy tests, imaging tests, lab tests, radiation procedures, room and ward facilities, pharmaceuticals and medical consumables, miscellaneous services, and total medical costs during radiation at 1 per cent level of significance.

iii. Chemotherapy: Respondents who sought chemotherapy treatment in a government hospital incurred lower medical costs than those who sought chemotherapy in a private hospital. The mean total medical cost of chemotherapy was ₹ 40,440.6 in a government hospital, while it was ₹ 46,152.8 in a private hospital. The cost of chemotherapy drugs, other pharmaceutical products and medical consumables contributed the highest to the total medical cost of chemotherapy. Respondents who had to take a twelve-cycle chemotherapy had incurred almost double the medical cost than those who took a four-cycle chemotherapy. Respondents with stage III breast cancer incurred higher chemotherapy costs because they usually had to take eight-cycle or twelve-cycle chemotherapy. From the ANOVA analysis, it can be concluded that there is a significant difference in costs incurred in government and private hospitals in the case of the cost of biopsy tests, imaging tests, lab tests, pharmaceuticals and medical consumables, miscellaneous services, and total medical costs during chemotherapy at 1 per cent level of significance.

iv. Targeted therapy: Respondents who took targeted therapy in a private hospital incurred almost 40 per cent more medical costs than those who took targeted therapy in a government hospital. The mean total medical cost of targeted therapy was ₹ 4,59,608 in a private hospital, whereas it was ₹ 2,53,018.6 in a government hospital. The cost of targeted therapy drugs, pharmaceutical products and medical consumables contributed to almost 90 per cent of the total medical costs incurred for targeted therapy. Respondents who took sixteen to twenty injections of trastuzumab as part of targeted therapy incurred the highest medical cost. From ANOVA analysis, it can be concluded that there is significant variation between groups with regard to the cost of lab tests, imaging tests, targeted therapy drugs, pharmaceutical products and consumables, miscellaneous services, and the total medical cost of targeted therapy at a 1 per cent level of significance.

v. Total cost of treatment for breast cancer: The total medical cost incurred for breast cancer treatment is calculated by summing up the total cost of surgery, radiation, chemotherapy, and targeted therapy. Stage III breast cancer respondents incurred higher costs compared to stage I and stage II breast cancer respondents. Stage I breast cancer respondents who took treatment from only a government hospital incurred a mean total medical cost of ₹ 88,797.1, while those respondents who took treatment from only a private hospital incurred ₹ 1,46,598.6, and those who took treatment from both government and private hospitals incurred ₹ 1,14,246.6. Stage II breast cancer respondents who took treatment from only a government hospital incurred on an average a mean total medical cost of ₹ 1,96,850.5, while those who took treatment from private hospitals incurred ₹ 2,69,776.5, and those who took treatment from both government and private hospitals incurred ₹ 2,22,873. Stage III breast cancer respondents who took treatment from only a government hospital incurred on an average a mean total medical cost of ₹ 2,67,054.3, while those who took treatment from private hospitals incurred ₹ 3,08,676, and those who took treatment from both government and private hospitals incurred ₹ 2,29,808.6.

On the basis of treatment protocol, the highest medical cost was observed for the treatment protocol- neoadjuvant chemotherapy followed by surgery, then adjuvant chemotherapy, then radiation and targeted therapy. The lowest mean total medical cost was incurred for the treatment protocol with surgery only. Treatment protocols with targeted therapy resulted in a higher total medical cost compared to other treatment protocols. Respondents who completed their treatment protocol in private hospitals incurred the highest mean total medical cost for the treatment of breast cancer.

vi. Determinants of total medical cost of treatment for breast cancer: Using a multiple regression model, the determinants of total medical cost of treatment were analysed. The significant determinants used in the final model were the TNM stage of breast cancer, duration of radiation received, number of chemotherapy cycles received, choice of provider for surgery, choice of provider for chemotherapy and choice of provider for targeted therapy.

The TNM stage of breast cancer of the respondent was a determinant of the total medical cost of breast cancer treatment. Through regression analysis, it was observed that respondents with stage IIB, IIIA and IIIC had incurred higher total medical costs than those with stage IA and IB breast cancer. The duration over which radiation factions were taken by the respondent was a statistically significant determinant of the total medical cost of breast cancer treatment. It was observed that the higher the duration, the higher the total medical cost. Respondents who took radiation factions over four to six weeks incurred higher costs than those who took over three to four weeks. The total medical cost was higher for respondents who took radiation factions over six to eight weeks than those who took over four to six weeks. Respondents who did not receive radiation as a part of their treatment incurred a significantly lower total medical cost than those who received radiation. The choice of provider of surgery, chemotherapy and targeted therapy was a statistically significant determinant of total medical cost. Respondents who sought surgery, chemotherapy and targeted therapy in a private hospital had incurred higher medical costs than those who went to a government hospital. As the number of chemotherapy cycles increases, the total medical cost also increases. Respondents who did not receive targeted therapy as part of their treatment incurred significantly lower medical costs than those who received targeted therapy.

c) Follow-up stage: Breast cancer patients, after completing the treatment protocol, have to be monitored on a regular basis and, hence, have to visit the doctor for regular follow-ups. Across all stages of breast cancer, the mean annual follow-up medical cost incurred was ₹ 6,216.4 for respondents who went to a government hospital. Respondents who went to a private hospital incurred a mean annual follow-up medical cost of ₹ 10,080.2. The cost of imaging tests contributed the highest to annual medical costs for follow-up. From ANOVA analysis, it can be concluded that there was a significant difference at a 1 per cent level of significance in average yearly costs incurred in government and private hospitals in case of cost of biopsy tests, imaging tests, lab tests, pharmaceuticals and medical consumables, miscellaneous services, and total medical costs during follow-up stage.

8.4.2 Direct Non-Medical Costs Incurred by Breast Cancer Patients

The direct non-medical costs incurred during the treatment of breast cancer include costs for food, transportation costs and accommodation costs.

a) Transportation costs: The mean transportation costs were higher for chemotherapy and targeted therapy when compared to surgery and radiation. The distance of the patient's household from the treatment hospital was one of the determinants of transportation costs. Respondents who sought treatment in government hospitals incurred lower transportation costs than those who went to private hospitals. The mean cost of transportation incurred during surgery was ₹ 3,515 for respondents who sought treatment in a government hospital, while it was ₹ 5,337.6 in the case of private hospitals. In the case of radiation, in government hospitals, the mean transportation cost was ₹ 5,935.3, while in private hospitals, it was ₹ 6,658.1. During chemotherapy, respondents who sought treatment in government hospitals incurred a mean transportation cost of ₹ 6,870.1, and those who went to private hospitals incurred ₹ 8,291.4. The mean cost of transportation incurred during targeted therapy was ₹ 4,276.5 in the case of government hospitals and ₹ 10,966.8 in the case of private hospitals. From ANOVA analysis, it was observed that there is a significant difference across choice of healthcare provider with regard to transportation costs incurred during surgery, radiation, chemotherapy, and targeted therapy at a 1 per cent level of significance.

b) Cost of food: The food cost incurred during radiation was higher than that of surgery, chemotherapy, and targeted therapy. Respondents incurred higher food costs in private hospitals than in government hospitals. The mean cost of food during surgery was ₹ 2,214.1 for respondents who sought treatment in a government hospital, while it was ₹ 2,350.3 in the case of private hospitals. In the case of radiation, the mean food cost was ₹ 5,993.1 in government hospitals, while in private hospitals, it was ₹ 6,280.4. During chemotherapy, respondents incurred a mean food cost of ₹ 1,666.3 in government hospitals, and those who went to private hospitals incurred ₹ 1,204.3. The mean cost of food consumption during targeted therapy was ₹ 778.6 in the case of government hospitals and ₹ 2,072.4 in the case of private hospitals. From ANOVA analysis, it was observed that there is a significant difference across the choice of a healthcare provider with regard to the cost of food consumption incurred during radiation, surgery, chemotherapy, and targeted therapy, which is at a 1 per cent level of significance.

c) Lodging costs: The cost of lodging incurred during radiation and chemotherapy was only analysed. This is because the accommodation taken during surgery is included as direct medical costs, and during targeted therapy, patients do not seek accommodation facilities. Lodging costs were higher in the case of radiation than chemotherapy. The mean cost of accommodation during radiation was ₹ 2,029.7 for respondents who sought treatment in a government hospital, while it was ₹ 8,596.4 in the case of private hospitals. During chemotherapy, respondents who sought treatment in government hospitals incurred a mean accommodation cost of ₹ 540.3, and those who went to private hospitals incurred ₹ 389.5. From ANOVA analysis, it was observed that there is a significant difference across choice of healthcare provider with regard to cost of lodging incurred during radiation at a 1 per cent level of significance. There has been no significant variation between groups with regard to the cost of lodging incurred during chemotherapy.

8.4.3 Indirect Costs Associated with Breast Cancer Treatment

Indirect costs are analysed based on missed workdays of the patient and their caregiver, loss of pay and job changes. Breast cancer treatment takes at least three months to complete. Also, breast cancer patients often take a long time to recover from treatment. This leads to job absenteeism, which further leads to loss of pay, promotion opportunities, and, in some cases, not being able to return to work among employed patients and their primary caregivers.

a) Employment-related burden faced by employed breast cancer patients: About 71.1 per cent of employed respondents missed between six to twelve months of work, and 22.6 per cent missed between three to six months of work. Only about 6.1 per cent of employed respondents missed less than three months of work. Around 76 per cent of the employed respondents suffered pay loss from work during treatment of breast cancer. Only 24 per cent of the employed respondents did not suffer pay loss during treatment. After completion of treatment, 52.6 per cent of employed respondents were not able to return to their work.

b) Employed-related burden faced by employed primary caregivers: Among employed primary caregivers, around 44.4 per cent had missed between one to two months of work, and around 42 per cent missed less than one month of work. Only about 13.5 per cent of employed primary caregivers missed more than two months of work. About 61.6 per cent of employed primary caregivers suffered pay loss, while 38.3 per cent did not suffer pay loss from work.

8.5 Health Schemes and Insurance Schemes Availed During Breast Cancer Treatment

In Kerala, several government health schemes are available which a breast cancer patient can avail during treatment. Along with government schemes, several employee benefit schemes and private health insurance schemes are also available. There are also several government and private health insurance schemes.

a) Employee benefit schemes: Around 9.2 per cent of total respondents availed employee benefit schemes during breast cancer treatment. Among this, 51 per cent availed of the Employees’ State Insurance scheme, 32 per cent availed of the Indian Railway employee benefit, 11 per cent availed of the Central Government Health Scheme, 3 per cent received the Indian Army Personnel health scheme, and 3 per cent availed of Employees’ Provident Fund scheme. Through the Employees’ State Insurance scheme, the average amount received for breast cancer treatment was ₹ 1,98,217. The average amount received through Indian Railway employee benefits was ₹ 2,06,434, while through the Indian Army Personnel health scheme, it was ₹ 1,12,830. Through the Central Government Health Scheme, the average amount received was ₹ 2,03,550, while through the Employees' Provident Fund scheme, it was ₹ 107200.

b) Government health schemes: It was observed that 33 per cent of respondents received only the Karunya scheme, 6.8 per cent received only the CHIS scheme, 1.5 per cent received only the Sukuratham scheme and 1 per cent received only the AB-PMJAY scheme. Around 15.1 per cent of respondents received two health schemes. Both the CHIS and Karunya schemes were received by 11.8 per cent of respondents. Around 3.3 per cent of the respondents received both Karunya and Sukuratham schemes. Around 1.8 per cent received three schemes-CHIS, Karunya and Sukuratham. Around 41 per cent of respondents did not receive any government health scheme. The mean amount of money received through the CHIS scheme was ₹ 68562, through Sukuratham, was ₹ 94,667 and through Karunya, was ₹ 1,02,418. The mean amount of money received through AB-PMJAY was ₹ 1,37,871. For patients who availed of more than one health scheme, the mean amount of money received ranged between ₹ 1,56,916 and ₹ 3,74,107.

c) Private health insurance schemes: Only 8 per cent of respondents availed of private health insurance, while 92 per cent of respondents did not avail of any private health insurance. The mean amount of money received through private health insurance for stage I breast cancer was ₹ 73,973. For stage II and stage III breast cancers, the mean amount of money received ranged between ₹ 1,71,287 and ₹ 2,02,440. Since the cost of treatment for advanced-stage cancers is higher, the mean amount of money received through private health insurance schemes is also higher.

Summarising the health scheme and insurance scheme availed by respondents: 9.2 per cent of respondents availed of employee benefit schemes, 59 per cent of respondents availed government health schemes and 8 per cent availed private health insurance schemes. Around 23.7 per cent of respondents did not avail any health or insurance scheme.

8.6 Out-of-pocket expenditures (OOPE) and Catastrophic health expenditures (CHE) Incurred During Breast Cancer Treatment

Expensive treatment of breast cancer leads to high out-of-pocket expenditures by patients and their families. Financial protection through government health schemes or private health insurance substantially reduces the amount that people pay directly for medical care, yet the burden of out-of-pocket spending can still create barriers to health care access and use.

a) Out-of-pocket expenditures (OOPE): The OOPE incurred by respondents who sought treatment in private hospitals was higher than the OOPE incurred by respondents who sought treatment in government hospitals. The mean OOPE incurred in a government hospital was ₹ 76,434, while in a private hospital, it was ₹ 2,50,594.6. Respondents who went to both government and private hospitals for treatment incurred a mean OOPE of ₹ 1,53,995.3

   As the stage of breast cancer advances, the OOPE also increases. The lowest OOPE incurred was for stage I breast cancer, and the highest was for stage III breast cancer. For respondents who went to only government hospital for treatment, the mean OOPE incurred for stage I breast cancer was ₹ 45,363.8; for stage II, it was ₹ 72,805; and for stage III, it was ₹ 1,12,488.6. The mean OOPE incurred by respondents who went to only private hospitals for treatment was ₹ 1,26,048.4 for stage I breast cancer, ₹ 2,46,356.5 for stage II, and ₹ 3,19,974 for stage III. The mean OOPE incurred by respondents who took treatment in both government and private hospitals was ₹ 77,223.3 hospitals for stage I breast cancer, ₹ 1,52,770 for stage II, and ₹ 1,78,474.3 for stage III.

b) Determinants of out-of-pocket expenditure incurred by patients during treatment of breast cancer: A multivariate regression analysis was done to determine the predictors of OOPE. In this model, the dependent variable was out-of-pocket expenditures. The significant determinants of OOPE used in the final model were: TNM stage of breast cancer, duration of radiation received, number of chemotherapy cycles received, choice of provider for diagnosis, choice of provider for surgery, choice of provider for follow-up treatment, amount received from employee benefit scheme during treatment, amount of money received through government health schemes during treatment, amount of money received through private health insurance scheme during treatment, total medical cost of treatment, and total non-medical cost of treatment. The goodness of fit of the model was 97 per cent.

The TNM stage of breast cancer was a statistically significant determinant of OOPE. It can be observed that as the TNM stage advances, the OOPE also increases. Through regression analysis, it was observed that patients with stage II and III breast cancer have a higher chance of incurring higher OOPE than those with stage IA and IB breast cancer. Patients who received radiation factions over six to eight weeks and over three to four weeks had a chance of incurring higher OOPE (than patients who received factions over four to six weeks. During diagnosis, patients who went to only government hospitals had a chance of incurring lower OOPE compared to those who went to only private hospitals and went to both government and private hospitals. It was also observed that patients who sought surgery in a private hospital had a probability of incurring higher OOPE by 2624 units than those who went to a government hospital. The parameter estimates revealed that those patients who went to a private hospital for follow-up incurred a higher OOPE by 11307 units than those who went to a government hospital.

The number of chemotherapy cycles received by the patient is another determinant of OOPE. It can be observed that as the number of chemotherapy cycles increases, the OOPE also increases. The amount of money received through employee benefit schemes, government health schemes, and private health insurance schemes during treatment is an important statistically significant determinant of OOPE. A patient who receives money through these schemes has a probability of incurring lower OOPE than those who do not receive any money through schemes. The total medical and non-medical costs of treatment are also statistically significant determinants of OOPE. The higher the total medical and non-medical cost of treatment, the probability of incurring a higher OOPE also increases.

c) Catastrophic health expenditure (CHE): Around 40 per cent of respondents experienced CHE during breast cancer treatment. Among respondents who experienced CHE, 22.5 per cent of respondents had an annual household income below ₹ one lakh, and 73.8 per cent of respondents had an annual household income between ₹ one lakh and five lakhs. Respondents whose household income was above ₹ five lakhs had lower chances of experiencing CHE when compared to respondents whose annual household income was below ₹ five lakhs.

8.7 Coping Mechanisms Used to Fund Breast Cancer Treatment

The common coping mechanisms observed were borrowing from relatives and friends, loans from money lenders and financial institutions, and mortgaging and selling assets. Around 87.7 per cent of respondents experienced financial hardship during the treatment of breast cancer.

a) Selling gold: Around 55.2 per cent of respondents had sold gold as a coping mechanism. Among these, 17.6 per cent of respondents belonged to households with an annual income category below ₹ one lakh, 71 per cent belonged to an annual income category between ₹ one lakh to ₹ five lakhs, and 11.4 per cent belonged to an annual income category above ₹ five lakhs.

b) Leasing gold: Around 36.2 per cent of total respondents had leased their gold as part of a coping mechanism. Out of these, 6.2 per cent had an annual household income below ₹ one lakh, 58.6 per cent belonged to the income category between ₹ one lakh and ₹ five lakhs, and 35.1 per cent belonged to the income category above ₹ five lakhs.

c) Leasing properties: Only 3.5 per cent of respondents had leased their property. Out of these, 35.7 per cent had an annual household income below ₹ one lakh, 57.1 per cent belonged to the income category between ₹ one lakh and ₹ five lakhs, and 7.1 per cent belonged to the income category between ₹ five lakhs to ₹ ten lakhs.

d) Borrowing from family or friends: 47 per cent of respondents had borrowed money from friends or relatives as part of a coping mechanism. Among these, 16.5 per cent of respondents belonged to the annual household income category below ₹ one lakh, 73.4 per cent belonged to the income category between ₹ one lakh to ₹ five lakhs, and 10.1 per cent belonged to the income category above ₹ five lakhs.

e) Bank loan: Around 22.7 per cent of total respondents took bank loans as part of a coping mechanism. Out of this, 18.7 per cent belonged to the annual household income category below ₹ one lakh, 78 per cent belonged to the income category between ₹ one lakh to ₹ five lakh, and 3.3 per cent belonged to the income category above ₹ five lakhs.

f) Financial grants from friends or relatives: Around 28.2 per cent of respondents received financial grants. Among these, 15 per cent belonged to the annual household income category below ₹ one lakh, 69 per cent belonged to the income category between ₹ one lakh to ₹ five lakh, and 15.9 per cent belonged to the income category above ₹ five lakhs.

8.8 Determinants of Economic Burden Experienced by Patients During Treatment of Breast Cancer

Using a multinomial logistic regression model, the determinants of economic burden experienced by patients were analysed. The important determinants of economic burden were the annual income of the household, TNM stage of breast cancer, whether the patient relocated for treatment, amount of money received through employee benefits scheme, amount of money received through government health schemes, amount of money received through private health insurance scheme, whether property was leased to fund treatment, whether gold was sold to fund treatment, and whether money was borrowed from a bank in order to fund treatment. The goodness of fit of the model was 68 per cent.

The annual income of the household was a statistically significant predictor of economic burden. It was observed that the higher the annual income of the household, the lower the probability of economic burden. Patients who belong to households with annual incomes higher than ₹ 5 lakhs had a very low probability of experiencing economic burden. The TNM stage of breast cancer was an important predictor of economic burden. It can be observed that as the TNM stage advances, the probability of experiencing economic burden also increases. Stage IIIC had the highest probability of experiencing economic burden, i.e., 38.7 times higher than stage IA and IB. Patients who relocate for treatment have 21. 06 times higher probability of experiencing economic burden than patients who do not relocate for treatment. The amount of money received through employee benefit schemes, government health schemes, and private health insurance schemes was found to have no association with the economic burden. Patients who leased their property to fund the treatment of breast cancer had the highest probability of experiencing economic burden. The odds of experiencing economic burden were 651,456,384 times higher than those patients who did not lease property to fund treatment. Patients who sold gold had a probability of experiencing an economic burden 11.61 times higher than those patients who did not sell gold. Patients who borrowed money from the banks had a probability of experiencing an economic burden 75.8 times higher than those patients who did not borrow money from the banks.

8.9 Patient Experience During Breast Cancer Treatment: Results from Qualitative Survey

Breast cancer patients face difficulties during the period of treatment. The common difficulties encountered are lack of transportation and lodging facilities, lack of cancer hospitals and specialists, lapse in treatment and availing health schemes, and high cost of treatment. Around 35.8 per cent of total respondents felt there is a lack of cancer hospitals close to their residences, and 42.3 per cent felt there are not enough cancer specialists in hospitals close to their residences. Around 61.5 per cent of total respondents felt that there is a long distance from their residence to the cancer hospitals from where they received treatment, and 44.3 per cent experienced transportation difficulties while commuting to cancer hospitals. Lodging difficulties were experienced by 30.5 per cent of respondents. Around 14.8 per cent and 12 per cent of respondents felt the quality of infrastructural facilities and the quality of treatment in cancer hospitals were not up to the standard, respectively. Almost 27 per cent of respondents felt that there were not enough nursing homes close to their residences. The burden of the high cost of medicines and treatment of breast cancer was experienced by 81.3 per cent of respondents. Around 58 per cent of respondents had difficulty in availing health and insurance schemes during breast cancer treatment. Only 53 per cent of the respondents received cancer pension post their treatment.

8.10 Discussion

Breast cancer imposes an economic burden on patients and their families. This study analysed the direct and indirect costs associated with the treatment of breast cancer. It was observed that the total medical cost of breast cancer treatment was high for advanced-stage cancers. Stage III breast cancer patients incurred higher costs compared to stage I and stage II breast cancer patients because of the intense multi-modal type of treatment. Treatment protocols with radiation, chemotherapy and immunotherapy led to expensive cancer care. Immunotherapy was the most expensive mode of treatment, which led to an escalation of total medical costs by ₹ 2 to 3 lakhs. Similar results were observed in studies by Grover. et al. (2017), Singh et al. (2018) and EY analysis (2022).

The study also analysed the difference in total medical costs incurred across government and private hospitals. Breast cancer patients who sought treatment in private hospitals incurred around 30 per cent higher mean medical costs than those who went to government hospitals. This disparity in costs across choice of healthcare provider was observed in studies by Nair et al. (2013) and Rajpal et al. (2018).

In this study, the out-of-pocket expenditures and catastrophic health expenditures incurred by patients are also analysed. The out-of-pocket expenditures incurred by respondents who sought treatment in private hospitals were higher than OOPE incurred by respondents who sought treatment in government hospitals. The mean out-of-pocket expenditure incurred in a private hospital was 70 per cent more than that incurred in a government hospital. In studies by Maurya et al. (2021) and Mahal et al. (2013), the average OOPE on cancers varied between ₹ 34,816 for head & neck, breast, and cervical cancer to ₹ 3,35,800 for palliative care. In this study, a higher range of out-of-pocket expenditure was observed, which ranged between ₹ 39500 for stage I cancers to ₹ 10 lakh for stage III cancers. The major determinants of OOPE were disease characteristics, treatment characteristics, and choice of healthcare provider. In this study, it was observed that around 40 per cent of the patients had faced catastrophic health expenditure during the treatment of breast cancer. In a study by Kastor and Mohanty (2018), about 79 per cent of Indian households faced catastrophic health expenditure due to cancer.

This study also analysed the various health and insurance schemes availed by patients during the treatment of breast cancer. Reimbursement through health and insurance schemes helps patients and their families cope with the cost of cancer care. Financial protection through government health schemes was only received by 59 per cent of the respondents. Around 9.2 per cent received employee benefit schemes, and only 8 per cent had private health insurance.

A significant number of patients and their households suffered from financial difficulty during the treatment of cancer. This study also analysed the various distress and coping mechanisms used by patients during the treatment of breast cancer. The most common methods of distress financing were selling gold and borrowing money from friends and relatives. Goyenka et al. (2023) in their study observed that 72 per cent– 92 per cent of cancer patients had to rely on their own income/savings for payments because of the absence of any financial protection schemes during the treatment of cancer. The causes of the economic burden of breast cancer were multifactorial and included socio-economic characteristics, disease characteristics and type of financial schemes received.

8.11 Limitations of the Study

The scope of the study is limited to exploring the economic burden of breast cancer on patients and their households. The study is constrained to the quantitative aspect of the expenditure on breast cancer care. It does not explore the qualitative aspects like personal hygiene, social hygiene, and health habits of the households. Furthermore, it does not explore the quality-of-life concept due to time and budget constraints. The study is retrospective. Due to the extensive time taken for the treatment of breast cancer, a prospective study was not practically possible. The present study is focused on the direct and indirect costs of breast cancer treatment and does not include the psychological cost of treatment. The study also does not consider stage four breast cancer patients due to the variation in treatment protocols and palliative care. In spite of these limitations, this study is a substantial attempt to analyse the different aspects of breast cancer care and their financial impact on the patient and their households.

8.12 Policy Recommendations

The following suggestions are recommended for policy making:

1) The financial burden associated with the treatment of cancer results in patients with cancer not accessing or receiving adequate care. The government should provide financial protection through sufficient reimbursement of treatment costs. Though there are health schemes, it does not cover half of the medical expenses incurred.

2) Medical costs contributed the highest to total treatment costs. The government should procure and provide medicines and other pharmaceutical products at a subsidised price.

3) Cancer control programmes with adequate infrastructure facilities and effective delivery should be implemented.

4) Promotion of early diagnosis and breast cancer screening among the public and general practitioners to identify cancer at an earlier stage when treatment is more effective and less expensive.

5) Assure equity in cancer care that is sustainable, affordable, and available to everyone– Medical professionals and cancer patients should advocate for this at national and global levels.

6) Identify and prioritise regions with high cancer incidence to provide efficient delivery of cancer care.

7) Addressing the geographical, sociocultural, and financial barriers that exist in various states of India in order to provide full population coverage for cancer care.

8) Improve coordination of cancer services and geographical accessibility through strengthening regional partnerships for cancer management.

9) Medical services like cancer experts and general practitioners travelling to less-populated areas to monitor and follow patients in between their medical appointments should be promoted.

10) Create a national network to improve the communication between urban and rural health centres.

11) Assuring that patients with low socio-economic status have enough insurance coverage for adequate cancer care.

12) Provide cancer care and service packages that are comprehensive, resource-appropriate, and evidence-based.

13) The cancer registries and health information systems in India should improve and collect standardised data which is comprehensive and accurate so that decision-makers can make informed and evidence-based policy decisions. Cancer registries form the backbone of cancer prevention and control activities

in India. Strengthening it will yield much-improved information to track and monitor population and hospital-level measures to track cancer.

14) Under the current National Cancer Registry programme in India, the medical expenses incurred by cancer patients are not collected. The government should instruct all healthcare providers to provide data regarding the total medical costs incurred during treatment.

15) Government should provide for the long-term palliative care needs of cancer patients, including vulnerable populations.

16) Awareness programmes about breast cancer should be increased in order to break the taboo around this disease.

17) Implement international collaborative projects among healthcare professionals and research centres in order to improve and foster excellence in cancer care.

18) Programmes to train adequate number of health workers in rural regions to provide high-quality medical services at the right place and at the right time.

19) Research which focuses on cost-benefit and cost-effectiveness analysis of cancer drugs should be encouraged.

20) At the national and state levels, the government should initiate studies that analyse the cost of illness associated with cancer.

21) Cancer patients should be provided with adequate free rehabilitation services and financial help, like a cancer pension, so that they can get back to their normal lives.

22) The government of India currently allocates around 2 per cent to 3 per cent of GDP to the health sector. Compared to developed countries, this budget allocation is very low. To improve the healthcare system in India, the government should allocate 5 per cent to 6 per cent of GDP to health.`

8.13 Areas for Future Research

The study focuses only on the economic burden of breast cancer. A comprehensive study that analyses the financial costs associated with all types of cancer is suggested for future research. Patients undergoing palliative care cancer treatment were excluded from the study. Since palliative care treatment is highly expensive and eventually leads to mortality, it has become an important area of research for the past few years. The indirect costs associated with cancer have not been adequately estimated in this study. Indirect costs like wage loss, caregiver cost and loss of employment opportunities are commonly associated with cancer care. Several previous studies have highlighted that indirect costs contribute significantly to the burden of cancer care, and hence, it has high scope for future research. This study used a retrospective approach to estimate the costs associated with cancer. Since there is a problem of recall bias, a prospective approach is suggested for future studies. Though prospective studies are time-consuming and costly, they are highly effective. The economic burden of cancer should be studied at a national level in order to formulate policies that reduce the burden of cancer on patients and their households.

8.14 Conclusion

Breast cancer is the leading type of cancer among women across the globe. The burden of treatment associated with breast cancer is a financial as well as a physical strain on patients and their households. Patients are sometimes afraid to seek treatment because of the high cost associated with cancer care. In that light, this study is of importance because it gives information regarding the factors which determines the treatment costs. It also provides insights regarding government health and insurance schemes. All this information can help patients prepare themselves during treatment. Apart from this, it also helps the government and policymakers to understand the burden experienced by patients and make policies to overcome the economic burden of breast cancer.

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APPENDIX

INTERVIEW SCHEDULE

Hospital:

Date:

PART A: SOCIO-ECONOMIC BACKGROUND OF THE PATIENT

1. Age:
2. Occupation:
3. Annual income of the household:
4. Education:
5. Marital status:
6. Number of members in the family:
7. Number of employed members in the family:

Occupation of employed members:

8. Do you have health insurance?

a) Yes b) No

If yes, then which one:

9. Were any governmental aids/ assistance (like unemployment wage, etc) availed during treatment period?
10. Is this the first follow-up: Yes or No

If no, then:

i) The number of follow-ups before:

ii) How many months since the last follow-up?

PART B: DIAGNOSIS FORM

11. TNM staging for the cancer diagnosed:
12. Which hospital was the cancer diagnosed?
13. Year and month during which cancer was diagnosed:
14. Investigative tests done during the time of diagnosis:

No:	Test	Cost incurred (₹)
1.	Physical examination	
2.	Laboratory Test:	
	a) Blood test	
	b) Any other	
3.	Imaging test:	
	a) CT scan	
	b) X-ray	

	c) MRI	
	d) PET scan	
	e) Ultrasound	
	f) Any other	
4.	Biopsy (Mention which)	
6.	Any other test:	

15. Other costs incurred during the time of diagnosis:

No:	Type	Cost (₹)
1.	Hospital cost excluding the test: a) Registration cost b) Consultation fees c) Medical equipment's (like syringe, medicine etc) d) Any other	

PART C: TREATMENT FORM

PRIMARY TREATMENT

16. Treatment Details:

Type of treatment	YES or NO
a) Surgery	
b) Radiotherapy	
c) Chemotherapy	
d) Targeted Therapy	

17. Order of treatment strategy:

18. Treatment by surgery:

i) Treatment in which hospital:

ii) Type of surgery:

iii) Details regarding complications:

iv) Whether second surgery was required?

If yes, then details:

v) Number of days stayed in the hospital:

vi) If employed, number of days of work missed:

vii) Cost of surgery:

19. Treatment by Chemotherapy:

i) Treatment in which hospital:

ii) Number of chemotherapies:

iii) Cost of Chemotherapy

iv) If employed, number of days of work missed:

20. Treatment by Radiotherapy:

i) Treatment in which hospital:

ii) Number of radiotherapies:

iii) Cost of Radiotherapy:

iv) If employed, number of days of work missed:

21. Treatment by targeted therapy:

i) Treatment in which hospital:

ii) Number of radiotherapies:

iii) Cost of Immunotherapy details:

iv) If employed, number of days of work missed:

FOLLOW-UP CARE

22. Duration after the last treatment:

23. Type of follow-up care:

24. Average cost of follow-up care:

DIRECT NON-MEDICAL COSTS

25. Non-medical costs

No:	Type of non-medical cost	Cost incurred (₹) per visit	Number of visits
1.	Food (from where and how many meals) a.Surgery b.Radiation c.Chemotherapy d.Targeted therapy		
2.	Lodging		

	(Specify location of lodging , number of days and how many people stayed) a.Surgery b.Radiation c.Chemotherapy d.Targeted therapy		
3.	Transportation (also specify the mode of travel) a.Surgery b.Radiation c.Chemotherapy d.Targeted therapy		

PART C: INDIRECT COST

<u>A)</u> Employed patients

26. Income per month of the patient:

27. Duration of absence from work (Patient):

28. Was the patient able to return to work after treatment:

29. Any job changes for the patient: Yes or No

If yes, then was it a higher paying or lower paying job

30. Loss of opportunities like promotion, etc: Yes or No

<u>B)</u> Caregivers of the patient

31. Caregiver employed: Yes or No

If yes, please answer the following questions

a) Income per month:

b) Occupation:

c) Duration of absence from work due to treatment of the patient:

d) Able to return to work after the treatment: Yes or No

e) Any job changes: Yes or No

f) Loss of opportunities like promotion, etc: Yes or No

PART D: FINANCIAL AID AND FUNDING OF CANCER CARE

32. Financial Aid received

No:	Type of financial aid	Amount received
1.	Government health schemes: a) Karunya scheme b) Ayushman Bharath	

	c) Cancer Suraksha d) PM cancer patient fund e) CGHS f) Mediclaim g) Any other	
2.	Government insurance schemes a) RSBY b) RAN c) Any other	
3.	Aid from place of employment	
4.	Private medical insurance	
5.	Aid from NGO	
6.	Aid from any other sources	

33. Funding of cancer care excluding financial aid:

No:	Types of funding	Amount received
1.	Property sold	
2.	Property leased	
3.	Gold sold	
4.	Gold leased	
5.	Borrowing of money	
6.	Any other assets sold /leased	
7.	Chit funds	
8.	Bank deposits	
9.	Any other financial derivatives	

34. Is the patient receiving cancer pension scheme: Yes or No

If yes, please mention the amount

35. Additional details regarding funding of cancer care:

PART E: MISCELLANEOUS

36. Difficulties faced by the patient:

No:	Difficulty	Yes or No
1.	Lack of cancer hospitals	
2.	Lack of specialists	
3.	Long distance to cancer centres	
4.	Transportation problems	
5.	Lodging problems	
6.	Quality of cancer hospitals	
7.	Quality of treatment	
8.	Lack of availability of nursing homes, home care, palliative care centres	
9.	High Cost of medicines and treatment	
10.	Availing of health schemes and insurance schemes	
12.	Debt problems	

37. Additional Notes regarding the problems faced by cancer patients

INFORMED CONSENT FORM

Study Title: **“Economic burden of breast cancer on households in Kerala”**

Date of Birth / Age:

1) I confirm that I have read and understood the information sheet dated _________ for the above study and have had the opportunity to ask questions.
2) I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3) I understand that the principal investigator of the research study, others working on the investigator’s behalf, IRB and the regulatory authorities will not need my permission to look at my health records in respect of both the current study and any further research that may be conducted in relation to it, even if I withdraw from the study. I agree to this access. However, I understand that my identity will not be revealed in any information released to third parties or published.
4) I agree not to restrict the use of any data or results that arise from this study provided such a use is only for research purpose(s)
5) I agree to take part in the above study. I have read the above information and agreed to participate in this study.

Participant’s Subject Number	
Participant’s signature with Date	
Witness’s signature & Date	
Name of PI or Co PI	
PI or Co PI person’s signature Date	

PARTICIPANT INFORMATION SHEET

Project Title:

'Economic burden of breast cancer on households in Kerala'

Introduction:

You are invited to participate in a study. This document gives you a description of the study in which you are being asked to participate. Your participation in this study is voluntary. You can enquire about more details before giving your written consent to participate in the study

Purpose:

The purpose of this study is to analyze the economic burden of breast cancer. This study is for the completion of Ph.D. thesis requirement.

Information

You have been chosen for this study because you have completed the treatment for breast cancer. This study aims to analyze the total cost you have incurred during treatment, the financial aid you have received and the quality-of-life post treatment.

Benefits:

There may not be an obvious direct benefit to you. However this study will help us in analyzing the economic burden incurred by patients during cancer treatment, which will help policymakers to allocate economic resources efficiently. The results of this study if positive will be beneficial to patients in future.

Confidentiality:

The information in the study records will be kept confidential. Data will be stored securely and will be made available only to persons conducting the study and to the regulatory authorities. The data will not be made available to another individual unless you specifically give permission in writing. No reference will be made in oral or written reports which could link you to the study. Result of the study will not be communicated to the subject unless deemed necessary.

Compensation:

There will not be any compensation paid for the participation in the study.

Contact:

In case you have any queries or doubts or experience some adverse reactions or unusual symptoms, do not hesitate to contact the principal investigator

Esta Martin

Ph.D. Research Scholar

Department of Economics

St Josephs' College, Kozhikode

Phone number 8971733653

Email id- estamartintvm@gmail.com

Participation:

Your participation in this study is voluntary; you may decline to participate at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study prior to its completion, you will receive the usual standard of care for your disease, and your non participation will not have any adverse effects on your subsequent medical treatment or relationship with the treating physician. If you withdraw from the study before data collection is completed, your data will not be entered in the study report.