(स्थापना / Established in 1956)
बेहतर भविष्य के लिए क्षमता निर्माण
Capacity Building for a Better Future

Health Expenditure on Breast Cancer Treatment in Women: A Study from Public Sector Tertiary Cancer Centre

(EXPERT)

2019-2023

Report of

Health Expenditure on Breast Cancer Treatment in Women: A Study from Public Sector Tertiary Cancer Centre (EXPERT)

Mumbai, India
2023

International Institute for Population Sciences

Govandi Station Road, Deonar, Mumbai-400 088, India

Principal Investigators

IIPS
Prof. Sanjay K. Mohanty
Professor & Head
Department of Population and Development
IIPS, Mumbai

TMC
Prof. Tabassum Wadasadawala
Professor
Department of Radiation Oncology
ACTREC, TMC, Mumbai

List of Project Staff

Dr. Pijush Kanti Khan (Senior Research Officer)
Mr. Soumendu Sen (Senior Research Scholar)
Ms. Jishna E (Research Officer)

ACKNOWLEDGEMENTS

The study "**Health Expenditure on Breast Cancer Treatment in Women: A Study from Public Sector Tertiary Cancer Centre (EXPERT)**" was carried out at Tata Memorial Centre, Mumbai and the International Institute for Population Sciences (IIPS), Mumbai. The project was launched in June, 2019 and completed in March, 2023. Based on the project's findings, eight research papers/report and one research brief have been prepared.

We acknowledge the contributions of the members of the Board of Studies and the Academic Council in providing valuable comments at the beginning of the project. We are grateful to Prof. K.S. James, Director & Sr. Professor, IIPS for providing constant guidance and support at each stage of the project. We thank Sudeep Gupta, Director, Advanced Centre for Treatment, Research and Education in Cancer (ACTREC), Homi Bhabha National Institute for approving data collection from patients at TMC. We acknowledge the medical social workers in collecting reliable data professionally. We thank Mr. Suraj Maiti and Mr. Radheshyam Mishra for their research assistance during compiling the report.

Prof. Sanjay K. Mohanty
Professor & Head
Department of Population and Development
IIPS, Mumbai

Prof. Tabassum Wadasadawala
Professor
Department of Radiation Oncology
ACTREC, TMC, Mumbai

PUBLICATIONS

1. Mohanty S. K, Wadasadawala T., Sen S., Maiti S., Jishna E (2023). “Financial Catastrophe of Breast Cancer Treatment: Evidences from a Longitudinal Cohort study in India”, Working Paper No. 27, International Institute for Population Sciences, Mumbai.
2. Wadasadawala T, Sen S, Watekar R, Rane P, Sarin R, Gupta S, Parmar V, Kannan S, Mohanty SK (2021). Economic Distress of Breast Cancer Patients Seeking Treatment at a Tertiary Cancer Center in Mumbai during COVID-19 Pandemic: A Cohort Study. *Asian Pac J Cancer Prev*. 2021 Mar 1;22(3):793-800. doi: *10.31557/APJCP.2021.22.3.793*
3. Mohanty, S.K., Wadasadawala, T., Sen, S, Khan, P.K (2023),. Socio-economic variations of Breast Cancer treatment and discontinuation: a study from a public tertiary cancer hospital in Mumbai, India. *BMC Women's Health* **23**, 113 (2023). https://doi.org/10.1186/s12905-023-02275-6
4. Wadasadawala, T., Mohanty, S., Sen, S., Khan, P., Pimple, S., Mane, J. V., Sarin, R., Gupta, S., & Parmar, V. (2023). Health-Related Quality of Life (HRQoL) Using EQ-5D-5L: Value Set Derived for Indian Breast Cancer Cohort. *Asian Pacific Journal of Cancer Prevention*, *24*(4), 1199-1207. doi: 10.31557/APJCP.2023.24.4.1199
5. Wadasadawala, T., Mohanty, S., Sen, S., Kanala, T., Maiti, S., Puchali, N., Gupta, S., Sarin, R., & Parmar, V. (2023). Out of Pocket Expenditure and Financial Risk Protection for Breast Cancer Treatment: A Prospective Study from India., paper submitted for publication.
6. Mohanty, SK., Wadasadawala, T., Sen, S., Maiti, S., Jishna E (2023). Catastrophic Health Expenditure and distress financing of Breast Cancer in India: Evidence from a longitudinal cohort study, paper submitted for publication
7. Mohanty, S.K., Wadasadawala, T., Sen, S., Maiti, S., Jishna E (2023). Stage, duration, and cost of breast cancer treatment in India, Research Brief No. 23, International Institute for Population Sciences, Mumbai.
8. Mohanty, SK., Wadasadawala, T., Khan, PK., Sen, S., & Jishna E., (2023). Health Expenditure on Breast Cancer Treatment in Women: A Study from Public Sector Tertiary Cancer Centre (EXPERT)”, IIPS project report. IIPS: Mumbai
9. Wadasadawala,T., et al.,(2023).Prospective Study Of Incidence And Impact Of Comorbidities On Breast Cancer
10. Wadasadawala.T., et al.,(2023) Survival: Real-World Data from A Tertiary Cancer Center In India, submitted at JCO JGO

CHAPTERISATION

Chapter 1:	Introduction
Chapter 2:	Socio-economic variations of breast cancer treatment and discontinuation
Chapter 3:	Estimating the cost, out-of-pocket expenditure and reimbursement of breast cancer treatment
Chapter 4:	Catastrophic health expenditure and distress financing of breast cancer
Chapter 5:	Health and quality of life of breast cancer survivor
Chapter 6:	Summary and conclusion
Appendix 1:	Household schedule
Appendix 2:	Individual schedule
Appendix 3:	Follow-up schedule
Appendix 4:	Quality of life schedule
Appendix 5:	Non-cancerous schedule

CONTENTS

LIST OF TABLES

Chapter Five: State of health and quality of life of breast cancer survivors

LIST OF FIGURES

ABBREVIATIONS

CHE	Catastrophic Health expenditure
OOP	Out-of-pocket
IIPS	International Institute for Population Sciences
TMC	Tata Memorial Centre
OBC	Other Backward Class
DALYs	Disability Adjusted Life Years
LMICs	Lower-Middle - Income Countries
QoL	Quality of Life
WHO	World Health Organization
NFHS	National Family and Health Survey
CTRI	Clinical Trial Registry of India
ACTREC	Advanced Centre for Treatment, Research and Education in Cancer
e-CRF	electronic Case Report Form
MSW	Master of Social Work
SES	Socio-economic Status
MPCE	Monthly per capita Consumption expenditure
SC	Scheduled Caste
ST	Scheduled Tribe

ABSTRACT

In India, breast cancer accounts for one-seventh of the two million cancer cases. Breast cancer treatment exerts high economic, social, and health burden on patients and households. Studies on patient characteristics and household economic condition of breast cancer is very limited in India. The aim of this study was to examine the social, demographic, economic and health conditions of breast cancer patients during and after treatment. We specifically estimated the cost of treatment, out-of-pocket (OOP) payment, reimbursement, and catastrophic health expenditure (CHE). This is the first ever study that comprehensively collected data on expenditure of breast cancer patients in each time of visit over the stipulated span of treatment (longitudinally). Data was collected from a prospective cohort study of 500 breast cancer patients who sought treatment from June 2019 to March 2022 from Tata Memorial Centre (TMC) in Mumbai.

Our findings suggest that 14% patients discontinued treatment (5.2% due to death, 4.8% due to financial reason and 4.2% due to other reasons) and only 41% had follow up visit after six months of completion of treatment. The median age of diagnosis of breast cancer was 47 years and two-third of the patients were diagnosed at an advanced stage. At the time of registration for treatment, 25% of breast cancer patients had any co-morbidity (mostly diabetes and hypertension) and at the time of completion of treatment it increased to 32% following treatment.

The mean cost and OOP payment of breast cancer treatment was estimated at ₹258,095 and ₹186,461, respectively. The OOP payments accounts 72.2% of cost of treatment and less than 10% of the patients had insurance coverage at the start of treatment. Though, three-fourth of patients had any form of reimbursement, the mean reimbursement was ₹78,016 covering only 30.2% of the total cost of treatment. About 85% of the patients incurred CHE and 72% had distress financing (borrowing/selling assets). The significant predictors of distress financing are CHE, duration of treatment, level of education, main source of income, health insurance and state of residence.

Breast cancer in India is primarily affecting women in the prime working and reproductive age group and the economic burden of breast cancer treatment is high. We found early age at onset, late diagnosis, and high indebtedness in treating breast cancer. It is recommended to increase awareness, early diagnosis, multi-disciplinary treatment and increase coverage of health insurance for breast cancer patients.

Key Words: Breast cancer, OOP, catastrophic health expenditure, health insurance, India

KEY FINDINGS

1. The study used a longitudinal design and data was collected over a period of 34 months; from June, 2019 to March, 2022. Data using structured schedule was collected at baseline, endline and follow up visit and expenditure on cancer treatment was collected at each visit of treatment to TMC. From a cohort of 500 breast cancer patients registered for treatment at Tata memorial Center (TMC), 86% (429) patients successfully completed treatment, 5.2% discontinued their treatment due to death and 4.8% due to financial hardships. Among those completed treatment, only 48% (206) of them received follow up treatment at TMC after 6 months.
2. More than half of the patients were from outside of Maharashtra and on an average they travelled 1813 km from their native place to get treatment from TMC, Mumbai.
3. The median age of breast cancer patients at diagnosis was 47 years and over two-third of the breast cancer patients were diagnosed at an advanced stage of cancer (Stage III/IV).
4. The mean duration of the treatment for breast cancer patients was 276 days and on average a breast cancer patient made 49 visits to TMC, Mumbai to complete their treatment.
5. Late diagnosis and longer duration of treatment was higher among less educated and poorer women
6. Average monthly household income of breast cancer patients was ₹ 17,802 before diagnosis of cancer treatment which decreased to ₹ 15,376 soon after cancer diagnosis. Decrease in household income was higher among poor and laborer households.
7. Less than 10% of the breast cancer patients had any insurance coverage in the baseline.
8. About 85% of the patients incurred CHE and 72% of the patients had distress financing during cancer treatment. Both CHE and distress financing were higher among rural patients, poor households, patients who came from outside of Maharashtra and households who primarily depend on agriculture for their livelihood.
9. Though three-fourth of breast cancer patients had some form of reimbursement, only 30% of the total cost of treatment was reimbursed and reimbursement reduced the incidence of CHE by only 14%.
10. Patients with breast cancer seek financial help from multiple sources. Almost four-fifths of the patients had used more than one sources to finance their cancer treatment
11. At the time of registration for treatment, one-fourth of the breast cancer patients had any co-morbidity and at the time of completion of treatment it has increased to 32%
12. The average cost of treatment of breast cancer treatment was ₹ 258,095 ; ₹ 219,621 for general or non-changeable patients and ₹ 416,198 for private patients
13. About 73.2% patients had any form of reimbursement for cancer treatment. The mean out-of-pocket expenditure on breast cancer treatment was ₹ 149,315 for general or non-chargeable patients and ₹ 414,910 for private patients
14. At the time of beginning cancer treatment, 38% had loans for treatment and it has increased to 65% during completion of treatment at TMC

INTRODUCTION

Introduction

Chapter 1

1.1. Introduction

Cancer is the second leading cause of death worldwide. It accounts for 9.6 million deaths annually and an estimated 233.5 million disability adjusted life years (DALYs) in 2018 (Bray et al., 2018; Fitzmaurice et al., 2019). Globally, breast cancer is now the leading cause of cancer accounting for 11.7% of 2.3 million new cancer cases. In 2020, breast cancer accounts 7% (0.6 million) of 9.9 million all cancer deaths annually (Sung et al.,2020). In recent decades, while there has been a decline in stomach, cervical and penile cancer but the incidence of breast cancer along with colorectal and prostate has been on rise (Smith et al.,2019). Estimates suggest that there would be 3 million of new breast cancer cases diagnosed every year by 2040 (Arnold et al.,2022). In last three decades, the incidence of breast cancer has increased by 30% in both developed and developing countries (Herback &Grant, 2017).

The prevalence, incidence and mortality from breast cancer varies enormously within and between countries (Sung et al., 2021). These variations and increase in breast cancer may be attributed to a set of metabolic (weight, height, BMI), reproductive (early age at menarche, late menopause, childlessness, late childbearing, less breastfeeding), lifestyle factors (diet, lack of physical activity, substance abuse etc.),environmental and occupational factors (exposure to radiation, shift work involving disruption of circadian cycle etc) (IARC 2002; IARC 2003; IARC 2010; Weiderpass et al., 2011; Sasco et al., 2003; Sponholtz et al., 2017). Besides, advancement of medical technology, availability and accessibility to cancer screening and treatment have increased the diagnosis of this disease and its burden in low- and middle-income countries (LMICs) (Pearlman et al., 2016). In LMICs lack of

awareness, social stigma, familial negligence, inefficiency in the referral pathways, lack of essential health infrastructure in regional centers, incomplete treatments and inadequate follow-up are the major contributing factors to for , late diagnosis, and high mortality due to cancer (Jemal et al.,2011; Pati et al., 2013; Jones et al., 2014; Dey et al., 2014).

1.2. Economic Burden of Breast Cancer

Economic burden of breast cancer is immense both at the micro and macro level. At micro level, cancer treatment is the most expensive and of longer duration. It reduces the income of the households and increases the work absenteeism of the treatment seeker as well as the caregiver in the long run. In 2018, the mean OOP payment of any cancer treatment on hospitalization in India was estimated at 85,595 (₹38,859) at public and (₹115,771) at private hospitals (Goyanka et al., 2021). On the other hand, the direct treatment cost of breast cancer patients contributed 79% of the total cost-of-illness and more than 60% of the direct cost is contributed by medicine and hospitalization charges (Jain & Mukherjee, 2016). Rising cancer treatment costs along with the lower penetration of insurance coverage leave no choice to cancer affected households but to incure OOP payment. The financial toxicity of households with cancer patients is huge as more than 75% of the households meet cancer expenditure through OOP payment, almost 80% incurred catastrophic health spending and half of them arrange money by selling assets or by borrowing to finance their treatment (Pramesh et al., 2019; Rajpal et al., 2018; Kastor & Mohanty, 2018). The high OOP for treatment with poor financing mechanism leads cancer households to financial catastrophe. Almost 40% of the total cancer treatment cost in India is financed through selling assets, jewellery or borrowing from friends and relatives (Rajpal et al., 2018). A study in Punjab state showed that 84% of the households with breast cancer patients experienced catastrophic CHE and 51% of them faced distress financing (Jain & Mukherjee 2016). The treatment cost for cancer is rising at an unparalleled rate due to the improved accessibility and affordability of prescribed medicine, new-technology based diagnosis, and need of multimodality treatment strategies (Natarajan et al., 2020). At the macro level, the cancer treatment demands higher allocation of resources and specialised personnel.

1.3. Health among Breast Cancer Survivors

The burden of breast cancer on social and mental health is paramount. An observational study with 378 breast cancer patients showed that half of the patients expressed their concerns related to their ability to fulfil their role as a mother, spouse, or daughter (Alexandar et al., 2019). The study also revealed that patients had a higher concern about the schooling of their children, providing care of dependent parents, the health of their spouses and employments. Depression among breast cancer patients is prevalent and majority of the patients are diagnosed with mild depression (Thakur et al., 2019). Cancer patients have compromised quality of life (QoL). A study among breast cancer patients in rural India showed that the patients had moderate QoL. The QoL is negatively associated with young age, lack of education, being without a partner but positively associated with employment, higher income and self-efficacy (Gangane et al., 2017).

1.4. Indian Scenario

India accounts for 6.4% of global cancer patients and among them 14% are breast cancer patients (Bray et al., 2018 & WHO 2020). Women in India are disadvantageous not only due to high concentration of disease but also due to familial neglect for health care. According to the Global Cancer Statistics report 2018, the age-standardized incidence rate of cancer among Indian females is 90 per 100,000 person-year similar to male (89.8 per 100,000 person-year). Breast cancer is the most common type of cancer in India with 28% incidence only among women (Bray et al., 2018). The burden of cancer among women is growing in India and is likely to increase in the future (Dhillon et al., 2018). Studies suggest that over one million malignant diseases are diagnosed in India annually (Ferlay et al., 2015).

1.5. Need for the study

Though breast cancer is a growing disease of concern in India, there is a lack of comprehensive data on the socio-economic and health condition of breast cancer patients over course of treatment. In this context, this is the first-ever study that examines the economic and health burden of breast cancer patients who were seeking treatment at the county's largest tertiary public cancer hospital. In the health domain,

this study examines the self-reported health condition and co-morbidity status of the patients at various time points during the treatment phase.

This research has been conceptualised with following rationale. Frist the economic burden of cancer treatment is tremendous, as patients often borrow or sell asset to meet the high treatment cost. Studies on economic impact of breast cancer is very limited in India. The National Sample Survey through its health surveys collected data on type of ailment, hospitalisation, expenditure on treatment and related characteristics. However, it considers any cancer and does not segregate by type of cancer. We came across only two small scale unrepresentative in last decade; one in Punjab in 2012-13 in Punjab and other in Andhra Pradesh in 2016-17 on breast cancer treatment (Shankar et al.,2018; Jain & Mukherjee, 2016). These cross-sectional data are likely to suffer from recall lapse and may not adequately collect expenditure on treatment. Second, the health insurance coverage in the country has increased from 4% in 2005-06 to 41% by 2019-21 (IIPS & ICF, 2021). But it is not known to what extent health insurance/reimbursement reduced the CHE in the country. Third, though utility values for breast cancer have been published earlier from other countries, it is unlikely that these values will be useful for Indian patients because of the differences in the sociodemographic profile, per capita income, insurance coverage and country requirements. As no utility values have been reported till date for breast cancer cohort in India, the current study aims to report the comprehensive cost of breast cancer treatment as well as the utility values using various health value assessment tools from the actual health related quality of Life (HRQoL) data collected from the study sample.

1.6. Objectives

Primary Objectives

- Establish standards for average health expenditure and financial catastrophe for breast cancer treatment at a public sector tertiary cancer center in India.

- Establish standards for health utility values for women with breast cancer received treatment at a public sector tertiary cancer center in India.

Specific Objectives

- To estimate the out-of- pocket expenditure incurred by the household for treatment of breast cancer using longitudinal survey data
- To estimate the incidence of CHS and distress financing of breast cancer patients.
- To estimate the incidence of catastrophic health spending before and after reimbursement
- To map the EORTC, QLQ30, BR23 and EQ-5D-5L for the calculation of utility value using appropriate algorithms

1.7. Study Design

The study entitled "Health Expenditure on Breast Cancer treatment in Women: A study from Public Sector Tertiary Cancer Centre" (EXPERT) is a collaborative study conducted by the and the Tata Memorial Center (TMC) Mumbai and the International Institute for Population Sciences (IIPS), Mumbai. TMC is a dedicated tertiary public cancer treatment and research institute located in Mumbai dedicated for cancer. This centre is the national comprehensive cancer centre for the prevention, treatment, education, and research in cancer and is recognized as one of the leading cancer centres in South East Asia. IIPS is a demographic and public health research institute under the direct administrative control of Ministry of Health and Family Welfare, Government of India. IIPS is engaged in high quality teaching and research on population and health. In last three decades, IIPS has conducted many large-scale population-based surveys such as various rounds of NFHSs, LASI, SAGE etc. The current study has received approval from the institutional ethics committee of TMC and is registered on the Clinical Trial Registry of India (CTRI/2019/07/020142). In this project, a team of oncologists, health economists, demographers and medical social workers meticulously designed and executed the study.

1.8. Study Participants

TMC treats cancer patients from all over the country and is a tertiary cancer referral centre in the country. The total number of patients registered for breast cancer treatment at TMC was 4,518 in 2019, 2,505 in 2020 and 3,588 in 2021. We have selected a total of 500 patients that account for about 8% of the breast cancer patients registered for treatment at TMC between June 2019 and March 2022. Our selection of 500 cases is guided by the fact that it provides enough power for disaggregated analyses of the economic condition of breast cancer patients and captures those treated under private and general category. According to WHO protocol, 200 samples is the minimum requirement for any health study (Lwanga et al.,1991). Assuming 79% of catastrophic health spending by cancer households in India (Kastor & Mohanty,2018) and 95% confidence interval with 5% margin of error, a 255 sample size would require to estimate treatment-related cost. A similar procedure has been adopted in a Lancet study on catastrophic expenditure and treatment attrition among colorectal cancer patients in India (Bose et al.,2022). Our sample size is about twice higher than the required sample. On average, 12 to 15 newly invasive breast cancer patients were registered every day in the hospital and 4 to 5 patients were selected. The data was collected on working days only (excluding public holidays and weekends). There was disruption in data collection during March 2020-March 2021 due to COVID-19 restriction.

The selected patients were chosen and the consent form was canvassed before enrolling for study. Those who consented for study were taken in the study. The inclusion and exclusion criteria for surveying cancerous patients are as follows;

i. Pathologically confirmed new invasive breast cancer cases
ii. Intending to receive entire treatment at TMC
iii. Planned for multi-modality treatment comprising of surgery, chemotherapy, and radiotherapy with or without hormone therapy or targeted therapy
iv. Age > 18 years
v. Patient willing to provide all estimates of expenditure before and after coming to the tertiary hospital.
vi. Patient willing to share relevant socio-demographic information.
vii. Willing to fill or respond to QOL instruments.

The exclusion criteria were

i. Unable or unwilling to give written informed consent
ii. Inability to follow up after treatment completion.
iii. Recurrent or progressive disease.

Participants who did not fulfil the above criteria were excluded from the study. After carefully considering the inclusion criteria each participant was assigned a unique identification number (record id) for further reference. Written informed consent was taken from the participants and their accompanying person before conducting the interviews.

1.9. Study questionnaire

A total of five schedules were canvassed (**Table 1.1**). Apart from these five schedules, a short questionnaire on non-cancerous women was also developed. In the baseline survey, a household and an individual questionnaire were used for data collection. The household questionnaire covered demographic and socio-economic characteristics of the participant's household, including income, consumption pattern, health expenditure in last one year, health-seeking behaviour, debts and loans taken by the households. The individual questionnaire has captured the information on socio-demographic characteristics of patients, treatment history at TMC, detailed information on direct and indirect health expenditure of each visit to the TMC, health status of the patient, quality of life. The cost data were collected on each visit which was over 49 times on an average in the span of entire treatment. As comprehensive record of the direct and indirect medical cost was collected from the patients during each visit to the hospital for treatment. After completion of treatment, limited information was collected using a structured schedule and termed as endline or conclusion survey. As Cancer patients following completion of treatment visit the TMC for follow up after six months from date of completion of breast cancer treatment. The schedules on quality of life (QoL) were introduced in each stage of data collection process.

As Covid-19 pandemic and nationwide lockdown coincided with our study period, we have used a separate schedule on economic burden of breast cancer patients treated at the hospital during Covid-19 lockdown. For the cancer treatment

during Covid-19 scheduled, a structured questionnaire was prepared and telephonic interviews were conducted. The questionnaire covered household, demographic and socio-economic characteristics including income and detailed record of the direct and indirect health expenditure of each visit to the hospital as well as inpatient care. This is based on 138 non-metastatic breast cancer patients who were accrued in this study at TMC before lockdown and continued their treatment during lockdown. In addition, a schedule for non-cancerous patients were developed and canvassed to 200 non-cancerous individuals visited TMC for cancer screening. All these scheduled are given in Appendix **(Appendix 1-5)**.

Table 1.1 Data collection schedule at baseline, endline and follow up

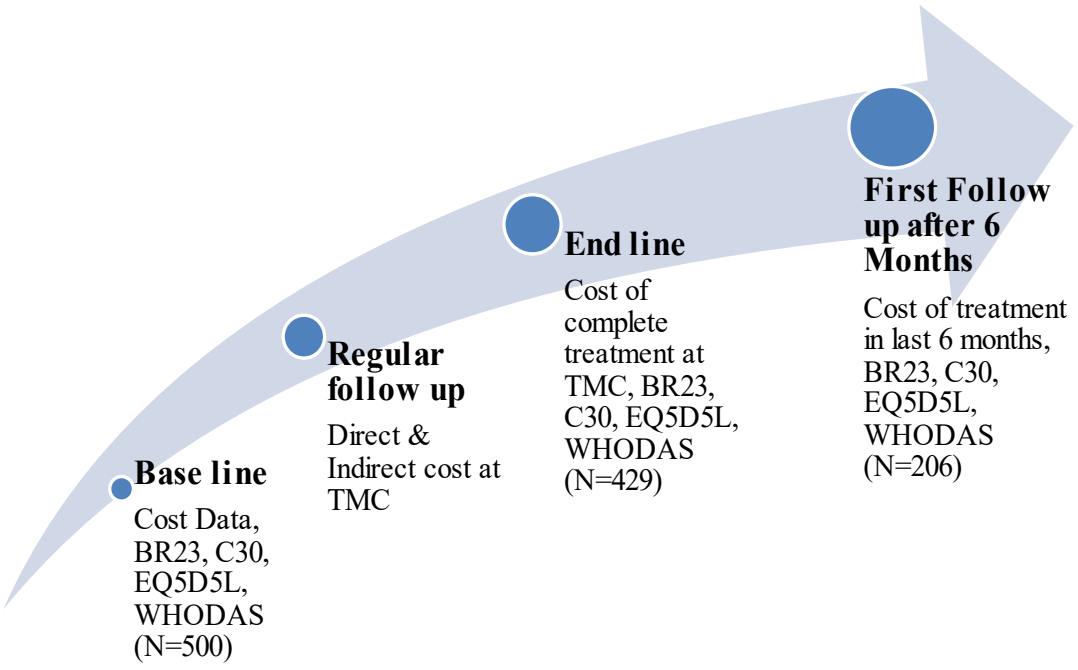
Baseline	Endline	Follow up
Household Schedule	**Endline extended schedule**	**Follow-up extended schedule**
Socio- demographic profile of the household	Health and Comorbidity	Health and Comorbidity
Consumption expenditure of the household	Insurance and Reimbursement	Insurance and Reimbursement
Income details of the household and patients	Health financing	Health financing
Health seeking behaviour of the household	Loans and debts	Loans and debts
Individual Schedule	**Quality of life schedule**	Income work and employment
Demographic	C30	**Quality of life schedule**
Medical history of the patients	BR23	C30
Treatment history at TMC	WHODAS	BR23
Socio- economic and work	EQ-5D-5L	WHODAS
Salary and wage		EQ-5D-5L
Health and comorbidities		
Insurance		
Cost of hospitalization		
Quality of life schedule		
C30		
BR23		
WHODAS		
EQ-5D-5L		

The questionnaire was first drafted in English and then translated into local languages like Hindi and Marathi for a better understanding by the participants during the time of interview. The questionnaires were validated by a panel of experts comprising of oncologists, health economists, demographers and university professors with expertise in the relevant fields. The medical terminologies were explained to the participants during the time of interviews and no difficulties were reported.

1.10. Data collection

Data were collected from the patients registered at Tata Memorial Centre (TMC) after pre-treatment evaluation with a treatment plan in the multi-disciplinary joint clinic. Patients treated with curative intent undergo multi-modality therapy comprising of surgery, chemotherapy, and radiotherapy while patients treated with palliative intent primarily receive systemic therapy with or without surgery and radiotherapy. All consecutive patients who had their final treatment plan for implementation have been screened over a period of 6 months and accrued after informed consent. The objectives and methods of data collection were explained before taking informed consent from each participant and their accompanying person. The data collection process has been executed by three trained medical social workers at various time points during the entire treatment period and till the first follow up. A face-to-face interview was conducted for data collection using the pre-tested questionnaires. **Figure 1** presents the schematic diagram of data collection point.

Figure 1. Stages of data collection at TMC, 2019-22



Patients were categorised into non-chargeable, general, and private as per their ability to pay for the treatment, by TMC at the time of registration. Private patients pay the treatment cost as per the market rate whereas, general patients were charged a

subsidized rate and non-chargeable patients were charged the lowest rate for treatment. Various Measures like regular monitoring of data collection, re-validation was done to ensure data quality. Inconsistency and irrelevance of data were identified and corrected at regular intervals.

1.10.1. Development of e-CRF in redcap

Data was collected electronically in order to avoid paper wastage and make data collection user friendly. It took 4-6 weeks to fully develop the e-CRF (though the work was initiated even before the study started). Multiple trouble shooting issues were forwarded by the statistician to the concerned international agency to resolve our issues which basically pertained to creation of long tables in redcap. The MSW on the project was actively involved in this stage also and received thorough training on data entry on redcap.

1.11. Challenges

There were certain challenges that were faced during the data collection phase. They have been summarized below:

1.11.1. Challenges during data collection:

- Due to the multimodal nature of the cancer treatment, patients and their accompanying person had to visit different departments within the facility. Therefore, it was difficult for MSWs to locate the participants. In-turn this posed several challenges towards data collection. Sometimes it took six or more hours to gather information from one participant.

- It was difficult for the MSWs to take consent from the private patients as they were reluctant to share their information.

- Due to the temporary suspension of interviews and repeated follow-ups during COVID times, many interviews took longer time than expected.

1.11.2. Challenges during the COVID-19 pandemic:

- The project suffered and was delayed due to COVID-19 pandemic. Fewer patients visited during lockdown due to travel restriction that increased time span for the data collection. Many patients had stopped treatment due to financial

crisis during lockdown period and treatment got delayed.

- Many patients had missed follow-up after completing the treatment due to travel restrictions.
- Project staff and PIs were suffered from COVID-19, thus halted the progress of the project.

1.11.3. COVID Protocol:

1.11.4. Challenges during 1st follow-up:

The major problem faced by MSWs during follow up period was to contact the eligible patients. As the first follow-up is typically scheduled after six months of treatment completion, patients usually return to their native places and remained out of contact with TMC for at least six months. In many cases, MSWs could not contact the patients over phone with their registered phone number what they have provided at the time of registration (which was at least one and half year ago).

1.12. Chapterisation

The report consists of 6 chapters. Chapter 1 is an introductory chapter. Chapter 2, describes the socio-demographic profile of patients and economic conditions of breast cancer households. It also examines the treatment discontinuation across patient and household characteristics. In chapter 3, we provided the estimates of the cost of treatment and OOP payment of the breast cancer patients. Chapter 4, provides the CHE burden and distress financing among the breast cancer patients. Chapter 5 describes the state of health and quality of life of the breast cancer survivors. Finally, chapter 6 provides the summary, conclusion and policy implications of the study

.

Socio-economic variation of breast cancer treatment and discontinuation

Chapter 2

2.1. Introduction

Women in India are at a disadvantage, not only due to the high morbidity but also due to familial neglect of health care (Saha &Saha, 2010). The disease burden due to breast cancer in India is higher than the world average. In the year of 2020 almost 13% of global mortality due to breast cancer only. Among women in India, breast cancer accounts for 13.5% new cases and 10.6% of cancer related mortality. Treatment discontinuation is one of the major factors that affect the span of treatment and disease progression. The discontinuation of breast cancer treatment is important as cancer patients often come from outside the states to get treatment, it primarily affects women in working and reproduction age group, the mortality level is high and there has been rise in risk factors of breast cancer. The economic and social loss due to the disease is numerous to women, mother, children and family and also to the nation. To our knowledge, no scientific study on treatment discontinuation of breast cancer patients examined in the Indian context. In this context, this chapter examines the socioeconomic variation in the treatment discontinuation of breast cancer patients.

A recent study suggests that the screening of breast cancer is abysmally low (Sen et al., 2022). Studies on breast cancer in India is very limited. Based on the rationale discussed in chapter 1, this chapter provides the socio-demographic profile of breast cancer patients in India.

2.2. Socio-demographic profile of the breast cancer patients at TMC

Table 2.1 presents the socio- demographic profile of 500 breast cancer patients selected for study and registered for treatment at TMC Mumbai. The sample characteristics of breast cancer patients were collected at various stages baseline, endline and follow-up. The demographic and social characteristics did not change

Table 2.1: Socio- demographic profile of the breast cancer patients and economic profile of households at baseline, end line and follow-up

Patient's characteristics	Baseline		Endline		Follow up	
	%	N	%	N	%	N
Age						
< 30	5.6	28	5.6	24	4.4	9
31- 40	24.8	124	25.9	111	28.6	59
41- 50	32.6	163	33.8	145	34	70
51- 60	26.8	134	25.2	108	24.8	51
> 60	10.2	51	9.6	41	8.3	17
Years of schooling						
Never attended	26.6	133	23.1	99	21.8	45
Up to secondary	45.8	229	47.3	203	47.6	98
Higher secondary and above	27.6	138	29.6	127	30.6	63
Marital status						
Currently married	84.4	422	85.3	366	88.4	182
Other	15.6	78	14.7	63	11.7	24
Health insurance						
Yes	9	45	8.9	38	12.6	26
No	91	455	91.1	391	87.4	180
Health characteristics						
Patient category						
Non-chargeable	1.2	6	5.4	23	9.2	19
General	85.8	429	80.7	346	77.2	159
Private	13	65	13.9	60	13.6	28
Co-morbidity						
No co-morbidity	75.6	378	69	296	74.3	153
One or more co-morbidity	24.4	122	31	133	25.7	53
Household characteristics						
Residence during treatment						
Hotel or rental room	37	185	38.2	164	34.5	71
Own house	28.6	143	28.2	121	27.2	56
Relatives and friends house	23	115	22.6	97	26.7	55
Ashram and others	11.4	57	11	47	11.7	24
Religion						
Hindu	78.8	394	77.4	332	80.1	165
Muslim	17.2	86	18.7	80	14.6	30
Other	4	20	4	17	5.3	11
Social group						
General	51.8	259	52.7	226	43.2	89
OBC	33.8	169	33.8	145	40.8	84
SC/ ST / Others	14.4	72	13.5	58	16	33
Residence						
Urban	46.4	232	45.7	196	49	101
Rural	53.6	268	54.3	233	51	105
State						
Maharashtra	45.4	227	55.2	237	46.6	96
Outside of Maharashtra	54.6	273	44.8	192	53.4	110
Distance from native place						
< 500 kms	43.4	217	43.1	185	44.2	91
501 - 2000 kms	37.2	186	36.4	156	39.8	82
> 2000 kms	19.4	97	20.5	88	16	33
Major source of income						
Agriculture	12.8	64	12.6	54	12.6	26
Labour	25.8	129	24	103	30.1	62
Self-employed	15.8	79	15.4	66	13.1	27
Service	45.6	228	48	206	44.2	91
Income tertile						
Poor	35.6	178	33.3	143	35.4	73
Middle	31.8	159	32.6	140	33.5	69
Rich	32.6	163	34	146	31.1	64
Total	**100**	**500**	**100**	**429**	**100**	**206**

during baseline and endline. At the time of baseline, 5.6% patients were under 30 years, 57.4% were between 31-50 years, and 37% were 50 years and older.

The distribution remains similar at the endline. Almost half of the patients in the baseline/endline had only secondary schooling (46%), and the mean years of schooling were 7 years. More than four-fifths of the patients were married at the time of baseline and endline. Only 9% of the patients were covered by any health insurance scheme in the baseline and endline each and it was 13% at follow-up. During baseline, about 86% of the patients were registered under the general category to get treatment at TMC and it was 81% at the time of endline. The share on non-chargeable patients has increased from 1.2% at baseline to 5.4% at the time of endline. The majority of the patients belonged to the Hindu religion (78%). More than half of the patients were from outside of the state of Maharashtra. On average, a patient travelled 1,052 kilometers to get breast cancer treatment at TMC. More than half of the patients resided in rural areas.

2.3. Stage at diagnosis of breast cancer and median age

Majority of breast cancer patients were diagnosed at an advanced stage; 1% at stage I, 33% at stage II, 60% at stage III and 6% at stage IV. We found variations in stage of diagnosis and age of diagnosis of breast cancer (**Table 2.2**). The stage of late diagnosis declines with educational attainment. Among those never attended school, about 78% breast cancer patients were diagnosed at stage III/IV compared to 60% among those completed higher secondary and above. Late diagnosis was higher among Muslims, SC/ST and rural residents. The mean/median age at diagnosis of breast cancer also varies across these characteristics. Among those never attended school, the median age at diagnosis was 52 years, 46 years for those attended secondary schooling and 42 years for those attended higher secondary and above. Median age at diagnosis was relatively higher among those from richer households.

Table 2.2: Mean/median of age at diagnosis and stage of diagnosis of breast cancer by socio-economic characteristics

Patients' characteristics	Age		Stage III/IV	Sample Size
	Mean	Median	%	N
Years of schooling				
Never attended	52	51	78.2	133
Up to secondary	46	46	63.32	229
Higher secondary and above	42	42	60.14	138
Marital status				
Currently married	55	53	64.1	78
Other	45	45	66.82	422
Health insurance				
Yes	50	50	62.22	45
No	47	46	66.81	455
Health characteristics				
Patient category				
General	47	46	66.97	433
Private	47	46	62.69	67
Co-morbidity				
No co-morbidity	45	44	65.08	378
One or more co-morbidity	54	52	70.49	122
Household characteristics				
Residence during treatment				
Rented	46	45	68.65	185
Charitable	47	48	84.21	38
Non-charitable	48	48	62.45	277
Religion				
Hindu	47	47	65.23	394
Muslim	45	43	72.09	86
Other	52	51	65	20
Social group				
General	47	46	76.11	226
OBC	47	46	77.93	145
SC/ ST / Others	46	45	81.03	58
Residence				
Urban	49	49	64.66	232
Rural	45	45	67.91	268
State				
Maharashtra	45	44	80.17	237
Outside of Maharashtra	50	50	73.96	192
Distance from native place				
< 500 kms	50	50	70.27	185
501 -1500 kms	46	44	88.33	60
>1500 kms	45	45	24.46	184
Major source of income				
Agriculture	43	42	67.19	64
Labour	45	45	73.64	129
Self-employed	48	46	64.56	79
Service	49	49	62.72	228
Income tertile				
Poor	45	44	69.1	178
Middle	47	48	69.18	159
Rich	49	49	60.74	163
Total	**47**	**46**	**66.4**	**500**

2.4. Duration of treatment of breast cancer patients

Table 2.3 presents the average number of visit and mean duration of treatment of breast cancer patients in TMC. On an average, a patient made 49 visits to TMC and received treatment for an average of 276 days. Both number of visits and duration of treatment varied by patient characteristics. The duration of treatment was higher among patients with no education, low income, and those from rural areas. Similarly, those who had health insurance had longer duration of treatment (287 days) compared to uninsured patients (275 days). The mean duration of treatment was higher among non-chargeable patients (321 days) and the patients who were staying in relative or friend's house (303 days) at the time of taking treatment. Patients who came from outside of Maharashtra had longer duration of treatment (288 days) compared to (262days) from those from the state of Maharashtra. Similarly, the mean number of hospital visits was higher among patients who had advanced stage of treatment (52 times).

2.5. Discontinuation of treatment by socio-demographic variations

The socio-demographic variation of the patients who discontinued treatment at TMC describes in table 2.4. Discontinuation of treatment was higher among those never attended school (25.6%), not currently married (19.2%), treated under general or non-chargeable category (14.9%), diagnosed at stage IV (46.4%), had at least one comorbidity (19.7%), had labour as major source of household income (20.2%) and belonged to poor income tercile (18.6%). Discontinuation due to financial reason were higher by the households with self-employment (9%), followed by labour income (5%). Relatively higher discontinuation due to death was reported by households with agricultural income (8%) followed by labour income (7%).

Table 2.3: Average number of visits and duration of treatment of breast cancer at TMC, Mumbai

Patients' characteristics	Average number of visits		Mean duration of treatment (Days)	
	Mean	SD	Mean	SD
Age				
<= 40	51	15	281	84
41-59	50	15	277	82
> 60	42	20	257	92
Years of schooling				
Never attended	52	17	293	91
Up to secondary	49	15	274	87
Higher secondary and above	50	16	269	71

Marital status				
Currently married	50	16	278	84
Other	48	16	269	82
Health insurance				
Yes	50	16	287	112
No	45	13	275	80
Health characteristics				
Treatment taken outside before coming to TMC				
Yes	52	16	269	64
No	49	16	278	86
Patient category				
Non-chargeable	57	15	321	99
General	49	16	274	83
Private	47	14	275	83
Co-morbidity				
No co-morbidity	50	16	277	85
One or more co-morbidity	48	16	274	81
Stage of cancer diagnosis				
I-II	45	15	258	86
III	52	16	287	76
IV	49	13	289	154
Household characteristics				
Residence during treatment				
Hotel or rental room	51	15	281	72
Own house	46	16	253	75
Relatives and friends house	50	16	303	100
Ashram and others	54	18	273	92
Religion				
Hindu	49	17	275	84
Muslim	50	12	292	86
Other	46	11	232	69
Social group				
General	49	16	268	63
OBC	52	17	290	95
SC/ ST / Others	47	15	280	118
Residence				
Urban	49	16	268	71
Rural	50	16	284	93
State				
Maharashtra	47	16	262	79
Outside of Maharashtra	51	15	288	85
Distance from native place				
< 500 kms	47	16	262	79
501 -1500 kms	50	16	311	112
>1500 kms	51	15	280	74
Major Source of income				
Agriculture	51	18	276	82
Labour	51	15	284	89
Self-employed	48	15	290	95
Service	49	16	268	78
Income Tertile				
Poor	50	17	285	92
Middle	50	14	272	85
Rich	49	16	273	74
Total	**49**	**16**	**276**	**84**

Table 2.4: Socio-demographic variations in discontinuation of breast cancer treatment by reasons

Patients' characteristics	% discontinued	N	p-value (log-rank test)	Reason for discontinuation		
				Financial reason (%)	Death (%)	Others (%)
Age						
< 45	12.2	230	0.091	4.3	4.8	3
> 46	15.9	270		5.2	5.6	5.2
Years of schooling						
Never attended	25.6	133	0.007	9.8	8.3	7.5
Up to secondary	11.4	229		4.4	4.8	2.2
Higher secondary and above	8.0	138		0.7	2.9	4.3
Marital status						
Currently married	13.3	422	0.352	4.5	4.7	4
Other	19.2	78		6.4	7.7	5.1
Health characteristics						
Patient category						
General/Non	14.9	435	0.482	5.3	5.7	3.9
Private	9.2	65		1.5	1.5	6.2
Co-morbidity						
No co-morbidity	12.4	378	0.047	4	4.8	3.7
One and more co-morbidity	19.7	122		7.4	6.6	5.7
Stage of cancer diagnosis						
I-II	7.7	168	0.009	3.6	1.8	2.4
III	14.8	304		5.3	5.3	4.3
IV	46.4	28		7.1	25	14.3
Household characteristics						
Religion						
Hindu	15.7	394	0.13	5.3	5.8	4.6
Muslim/ Others	8.5	106		2.8	2.8	2.8
Social group						
General	12.7	259	0.627	3.9	4.6	4.2
OBC	14.2	169		5.9	4.7	3.6
SC/ST/Other	19.4	72		5.6	8.3	5.6
Residence						
Urban	15.5	232	0.034	5.6	3	6.9
Rural	13.1	268		4.1	7.1	1.9
State						
Maharashtra	13.2	227	0.009	4	6.6	2.6
Outside of Maharashtra	15.4	273		5.7	3.5	6.2
Distance from native place						
< 500 kms	14	215	0.114	6	1.9	6
> 501 kms	14.4	285		3.9	7.7	2.8
Major source of income						
Agriculture	15.6	64	0.255	4.7	7.8	3.1
Labour	20.2	129		5.4	7	7.8
Self-employed	16.5	79		8.9	6.3	1.3
Service	9.6	228		3.1	3.1	3.5
Income tertile						
Poor	18.6	178	0.457	4.2	10.2	4.2
Middle	12.8	159		5.6	2.2	5
Rich	11	163		4.5	3.2	3.2
Total	**14.2**	**500**		**4.8**	**5.2**	**4.2**

2.6. Hazard ratio of continuation of treatment at TMC

Table 2.6 presents the hazard rates of discontinued patients by socio-economic variables. The estimated hazard shows that compared to the patients aged 45 years and below, patients aged 46 years and above were more likely (HR: 1.14, 95% CI: 0.66-1.97) to discontinue treatment. Similarly, patients who are not currently married, had advanced stage of cancer, had at least one comorbidity, belonged to household size 7 and more and from Maharashtra were more likely to discontinue treatment at TMC. On the other hand, patients with education level up to secondary (HR: 0.48; 95% CI: 0.27-0.84) and higher secondary or above (HR: 0.42; 95% CI: 0.19-0.92) were significantly less likely to discontinue the treatment.

2.7. Consumption pattern of breast cancer patients during treatment

The rising cost of cancer diagnosis and treatment has imposed a hug financial burden on the affected household. Table 2.6 presents the monthly per capita consumption expenditure (MPCE) of breast cancer households before and after breast cancer diagnosis. The MPCE increased by 69.7% from ₹ 2,900 to ₹ 4,921 during the treatment

The MPCE on food was ₹ 1,345 before cancer diagnosis compared to ₹1,788 after cancer diagnosis, an increase of 33 %. The MPCE of non-food expenditure had increased from ₹1,555 before cancer diagnosis to ₹3,133 after cancer diagnosis. Utility and entertainment related expenditure declined following cancer diagnosis. The mean travel expenditure has increased almost fivefold following cancer diagnosis while the rent has increased six times.

Table 2.5: Hazard ratio and 95% confidence interval of patients discontinued treatment at TMC

Socio economic variables	Hazard Ratio	95% CI
Age		
45 and below ®	1	
46 and above	1.14	0.66-1.97
Years of schooling		
Never attended	1	
Up to secondary	0.48**	0.27-0.84
Higher Secondary and above	0.42**	0.19-0.92
Marital Status		
Others ®	1	
Currently married	1.19	0.62-2.29
Health insurance		

Yes ®	1	
No	0.92	0.35-2.39
Patients category baseline		
Private ®	1	
General/Non	0.60	0.22-1.60
Stage		
I-II	1	
III	1.45	0.76-2.77
IV	3.61**	1.58-8.29
Diagnosed with cancer		
Within 1 month	1	
More than 1 month	1.19	0.72-1.96
Comorbidity status		
No comorbidity	1	
At least 1 morbidity	1.50	0.85-2.62
Religion		
Hindu	1	
Muslim/ others	0.46*	0.22-0.97
Social Group		
General	1	
OBC	0.60	0.34-1.07
SC/ST/Other	0.94	0.47-1.88
Income range		
Upto 10k	1	
10k-25k	0.77	0.41-1.43
25k-50k	0.50	0.18-1.38
50k+	0.25	0.05-1.18
Household size		
1 to 4	1	
5 to 6	1.52	0.86-2.69
7 and more	2.05*	1.00-4.21
Residence		
Urban	1	
Rural	0.79	0.42-1.50

*<0.05, **<0.01, ***<0.

Table 2.6 Monthly per capita expenditure of breast cancer patients (in ₹) before and after diagnosis of breast cancer

	Before cancer diagnosis		After cancer diagnosis		Percentage change
Variable	**MPCE (in ₹)**	**SD**	**MPCE (in ₹)**	**SD**	
Food	1345	1407	1788	1143	33
Utility	393	298	387	334	-1.4
Travel	201	313	1024	1420	408.7
Entertainment	62	131	60	143	-4
Maid, cook, laundry etc	17	104	17	110	0
Rent	156	633	919	1780	489.5
Non-food	1555	3683	3133	5002	101.5
MPCE	**2900**	**4094**	**4921**	**5553**	**69.7**

2.8. Variation in income during treatment

Table 2.7 presents the variation of monthly median household income before and after diagnosis of cancer, collected at the time of baseline. The monthly median household income decreased from ₹ 10,000 to ₹ 8,834 soon after cancer diagnosis. Patients who were younger had higher decrease in household income following cancer diagnosis compared to the older patients. For instance, among the patients aged below 40 years, 41 to 59 years, and 60 years and above the monthly household income had declined by 31.9%, 5.8% and, 20.0%, respectively. Patients who never attended school had recorded higher decrease in income. The median monthly income before cancer diagnosis of the rural patients was ₹9,000 and it decreased to ₹7,000 after diagnosis cancer. Households that earned income by labour showed a drastic reduction by 64.0% post cancer diagnosis.

2.9. Summary

In this chapter, we examined the socio-economic condition of breast cancer treatment at TMC, Mumbai. Our findings suggest lower median age at diagnosis of breast cancer patients (47 years) suggesting that the majority of patients were young and in the reproductive age group. Reasons for low age at onset would be due to behavioural, environmental and reproductive factors. Second, over two-third of the breast cancer patients were diagnosed at an advanced stage of cancer. This is much higher to many other countries. This is possibly leading to high mortality of breast cancer and higher duration of treatment. The mean duration of the treatment for breast cancer patients was 276 days and on average a breast cancer patient made 49 visits to TMC, Mumbai to complete their treatment. Third, the average monthly household income of breast cancer patients was ₹ 17,802 before diagnosis of cancer treatment which decreased to ₹ 15,376 soon after cancer diagnosis. The decrease was higher among labourer households. Fourth, we found about 14% discontinued treatment and the discontinuation was significantly higher among poorer women, less educated and older women. The discontinuation is primarily due to three reasons; death, financial crisis and default. During two years period, 5% discontinued due to financial crisis and 5% died.

Table no 2.7: Variation in monthly average household income (in ₹) before and after cancer diagnosis

Patient's characteristics	Baseline				Percentage mean difference
	Before cancer diagnosis		After cancer diagnosis		
	Median	IQR	Median	IQR	
Age					
< 40	9333	5916.-20000	6352	500-15000	-31.9
41 - 59	10000	6250-20000	9416	4000-20000	-5.8
> 60	15000	6200-20000	12000	6000-20000	-20.0
Years of schooling					
Never attended	10000	5000-16666.	7000	1340-14500	-30.0
Up to secondary	10000	6000-18000	7500	3000-16500	-25.0
Higher secondary and above	16000	8000-35000	14250	6000-30000	-10.9
Marital status					
Currently married	10000	6000-20000	8002	3600-18000	-20.0
Other	10000	6000-20000	10000	3833-20000	0.0
Health insurance					
Yes	34000	6000-18000	30000	3272-16000	-11.8
No	10000	6000-18000	8000	3272-16000	-20.0
Health characteristics					
Patient category					
Non-chargeable	6000	5000-9000	0	0-2000	-100.0
General	10000	6000-18000	8000	4000-16000	-20.0
Private	30000	19000-65000	30000	17000-65000	0.0
Stage of cancer diagnosis					
I-II	14000	7000-25750	10000	5000-25000	-28.6
III	10000	6000-18000	8000	3000-17000	-20.0
IV	10000	7750-17000	6668	7750-17000	-33.3
Household characteristics					
Residence during treatment					
Hotel or rental room	10000	6000-20000	9000	3000-20000	-10.0
Own house	15000	8000-23000	12000	6404-22000	-20.0
Relatives and friends house	9000	6000-15000	5350	500-13500	-40.6
Ashram and others	8000	5000-18000	6000	0-12500	-25.0
Religion					

Hindu	10250	6000-20000	9208	4000-20000	-10.2
Muslim	9000	6000-16000	6000	0-12000	-33.3
Other	16000	7500-26250	16000	9000-30000	0.0
Residence					
Urban	13250	7500-22000	12000	5833-20400	-9.4
Rural	9000	6000-18000	7000	1683-15000	-22.2
State					
Maharashtra	13000	6000-20000	11400	1421-16872	-12.3
Outside of Maharashtra	9000	7500-20000	7000	5833-20000	-22.2
Distance from native place					
< 500 kms	13500	8000-20000	12000	6000-20000	-11.1
501 - 1500 kms	10000	6000-28000	8550	3800-25500	-14.5
> 1500 kms	9000	6000-16000	6301	0-15000	-30.0
Major Source of income					
Agriculture	6000	4583.-8500	5816	3466.-8000	-3.1
Labour	8333	6000-12000	3000	0-8668	-64.0
Self-employed	10000	6000-20000	8000	2000-20000	-20.0
Service	17000	9458.-33166.	16936	8000-30000	-0.4
Total	**10000**	**6000-20000**	**8834**	**3716-20000**	-11.7


RESERVE BANK OF IN

OOP Payment and reimbursement of breast cancer treatment

Chapter 3

3.1. Introduction

The treatment cost of cancer has been increasing in India . Households resort to multiple sources such as income, savings, loans, selling assets and borrowing, insurance and other organizations to meet the cost of treatment. The treatment cost is both direct and indirect and medical as well as non-medical. In this study, the expenditure on cancer treatment were collected during each visit to hospital. The OOP payment is defined as the expenditure less of reimbursement. In this chapter we present the direct medical and indirect cost of breast cancer treatment. Estimates of OOP payment and reimbursement were derived by household and patient characteristics. We used the term cost and household expenditure synonymously.

3.2. Household expenditure before and during treatment of breast cancer at TMC

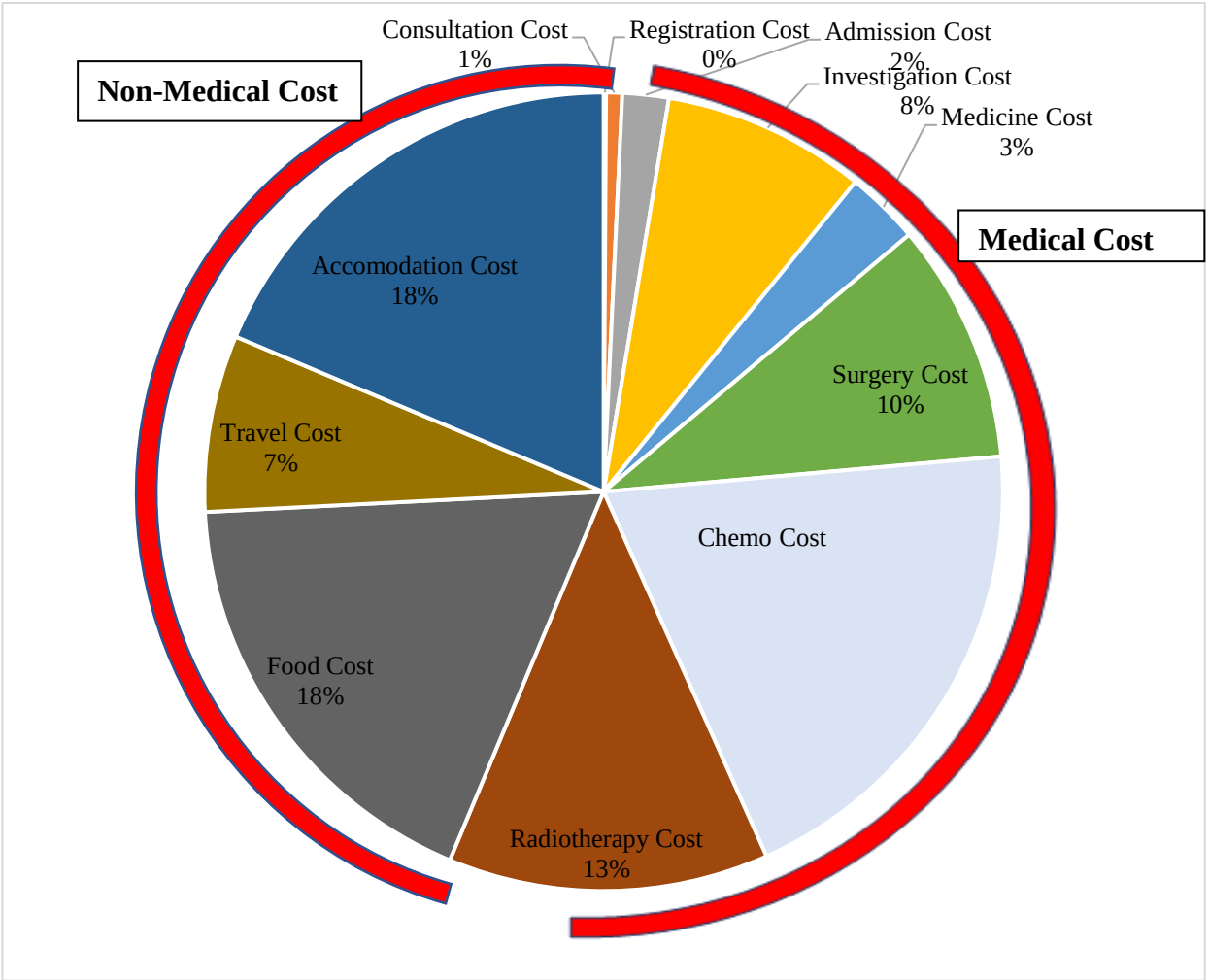
Table 3.1 presents the average treatment cost of breast cancer. The average treatment cost was ₹ 2,58,095 at TMC and ₹ 10,168 before coming to TMC. Of the total cost of treatment at TMC, 56% accounted to direct medical cost and 44% as non-medical cost (Fig 3.1). The distribution of total cost further suggests that chemotherapy accounted the largest share (20%) followed by food, accommodation (18% each) and radiotherapy (13%). However, the largest shares of medical cost of treatment were made by chemotherapy cost (35%), radiotherapy cost (23%) and cost of surgery (17%). The lion share for non-medical cost of treatment was by accommodation (43%) and food (41%) related expenditure. The pattern for cost of treatment was different before coming to TMC

and during treatment at TMC. The indirect cost of cancer treatment has increased from ₹ 1,011 before coming to TMC to ₹ 112,707 during treatment at TMC (10% vs 44%).

Table 3.1: Cost segregation of breast cancer (₹) before and during treatment at TMC, Mumbai

Type of Costs	Before registered at TMC			During treatment at TMC			Overall Cost		
	Mean cost (in ₹)	SD	% share to total	Mean cost (in ₹)	SD	% share to total	Mean (in ₹)	SD	% share to total
1.Total Medical Cost	***9157***	***11019***	***90.05***	***145388***	***126312***	***56.33***	***154545***	***127230***	***58***
Registration Cost	48	298	0.53	247	705	0.17	295	758	0.19
Consultation Cost	852	943	9.3	1684	4422	1.16	2536	4528	1.64
Admission Cost	21	283	0.23	4833	7556	3.32	4854	7567	3.14
Investigation Cost	7580	9526	82.78	21239	18481	14.61	28819	21548	18.65
Medicine Cost	656	4125	7.17	7751	10864	5.33	8407	11654	5.44
Surgery Cost	NA	NA	NA	25075	38886	17.25	25075	38886	16.23
Chemo Cost	NA	NA	NA	50869	68256	34.99	50869	68256	32.92
Radiotherapy Cost	NA	NA	NA	33483	48576	23.03	33483	48576	21.67
2.Total Non-Medical Cost	***1011***	***1888***	***9.95***	***112707***	***127808***	***43.67***	***113718***	***128068***	***42***
Food Cost	133	300	13.17	46149	44502	40.95	46282	44553	40.7
Travel Cost	746	1460	73.75	18460	23843	16.38	19206	23977	16.89
Accommodation Cost	132	804	13.08	48097	88603	42.67	48229	88663	42.41
3. Total Cost (1+2)	***10168***	***11535***	***100***	***258095***	***209064***	***100***	***268263***	***209995***	***100***

Figure 3.1: Percent distribution of treatment cost of breast cancer by component at TMC



3.3. Socio- economic variations in OOP payment of breast cancer patients

The mean OOP payment was ₹ 186,461 accounting 72% of the total cost. The socio-economic gradient of OOP payment is strong. Average cost of treatment, OOP and OOP as a share of total cost increase linearly with economic status of the households (measured by MPCE quintile), distance to Mumbai from the native place, stage at diagnosis and duration of treatment. On average, the mean OOP payment for the richest quintile was higher by more than three times higher than the poorest quintile. On the other hand, the share of OOP payment to total cost varied from 61% in poorest quintile to 78% in richest quintile. Similarly, the OOP payment for patients in stage I/II was ₹ 164,721 that accounted for 64% of the total cost as compared to ₹ 256,848 for stage IV patients which accounted 74% to total cost of treatment. The OOP payment also increased with the duration of treatment. Patients with less than 9 months of treatment period had incurred almost half OOP payment than that of patients treated for more than one year (₹156,628 vs ₹ 303,018). In general, the total cost of treatment and OOP payment at TMC was higher among younger patients, patients who belonged to rural areas, had comorbidity, diagnosed at higher stage, and sought at least one treatment outside TMC.

Table 3.2: Socio-economic variations in the total cost and OOP payment (in₹) for breast cancer treatment, and share of OOP payment to total cost at TMC, Mumbai

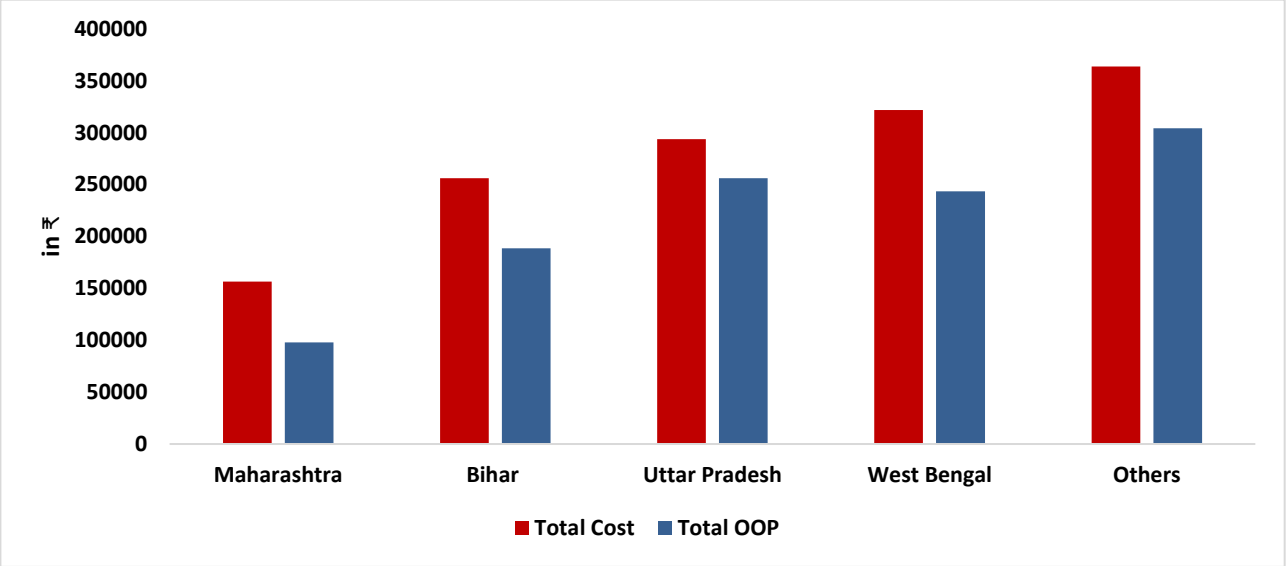
		Cost of treatment (in ₹)			OOP payment (in ₹)			OOP payment as a share of total cost	
SES Variables	**N**	**Mean**	**SD**	**Median**	**Mean**	**SD**	**Median**	**Mean**	**Median**
Age of Patients									
Up to 45 Years	202	266258	206515	203078	188367	190410	122746	70.7	60.4
Over 45 Years	227	250831	211496	196028	184765	205041	129396	73.7	66
Marital Status									
Others	63	192676	143139	155099	124540	112976	97261	64.6	62.7
Currently Married	366	269355	216577	207976	197120	207502	133406	73.2	64.1
Location of Residence									
Urban	196	206389	168610	146781	131193	144752	79508	63.6	54.2
Rural	233	301590	229302	239031	232953	223628	168688	77.2	70.6
Education Level									
Never Attended	99	236252	174948	199308	166617	152383	128938	70.5	64.7
Primary	36	235438	212503	146450	176455	205583	115697	74.9	79
Secondary	167	209950	143408	181628	141081	133004	105610	67.2	58.1
Higher Secondary	50	275740	216266	210003	214277	203545	146627	77.7	69.8
Above HS	77	389730	295105	322061	297013	296970	212713	76.2	66
Religion									
Hindu	332	263135	218016	203078	189326	204650	126859	72	62.5
Muslim	80	252210	180129	198839	193549	182085	156025	76.7	78.5
Others	17	187350	140208	144211	97149	101822	70597	51.9	49
Caste									
General	226	287088	234406	232646	214131	222445	149845	74.6	64.4

OBC	145	239628	184472	195045	168999	172390	119180	70.5	61.1
SC/ST/Other	58	191289	128787	150464	122299	127145	95986	63.9	63.8
Distance to Mumbai									
<500 kms	185	164606	136894	126897	95887	107201	58948	58.3	46.5
501-1500 kms	60	348865	217688	279415	290706	234587	196948	83.3	70.5
>1500 kms	184	322493	228902	257530	243534	217536	181237	75.5	70.4
Income Source									
Agriculture	54	280074	167454	277682	214717	157732	186843	76.7	67.3
Labour	103	216336	151523	182797	150144	135471	120902	69.4	66.1
Self-Employed	66	300722	277027	250029	230801	254569	152633	76.7	61
Service	206	259556	216000	188951	183007	210415	116679	70.5	61.8
MPCE									
Poorest	83	147955	99480	133938	90430	80432	81763	61.1	61
Poorer	78	175336	117582	138642	115596	113540	91213	65.9	65.8
Middle	89	218674	126750	199635	152673	126933	124478	69.8	62.4
Richer	89	293421	231277	232682	215062	228390	170478	73.3	73.3
Richest	90	435442	261561	389533	341569	254451	292253	78.4	75
Type of Patient									
General/ Non-chargeable	369	210246	145917	179275	149315	138086	112644	71	62.8
Private	60	552368	286145	512822	414910	322408	448882	75.1	87.5
Stage of Cancer									
I/II	155	231335	196810	166697	164721	175238	106154	71.2	63.7
III	259	271367	212571	216391	195395	206657	136931	72	63.3
IV	15	305444	252624	248612	256848	249931	183321	84.1	73.7
Comorbidities									
No Comorbidity	296	251805	187493	199697	182909	181845	129167	72.6	64.7
At least 1 comorbidity	133	272093	250738	211089	194367	230667	115494	71.4	54.7
Place of treatment									
TMC	243	217448	193408	163732	148239	178280	99481	68.2	60.1
At least one Outside TMC	186	311198	217211	250617	236397	211556	184705	76	73.7
Duration of Treatment									
< 9M	214	232674	186360	174066	156228	162259	105490	67.1	60.6
9 M-12 M	174	262883	202038	211647	196180	199095	139478	74.6	65.9
12M	41	370456	299491	280350	303018	298157	187141	81.8	66.8
Total	**429**	**258095**	**209064**	**200819**	**186461**	**198065**	**126988**	**72.2**	**63.2**

3.4. Variation of total cost and OOP payment by state

The total cost and OOP payment of breast cancer varied by state. Figure 3.2 represent the state-wise presentation of total cost and mean OOP payment among cancer patients. Patients belonged to Maharashtra had lower cost of treatment and OOP payment than those from outside Maharashtra.

Figure 3.2: Variation of total cost and OOP payment by state of origin for breast cancer patients



3.5. Estimates of Mean OOP payment for breast cancer treatment

In Table 3.3, estimate the OOP payment of breast cancer treatment are presented. Controlling for the covariates the estimated OOP payment for breast cancer treatment is ₹ 184,769 (95% CI: 166,446, 203,093), lower than unadjusted mean OOP payment of ₹ 186,461 (95% CI: 167,666, 205,257). The OOP payment for patients from urban areas was estimated to be higher than rural areas. Similarly, among patients with lower education levels, who belonged to OBC and SC/ST/Other category, who were from poorest or poorer quintile had their estimated OOP payment higher than the unadjusted OOP payment levels. Private patients and patients with above higher secondary educational attainment had their OOP payment reported higher to the tune of ₹ 92,865 and ₹ 102,486, respectively.

Table 3.3: Estimates of Mean OOP payment (in ₹) for breast cancer treatment at TMC, Mumbai using GLM regression

SES Characteristics	Total OOP payment (Estimated) (in ₹)	95 % CI	Mean OOP payment (in ₹)	95% CI
Age of Patients				
Up to 45 Years	170538	[141201,199874]	188367	[161950, 214784]
Over 45 Years	199659	[167407,231911]	184765	[157948, 211582]
Marital Status				
Others	148965	[112698,185233]	124540	[96088, 152993]
Currently Married	189451	[170000,208901]	197120	[175791, 218449]
Location of Residence				
Urban	172120	[144729,199510]	131193	[110802, 151584]
Rural	191248	[169063,213432]	232953	[204088, 261818]
Education Level				
Never Attended	190599	[156965,224232]	166617	[136225, 197009]
Primary	180855	[123594,238115]	176455	[106896, 246014]
Secondary	173525	[146183,200866]	141081	[120760, 161401]
Higher Secondary	185168	[147249,223088]	214277	[156430, 272124]
Above HS	194527	[156541,232513]	297013	[229610, 364417]
Religion				
Hindu	181719	[162865,200573]	189326	[167232, 211421]
Muslim	208850	[171926,245775]	193549	[153028, 234070]
Others	124805	[79269,170342]	97149	[44797, 149501]
Caste				
General	189892	[160689,219095]	214131	[184973, 243289]
OBC	182694	[145692,219696]	168999	[140702, 197297]
SC/ST/Other	161034	[117664,204405]	122299	[88868, 155730]
Distance to Mumbai				
<500 kms	167450	[115229,219670]	95887	[80337, 111437]
501-1500 kms	196957	[141745,252169]	290706	[230106, 351306]
>1500 kms	187971	[156383,219558]	243534	[211893, 275176]
Income Source				
Agriculture	226211	[179179,273242]	214717	[171665, 257770]
Labour	162284	[131594,192974]	150144	[123667, 176620]
Self-Employed	214222	[166172,262273]	230801	[168221, 293382]
Service	173344	[144389,202298]	183007	[154103, 211911]
MPCE				
Poorest	104632	[83010,126255]	90430	[72868, 107993]
Poorer	139696	[106822,172571]	115596	[89997, 141196]
Middle	157047	[124789,189306]	152673	[125935, 179412]
Richer	202500	[163295,241705]	215062	[166951, 263173]
Richest	261733	[217593,305872]	341569	[288275, 394863]
Type of Patient				
General	154014	[134118,173909]	149315	[135179, 163451]
Private	322045	[243643,400446]	414910	[331623, 498197]
Stage of Cancer				
I/II	187629	[157037,218221]	164721	[136915, 192527]
III/IV	183401	[161858,204944]	198759	[173880, 223639]
Comorbidities				
No Comorbidity	191067	[161119,221016]	182909	[173880, 223639]
At least 1 comorbidity	172708	[127545,217872]	194367	[162108, 203710]
Duration of Treatment				
< 9M	146672	[120403,172942]	156228	[134364. 178092]
9 M-12 M	209889	[179949,239830]	196180	[166389, 225971]
12M	283932	[155771,412093]	303018	[208908, 397128]
Place of Treatment				
TMC	184102	[152696,215509]	148239	[125711, 170767]
At least one outside TMC	185494	[151434,219555]	236397	[205794, 267000]
Total	**184769**	**[166446,203093]**	**186461**	**[167666, 205257]**

3.6. Cost of breast cancer treatment by patient's category

Table 3.4 represent the total cost of the breast cancer treatment by patient's category. The cost of the breast cancer patients who were treated at the general category and private category were ₹27,195 and ₹72,151 respectively. The mean medical cost incurred by the private category (₹340,339) was almost three time of general category patients (₹113,689). Similarly, the mean non -medical cost incurred by breast cancer patients who belong to private category was higher than its counterparts. The surgery cost incurred by the private category patients was six times higher compared to the counterpart. The highest component of the medical cost of patient who refers to the general categories and private category was attributed to chemotherapy cost to ₹44,884 and ₹87,677 respectively. Moreover, the travel cost had the lowest rate in breast cancer patients who refers to the general category at ₹16,509, and private category at ₹30,464 from non-medical cost. In contrast the higher cost among those referring to the private category and general category was related to the accommodation cost.

Table 3.4 Total cost of breast cancer treatment by patients' category

	General n=369			Private n=60		
Type of Costs	**Mean**	**SD**	**Median**	**Mean**	**SD**	**Median**
Total Medical Cost	***113689***	***80672***	***86454***	***340339***	***173815***	***323542***
Registration Cost	167	572	100	739	1127	500
Consultation Cost	433	1872	0	9376	7066	8350
Admission Cost	2902	2979	2360	16707	13861	13345
Investigation Cost	16482	10497	14718	50499	27895	45381
Medicine Cost	7168	9868	7217	11335	15282	4916
Surgery Cost	14297	21069	9284	91361	54826	81095
Chemo Cost	44884	55039	18805	87677	115325	43206
Radiotherapy Cost	27195	41060	13885	72151	69524	70000
Total Non-Medical Cost	***96557***	***96648***	***71025***	***212030***	***220389***	***151475***
Food Cost	41454	39454	35552	75022	60592	65743
Travel Cost	16509	20265	9360	30464	37310	16223
Accommodation Cost	38594	64663	3800	106543	163799	66135
Total Cost	***27195***	***41060***	***13885***	***72151***	***69524***	***70000***

3.7. Cost of breast cancer treatment by stage of cancer diagnosis

The cost of breast cancer treatment varies by the stage of cancer diagnosis. Table 3.5 represent the different type of cost incurring during breast cancer treatment by stage of cancer diagnosis. The cost was higher for patients whose cancer was more advanced stage (stage III & IV). Mean amount of total cost of advanced stage was ₹231335 where as it was ₹273233 in the early stage. The mean medical cost incurred by advanced stage of diagnosis was also higher compared to its counterparts. Similarly observed that the non-medical cost was lower among the

early stage of cancer diagnosis patients (₹94674) than the advanced stage of diagnosed (₹122908). The highest component of the medical cost of patients were contributed by chemotherapy cost (₹45620) among early stage and (₹53838) among advanced stage of cancer diagnosis respectively. However, for the non-medical cost the higher component was food cost for early stage whereas in the advanced stage it was accommodation cost.

Table 3.5: Cost of treatment breast cancer patients by stage of cancer diagnosis

Stage of Cancer	**I/II (n=155)**			**III/IV (n=274)**		
Type of Costs	**Median**	**Mean**	**SD**	**Median**	**Mean**	**SD**
Total Medical Cost	**91027**	**136661**	**127765**	**110192**	**150325**	**125447.4**
Registration Cost	100	208	355	100	269	840
Consultation Cost	0	1302	3516	0	1900	4850
Admission Cost	2450	4699	7091	2762	4909	7818
Investigation Cost	11083	17214	15883	18174	23517	19461
Medicine Cost	4274	7497	11711	4413	7894	10373
Surgery Cost	9613	26331	41276	9954	24366	37526
Chemo Cost	16366	45620	64262	23012	53838	70356
Radiotherapy Cost	13885	33608	51618	15000	33411	46864
Total Non-Medical Cost	**58560**	**94674**	**113433**	**91887**	**122908**	**134393**
Food Cost	30266	38925	41695	44646	50236	45582
Travel Cost	10200	17496	24942	10185	19006	23226
Accommodation Cost	0	38253	70721	17338	53666	96954
Total Cost	**166697**	**231335**	**196809**	**218236**	**273233**	**214562**

3.8. Cost of breast cancer treatment by age of the patients

Table 3.6 present the cost incurred by the age of breast cancer patients during cancer treatment. The mean total cost incurred by the young patients were (₹266258) higher than the older patients (₹250831) whereas medical cost and chemotherapy cost were incurred by the patients above age 45 were higher compared to the counterpart. Similarly, the non-medical cost incurred was higher among the patients who are in young age. The highest component of the medical cost was contributed by chemotherapy among the cancer patients irrespective of age. while in non-medical cost it was accommodation cost contributed major parts (₹52397) among younger and (₹44270) among older patients respectively.

Table 3.6: Cost of treatment of breast cancer patients by age of patients

	Up to 45 years (n=202)			**Over 45 years (n=242)**		
Type of Costs	**Median**	**Mean**	**SD**	**Median**	**Mean**	**SD**
Total Medical Cost	**105555**	**145111**	**119745**	**101592**	**145635**	**132144**
Registration Cost	100	315	985	100	186	261
Consultation Cost	0	2014	5248	0	1390	3510
Admission Cost	2762	5090	8148	2490	4604	6998
Investigation Cost	17001	21834	16990	15340	20711	19735
Medicine Cost	4317	7522	10410	4308	7954	11271
Surgery Cost	9749	25497	39703	9944	24701	38228
Chemo Cost	22183	47140	57367	18460	54186	76632
Radiotherapy Cost	15000	35315	50954	13885	31852	46409
Total Non-Medical Cost	**82602**	**121147**	**141604**	**69902**	**105196**	**113934**

Food Cost	42234	49888	45557	32867	42823	43370
Travel Cost	10555	18862	22083	9700	18103	25349
Accommodation Cost	17338	52397	102452	0	44270	74165
Total Cost	**203078**	**266258**	**206514**	**196028**	**250831**	**211496**

Table 3.7: Reimbursement (in ₹) received by the breast cancer patients varying across the socio-demographic characteristics

	% Reimbursed	Amount of Reimbursement (in ₹)			Share of Reimbursement to TC	
SES Variables	**%**	**Mean**	**SD**	**Median**	**Mean**	**Median**
Age of Patients						
Up to 45 Years	76.2	82906	135886	35500	31.1	17.5
Over 45 Years	72.7	73664	111570	34287	29.4	17.5
Marital Status						
Others	82.5	68680	93569	40917	35.6	26.4
Currently Married	73.0	79623	128047	34267	29.6	16.5
Location of Residence						
Urban	79.1	86731	139995	36748	42.0	25.0
Rural	70.4	70684	107573	33256	23.4	13.9
Education Level						
Never Attended	77.8	71659	87929	43644	30.3	21.9
Primary	69.4	67123	104481	29113	28.5	19.9
Secondary	82.6	71089	86254	40000	33.9	22.0
Higher Secondary	72.0	65949	106334	28378	23.9	13.5
Above HS	55.8	114140	214015	30000	29.3	9.3
Religion						
Hindu	72.3	81100	132201	34791	30.8	17.1
Muslim	81.3	61690	75028	33994	24.5	17.1
Others	82.4	94611	131104	34530	50.5	23.9
Caste						
General	70.4	79428	133999	35165	27.7	15.1
OBC	79.3	76267	108887	34287	31.8	17.6
SC/ST/Other	77.6	76882	117388	36769	40.2	24.4
Distance to Mumbai						
<500 kms	82.7	80033	135472	35594	48.6	28.0
501-1500 kms	58.3	64170	121398	14049	18.4	5.0
>1500 kms	71.2	80503	111473	46006	25.0	17.9
Income Source						
Agriculture	74.1	65881	85000	36753	23.5	13.2
Labour	86.4	70935	78066	40581	32.8	22.2
Self-Employed	65.2	72512	111636	30000	24.1	12.0
Service	71.4	86500	151243	34264	33.3	18.1
MPCE						
Poorest	79.5	61530	70367	37608	41.6	28.1
Poorer	83.3	65905	70012	40616	37.6	29.3
Middle	79.8	67751	85623	41965	31.0	21.0
Richer	71.9	90719	152908	30000	30.9	12.9
Richest	58.9	101304	181787	27662	23.3	7.1
Type of Patient						
General/ Non-chargeable	78.3	64650	79788	36000	30.7	20.1
Private	50.0	160215	251090	0	29.0	0.0
Stage of Cancer						
I/II	71.0	72461	140015	31547	31.3	18.9
III	77.2	83044	115025	40917	30.6	18.9
IV	60.0	48596	74119	25287	15.9	10.2
Comorbidities						
No Comorbidity	74.3	73913	109393	34409	29.4	17.2

At least 1 comorbidity	74.4	87146	150443	36689	32.0	17.4
Place of treatment						
TMC	77.6	82649	143691	36369	38.0	22.2
At least one Outside TMC	71.8	74469	105765	34585	23.9	13.8
Duration of Treatment						
< 9M	68.3	86546	151185	34562	37.2	19.9
9 M-12 M	71.0	69589	83719	39751	26.5	18.8
12M	77.0	69253	102672	24318	18.7	8.7
Total	**74.4**	**78016**	**123555**	**34611**	**30.2**	**17.2**

3.9. Reimbursement

Table 3.7 presents the mean reimbursement and its share to total cost of treatment by socio-economic characteristics. Almost three-fourth of the breast cancer patients had received any reimbursement and the mean reimbursement was ₹ 78,016. Yet, reimbursement only covered for one-third of the total cost of treatment. Reimbursement had strong economic gradient. For instance, the richest MPCE quintile had received the highest amount of reimbursement (₹ 101,304) while it was the lowest among the poorest (₹ 61,530). Reimbursement accounts 58.9% for richest quintile compared to 79.5% among poorest quintile. Similarly, patients who received complete treatment at TMC had higher amount of reimbursement than compared to the patients who had taken at least one treatment outside of TMC (₹ 82,649 vs ₹ 74,469). The share of reimbursement was higher among urban patients (42%), patients belonging to SC/ST category (40%), patients who had labour and service as the major source of household income (each 33%), cancer diagnosed at an early stage (31%) and completed treatment in less than nine months (37%).

Table 3.8 show the mean amount of reimbursement received by type of insurance. Majority of the patients had received reimbursement from social health insurance schemes (33.1%) followed by Tata trust (30%) and employee health insurance (5%) (Figure 3.3). We found some patients have received reimbursement from multiple sources. Reimbursement as a share of total cost was highest from private health insurance (71%) followed by employee health insurance (66%) and social health insurance (4%)

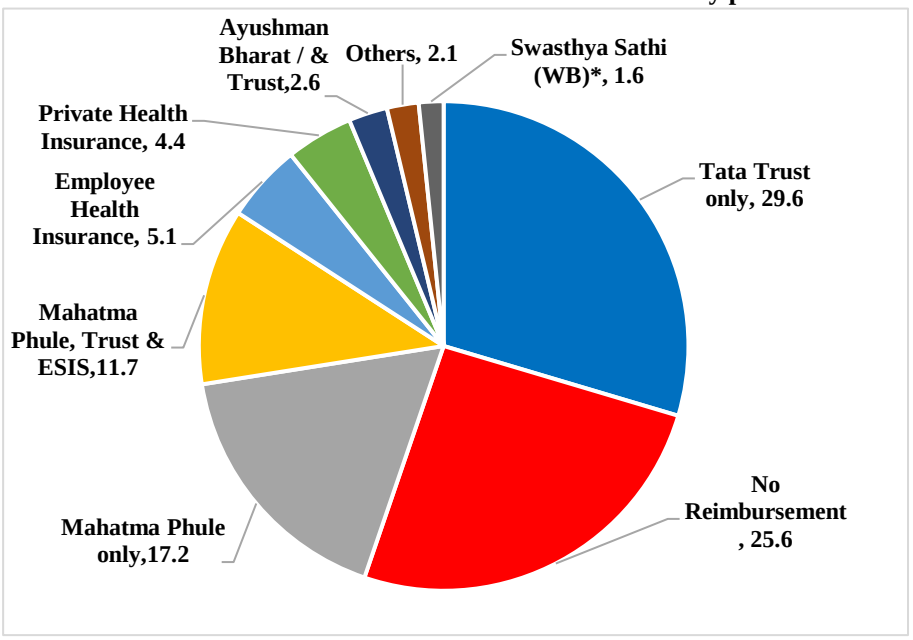
Table 3.8: Type of reimbursement and its share to total cost of treatment

		Reimbursement* (in ₹)		Total Cost of treatment (in ₹)		Reimbursement as share of TC
Type of insurance	**N (%)**	**Mean**	**SD**	**Mean**	**SD**	**% share**
None	**110 (25.6)**	**0**	**0**	**335152**	**242481**	***NA***
Any reimbursement	**319 (74.4)**	***104918***	***133099***	***231523***	***189502***	***NA***
Social Health Insurance	***142 (33.1)***	***62685***	***55228***	***147249***	***100579***	***42.6***
ABY /& Trust[+]	11 (2.6)	73598	46459	249360	137614	29.5
MJPJAY only	74 (17.2)	40979	39831	113867	76011	36.0
MJPJAY, Trust & ESIS[#]	50 (11.7)	85710	62480	154399	90816	55.5
Swasthya Sathi (WB) [@]	7 (1.6)	110542	61467	288618	109163	38.3
Employee Health Insurance	***22 (5.1)***	***220575***	***182530***	***336048***	***219042***	***65.6***
Private Health Insurance	***19 (4.4)***	***382947***	***294099***	***539710***	***390169***	***71.0***
TATA Trust Only	***127 (29.6)***	***91486***	***81459***	***260799***	***151599***	***35.1***
Others[&]	9 (2.1)	91109	93440	241950	152677	37.7
Total	**429**	**78016**	**123555**	**258095**	**209064**	***30.2***

ABY: Ayushman Bharat Yojana; MJPJAY: Mahatma Jyotirao Phule Jan Arogya Yojana; ESIS: Employee State Insurance Scheme

**There are 34 cases of breast cancer patients where the reimbursement received was higher than the total cost of treatment at TMC. [+] Contains 5 cases where patients got reimbursement from ABY and Trust; [#]Contains 2 cases of patients where they got reimbursement from ESIS & Trust along with MJPJAY respectively; [@]Contains 4 cases where patients got reimbursement from Swasthya Sathi as well as Trust. [&] Others contain unspecified sources and 1 case of government source.*

Figure 3.3: Percent distribution of the source of reimbursement received by patients at TMC



3.10. Summary

We summarise the main findings of this chapter. First, our estimates of breast cancer cost and OOP payment are much higher than the previous literatures (Mahal, 2013; Rajpal et al.,2018; Goyanka et al.,2021; Jain & Mukherjee., 2016; Kastor & Mohanty, 2018). A strong socio-economic gradient of OOP payment was observed. Second, of the total cost of treatment at TMC, direct medical cost accounts for 56% while indirect cost

accounts for 44% of total cost. The share of indirect cost increased during treatment at TMC. Third, we found almost three-fourth of the patients had received any reimbursement which accounts for only one-third of the total cost of treatment. Fourth, the social health insurance schemes, which are primarily government funded, accounted for almost one-third of the total reimbursement received among all concluded patients. Fifth, a significant difference was observed in OOP payment among general/non-chargeable and private patients. Private patients incurred almost three times higher OOP payments than general or non-chargeable patients.

Catastrophic Health Expenditure and Distress Financing of Breast Cancer treatment

Chapter 4

4.1. Introduction

The financial catastrophe of cancer is very high in India. While the publicly funded health care system in developed countries largely meet the treatment cost of cancer, in LMICs, household is the main source of meeting the cost of cancer treatment. The financial hardship poses hindrance in access to quality health care which often leads to high mortality and poor quality of life. Economic hardship is measured in multiple ways; high OOP payment, catastrophic health expenditure (CHE), impoverishment, borrowings, selling of assets (distress financing), indebtedness, loss of income and wage etc. The CHE, defined as OOP payment exceeding the threshold limit of household's capacity to pay and impoverishment, the poverty effect of cancer spending are two key monitoring indicators of financial protection.

Treatment of breast cancer makes everybody poorer irrespective of their economic condition. Empirical studies using limited cross-sectional data suggest that the CHE was highest for cancer in India. There are few studies that estimated the CHE with reference to type of cancer such as, cervical, colorectal, oral cancer. No study to date has estimated the burden of CHE and distress financing for breast cancer patients in India. This chapter gives estimates of financial protection of breast cancer in India. Specifically estimates of the incidence and intensity of CHE, impoverishment, and distress financing of breast cancer in the country.

4.2. Overview of household expenditure, income source and reimbursement

The median monthly per capita consumption expenditure (MPCE) (less health expenditure) was ₹ 3,953 (95% CI: 3604, 4230). The median OOP payment was ₹

126,988 (95% CI: 109749,144437), whereas the mean OOP payment was ₹ 186,461 (95% CI: 167666,205257) suggesting that the households faced a right skewed distribution of OOP payments. The monthly average OOP payment of the households was ₹ 20,419 (95% CI: 18468,22370). Almost two third of the breast cancer patients were reimbursed but that reimbursement was only able to cover 30.2% of the total health expenditure. The mean amount reimbursed was ₹ 78,016 (95% CI: 66291, 89741). The proportion of households who derived income from agricultural sources was 12.6% and from labour was 24.0%, and 54.3% of the patients belonged to rural areas (Table 4. 1).

Table 4.1: Descriptive statistics of household expenditure, income source and reimbursement for breast cancer patients' households seeking treatment at TMC, Mumbai

Variables	Descriptive Statistics (Mean, %)	
Median MPCE (in ₹)	3953	[3604, 4230]
Median OOP payment (in ₹)	126988	[109749, 144437]
Mean OOP payment (in ₹)	186461	[167666, 205257]
Monthly average OOP payment (in ₹)	20419	[18468, 22370]
% reimbursed	74.4	NA
Mean amount reimbursed (in ₹)	78016	[66291, 89741]
Reimbursement as a share of health expenditure.	30.2	NA
% of rural patients	54.3	NA
% with agriculture as household income source	12.6	NA
% with labour as household income source	24.0	NA
N	429	

4.3. Incidence and intensity of catastrophic health expenditure and impoverishment of breast cancer treatment

There is a strong socio-economic gradient for CHE and impoverishment. Overall, 84.6% of the households incurred CHE and 55.0% of the households were facing impoverishment. About 84.3% of the households in the poorest MPCE quintile incurred CHE. The differences in CHE between the poorest and richest MPCE quintile was small (1.3%). The intensity of CHE and impoverishment declined across each MPCE quintile. Both CHE and impoverishment was higher in rural areas compared to urban areas. CHE and impoverishment were lower among the patients who had self-employed and service as income source but higher among patients with labour and agriculture as income source. Patient without any education had higher prevalence of CHE and impoverishment than households with some levels of educational attainment. The households with general or non-chargeable patients had higher CHE compared to private patients but lower prevalence of impoverishment

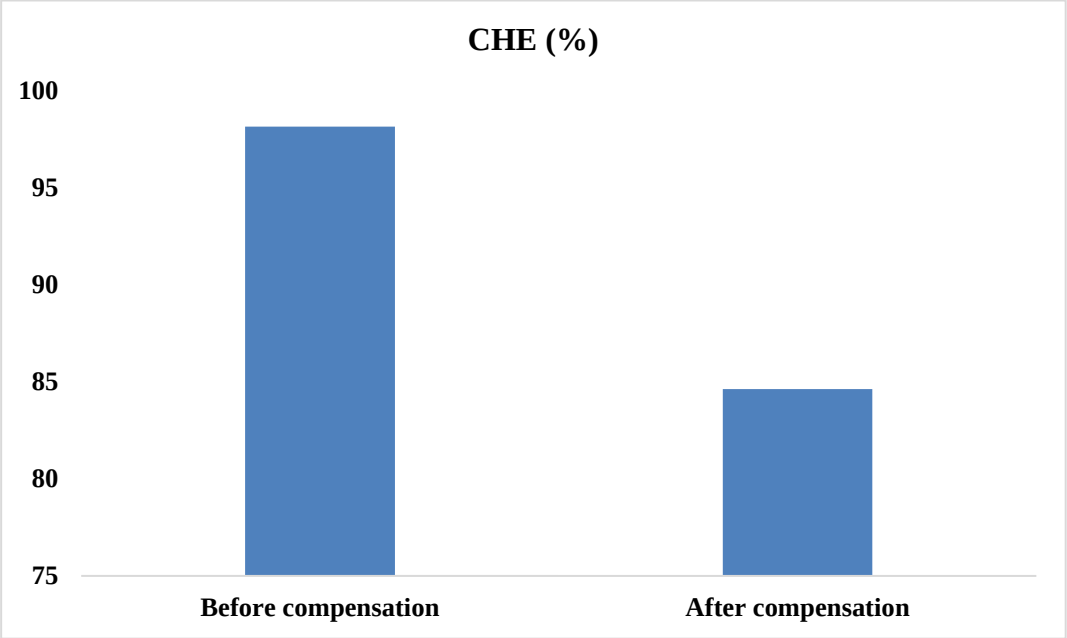
compared to private patients. Breast cancer patients who belonged to other states like Bihar and Uttar Pradesh had higher CHE and impoverishment compared to patients from Maharashtra. Religious variations in impoverishment were not much, however, Hindu households had higher prevalence of CHE followed by Muslim and Other religion. On average, households incurring CHE incurred 200% more of their capacity to pay **(Table 4.2)**.

Table 4.2: Incidence and intensity of CHE and impoverishment by socio-demographic and economic characteristics among breast cancer patients

Variables		Incidence of CHS		Intensity of CHS		Impoverishment	
Age	**n**	**%**	**95% CI**	**Mean**	**95% CI**	**%**	**95% CI**
Upto 45	202	85.2	[79.5, 89.8]	1.2	[0.9, 1.4]	53.5	[46.3, 60.5]
Over 45 years	227	84.1	[78.7. 88.6]	2.8	[0.7, 4.9]	56.4	[49.7, 62.9]
Marital Status							
Other	63	84.1	[72.7, 92.1]	1.2	[0.6, 1.8]	41.3	[29.0, 54.4]
Curently Married	366	84.7	[80.6, 88.2]	2.2	[0.9, 3.5]	57.4	[52.1, 62.5]
MPCE quintile							
Poorest	83	84.3	[74.7, 91.4]	7.3	[1.0, 13.6]	63.9	[52.6, 74.1]
Poorer	78	83.3	[73.2, 90.8]	1.3	[0.8, 1.7]	56.4	[44.7, 67.6]
Middle	89	84.3	[75.1, 91.1]	1.0	[0.7, 1.3]	55.1	[44.1, 65.6]
Richer	89	85.4	[76.3, 92.0]	0.8	[0.6, 0.9]	48.3	[37.6, 59.2]
Richest	90	85.6	[76.6, 92.1]	0.6	[0.5, 0.7]	52.2	[41.4, 62.9]
Place of residence							
Urban	196	78.1	[71.6, 83.6]	1.8	[-0.2, 4.3]	43.9	[36.8, 51.1]
Rural	233	90.1	[75.6, 93.6]	2.2	[0.8, 3.7]	64.4	[57.9, 70.5]
Level of Education							
Never Attended	99	89.9	[82.2, 95.0]	1.4	[1.0, 1.8]	60.6	[50.3, 70.3]
Primary	36	83.3	[67.2, 93.7]	5.7	[-3.4, 14.9]	55.6	[38.1, 72.1]
Secondary	167	82	[75.4, 87.5]	2.3	[0.2, 4.4]	47.9	[40.1, 55.8]
Higher Secondary	50	90	[78.2, 96.7]	1.1	[0.8, 1.4]	62.0	[47.2, 75.3]
Above HS	77			1.1	[0.8, 1.5]	58.4	[46.7, 69.6]
Religion							
Hindu	332	85.2	[81.0, 88.9]	2.2	[0.8, 3.7]	55.7	[50.2, 61.1]
Muslim	80	82.5	[72.4, 90.1]	1.3	[0.9, 1.6]	56.3	[44.7, 67.3]
Other	17	82.4	[56.6, 96.2]	1.5	[-0.2, 3.1]	35.3	[14.2, 61.7]
Caste							
General	226	84.1	[78.6, 88.6]	1.8	[0.3, 3.2]	55.8	[49.0, 62.3]
OBC	145	86.9	[80.3, 91.9]	2.7	[0.3, 5.2]	53.1	[44.7, 61.4]
SC/ST/Other	58	81	[68.6, 90.1]	1.2	[0.7, 1.8]	56.9	[43.2, 69.8]
Occupation							
Agriculture	54	98.1	[90.1, 99.9]	4.5	[-1.6, 10.7]	66.7	[52.5, 78.9]
Labour	103	86.4	[78.2, 92.4]	1.3	[0.9, 1.7]	56.3	[46.2, 66.1]
Self-employed	66	80.3	[68.7, 89.1]	1.2	[0.7, 1.6]	57.6	[44.8, 69.7]
Service	206	81.6	[75.6, 86.6]	2.0	[0.3, 3.7]	50.5	[43.5, 57.5]
Type of patient							
General	369	85.1	[81.0, 88.6]	2.2	[0.7, 1.3]	54.0	[48.7, 59.1]
Private	60	81.7	[69.6, 90.5]	1.0	[0.2, 3.9]	61.7	[48.2, 73.9]
State							
Maharashtra	145	75.5	[68.8, 81.4]	2.1	[0.2, 3.9]	41.1	[34.1, 48.5]
West Bengal	74	89.2	[80.4, 94.9]	1.4	[1.1, 1.8]	71.1	[60.1, 80.5]
Bihar	48	92.3	[81.5, 97.9]	4.4	[-1.9, 10.6]	59.6	[45.1, 73.0]
Uttar Pradesh	39	97.5	[86.9, 99.9]	1.5	[1.0, 2.1]	67.5	[50.8, 81.4]
Other	57	91.9	[82.2, 97.3]	1.1	[0.8, 1.3]	64.5	[51.3, 76.3]
Total	**429**	**84.6**	**[80.8, 87.9]**	**2.0**	**[0.9, 3.1]**	**55.0**	**[51.3, 76.3]**

Reimbursement from various sources play a major role in reducing CHE burden, However, in case of breast cancer, the CHE incidence before reimbursement was 98.14% and 84.62% after reimbursement, showing that reimbursement reduced CHE only by 13.78%. Yet, majority of the households were incurring CHE **(Figure 4.1)**.

Figure 4.1: CHE burden before and after compensation among breast cancer households



4.4. Sources of financing treatment

Only 5.7% of the patients resorted to income for financing, 48.56% resorted to savings only, 66.59% had loans & borrowings and 72.36% had either sold assets or borrow to finance the cost of treatment. The share of total cost of treatment was mainly covered by using either selling assets or borrowing (78.9%) followed by contribution from friends (63.4%) then followed by insurance (52.6%). Almost 44.0% of the patients had used two sources to finance the cost of treatment, followed by 32.21% who had to take help form 3 or more sources. Only 21.15% of the patients were able to cope with the treatment cost by using a single source of financing.

Table 4.3: Source of financing treatment and share to total cost of treatment

Source of financing	%		Mean amount spent from source	Average treatment cost	Source of financing as a share to total cost of treatment
Income	5.77	24	59917	173244	34.6
Savings	48.56	202	14097	280830	5.0
Selling assets, jewellery, property	11.78	49	251939	357209	70.5
Loans & borrowings	66.59	277	108179	238314	45.4
Either selling assets or borrowing	72.36	301	195195	247384	78.9
Contribution from friends	44.95	187	157101	247659	63.4
Insurance	39.66	165	106536	202673	52.6

4.5. Predictors of distress financing and association with CHE

Table 4.4 presents the odds ratios (OR) and 95% confidence interval (95% CI) of distress financing. In Model 1, we observe that there are significant odds of distress financing among the households undergoing CHE. The significance remains unaltered in the subsequent models. The odds of undergoing distress financing were significantly higher among patients who had more than a year of treatment (OR: 4.65, 95% CI: 1.31, 16.6), or were highly educated (OR: 2.54; 95% CI: 1.04,6.19). Patients who had only labour (OR:2.36, 95% CI:1.17, 4.75) or self-employed (OR:2.65, 95% CI:1.24,5.64) as income source were significantly more likely than patients who were in service to undergo distress financing. The odds were significantly lower among general patients (OR:0.33, 95% CI:0.16,0.67), who were from within Maharashtra (OR:0.42, 95% CI:0.22,0.77) and who had any insurance (OR:0.39, 95% CI:0.22,0.71).

4.6. Summary

We estimated that 84.6% (95% CI:80.8, 87.9%) breast cancer households incurred CHE. The CHE was higher among rural patients, poor households, patients who came from outside of Maharashtra and households who primarily depend on agriculture for their livelihood. Second, we found that 70% of breast cancer survivors had availed some form of reimbursement. Reimbursement reduced the CHE incidence by 13.78% and the reduction was higher among patients who were from Maharashtra, in the early stage of cancer, belonged to urban areas, and were in the poorest wealth quintile. Among various forms of reimbursement, reimbursement was higher from social

health insurance schemes (33.1%) followed by charitable trusts (30%) and employee

Table 4.4: Result of logistic regression models showing significant predictors of distress financing

Distress financing	Model 1			Model 2			Model 3		
	OR	**p-value**	**95% CI**	**OR**	**p-value**	**95% CI**	**OR**	**p-value**	**95% CI**
CHE	**2.48**	0.001	[1.44,4.29]	**2.03**	0.017	[1.14,3.64]	**1.89**	0.048	[1.01, 3.54]
Age									
Up to 45 years				1.00			1.00		
Over 45 years				0.86	0.551	[0.52,1.42]	1.02	0.956	[0.60, 1.73]
Marital status									
Not currently Married				1.00			1.00		
Currently Married				1.45	0.249	[0.77,2.75]	1.30	0.449	[0.66, 2.53]
Patients' Type									
General/Non-chargeable				1.00			1.00		
Private				**0.46**	0.018	[0.24,0.87]	**0.33**	0.002	[0.16, 0.67]
Stage of Cancer									
I/II				1.00			1.00		
III/IV				1.02	0.947	[0.62,1.64]	0.98	0.933	[0.60, 1.61]
Duration of Treatment									
<9M				1.00			1.00		
9M-1Y				0.99	0.977	[0.61,1.62]	0.85	0.522	[0.51, 1.41]
> 1Y				**4.65**	0.018	[1.31,16.6]	**3.84**	0.042	[1.05,14.10]
Patients Years of Schooling									
Never Attended				2.04	0.076	[0.93,4.50]	1.88	0.137	[0.82,4.32]
Primary				1.48	0.421	[0.57,3.87]	1.39	0.520	[0.51,3.81]
Secondary				1.69	0.116	[0.88,3.23]	1.94	0.067	[0.96,3.95]
Higher Secondary				**2.54**	0.04	[1.04,6.19]	**2.88**	0.029	[1.12,7.46]
Higher Secondary and Above				1.00			1.00		
Insurance									
No insurance				1.00			1.00		
Any Insurance				**0.39**	0.002	[0.22,0.71]	**0.59**	0.135	[0.30, 1.78]
Income Source									
Agriculture							0.76	0.49	[0.34, 1.67]
Labour							**2.36**	0.017	[1.17, 4.75]
Self-Employed							**2.65**	0.012	[1.24, 5.64]
Service							1.00		
Caste									
General							0.85	0.556	[0.49, 1.48]
OBC							0.88	0.741	[0.41, 1.87]
SC/ST/Other							1.00		
State									
Within Maharashtra							**0.42**	0.005	[0.22, 0.77]
Outside Maharashtra							1.00		

health insurance (5%). Third, the household with cancer patients resorted to multiple sources to meet the financial need for treatment. About 72.4% of patients met the expenses through either selling assets or borrowing. More than two-fifths of the households had to use more than two sources of financing to cover the cost of

treatment. Fourth, we found a strong association between distress financing (selling assets/borrowing) and CHE. Distress financing was significantly higher among patients who had more than a year of treatment, or with no education or up to higher secondary education and who had only labour or self-employed as income source. It was significantly lower among general patients, who were from within Maharashtra and who had any insurance. Our multivariate analyses suggest that the association remains significant across the three models after controlling for patient's and household characteristics.

State of health and quality of life of breast cancer survivors[1]

Chapter 5

5.1. Introduction

Breast cancer is becoming the fast-leading cause of oncologic morbidity and mortality among women worldwide. Due to improvement in healthcare systems and advent of new treatment methods, the chance of surviving from cancer has increased exponentially. However, the health condition of breast cancer patients be affected by many factors such as duration of the treatment, stage of cancer and types of treatment received. The cancer patients experience physical, emotional, and social challengers that can affect their quality of life (QoL). The QoL of cancer survivors can vary widely depending on various factors like stage of cancer diagnosed, age of patients, overall health of patients. This chapter describes the health condition and QoL of breast cancer survivors

5.2. Comorbidity among breast cancer patients

Comorbidity refers to the existence of a long-term health condition in the presence of a primary disease of interest (Porta et al., 2014). The questions on co-morbidity includes any of the following diseases: diabetes, hypertension, chronic lung disease, chronic heart disease, stroke, arthritis, neurological or psychiatric problems, cholesterol, solid tumour, hemiplegia, connective tissue disease, peptic ulcer etc. Our study reveals that at baseline, 24% of breast cancer patients had any co-morbidity and it has increased to 32% by endline (Table 5.1). However, the co-morbidity has declined to 26% at the time of follow-up. The prevalence of comorbidity has strong age and education gradient. For instance, at baseline, the prevalence of any comorbidity was 7% among those under 40 years compared to 49% among those aged

Table 5.1: Prevalence of comorbidity among breast cancer patients at baseline, endline and follow-up

[1] *A revised version of this chapter has been under the process of publication in Asian pacific journal of cancer titled Quantifying the health state utility (HSU) in breast cancer: first report of an Indian value set

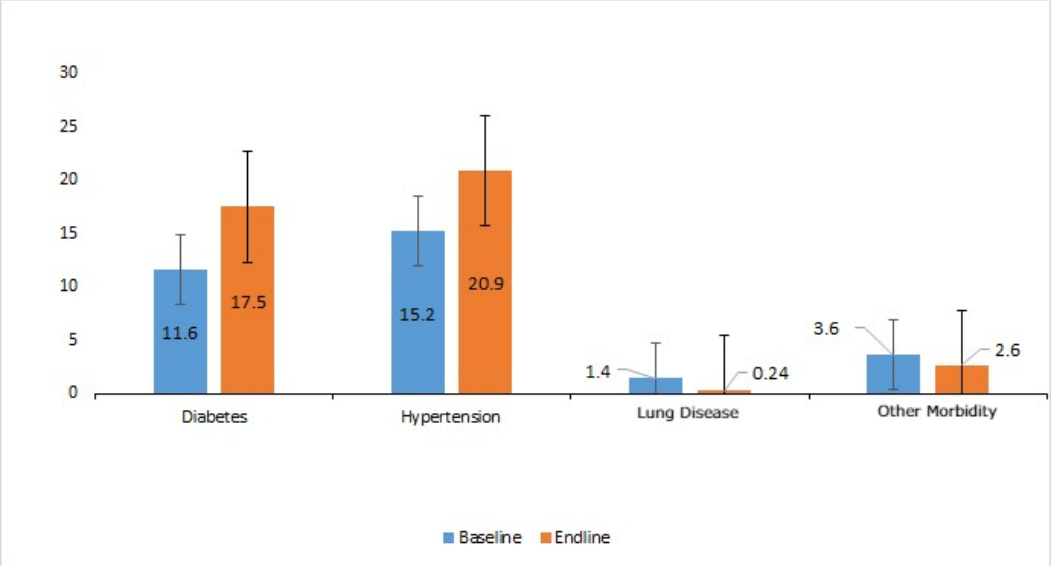
	Any co-morbidity		
Patients' characteristics	**Baseline (%)**	**Endline (%)**	**Follow up (%)**
Age			
< 40	7.2	9.3	7.5
41 - 59	28.2	36.5	29.4
> 60	49.2	71.7	65
Years of schooling			
Never attended	27.1	38.4	37.8
Up to secondary	26.2	28.4	24.5
Higher secondary and above	18.8	32.5	19.1
Marital status			
Currently married	20.9	28.5	23.6
Other	43.6	52.5	41.7
Health insurance			
Yes	26.7	38.9	28
No	24.2	31.3	25.4
Health characteristics			
Patient category			
Non-chargeable	24.1	34.8	26.3
General	23.5	29.4	24.5
Private	29.9	46.4	32.1
Treatment taken outside before coming to TMC			
Yes	21	34	20
No	24.9	32.1	26.9
Stage of cancer diagnosis			
I-II	21.4	34.4	24
III	26	30.8	26.7
IV	25	25	40
Household characteristics			
Residence during treatment			
Hotel or rental room	18.9	23.7	16.9
Own house	33.6	43.8	39.3
Relatives and friends house	20.9	30.5	27.3
Ashram and others	26.3	31.8	16.7
Residence			
Urban	29.7	37.9	30.7
Rural	19.8	27	21
State			
Maharashtra	28.2	38.3	33.3
Outside of Maharashtra	21.3	26.8	19.1
Distance from native place			
<500 kms	29.3	40.3	34.1
501 - 1500 kms	18.4	30.5	26.5
> 1500 kms	21.5	23.9	16.1
Religion			
Hindu	24.4	34	26.7
Muslim	18.6	19.2	16.7
Other	50	52.9	36.4
Social group			
General	26.3	33.9	24.7
OBC	18.9	28.4	25
SC/ ST / Others	30.6	33.3	30.3
Major source of income			
Agriculture	14.1	21.2	19.2
Labour	28.7	28.7	27.4
Self-employed	25.3	33.3	37
Service	24.6	36	23.1
Wealth tertile			
Poor	23.4	26.1	19.7
Middle	19.2	27.8	29.3
Rich	30.7	42	28.3
Total	**24.4**	**32**	**25.7**
N	**500**	**429**	**206**

60 years and above. The increase in co-morbidity was highest among older patients. Similarly, comorbidity prevalence was higher among the patients who had primary or

secondary education whereas, it was lower for the patients with higher education level. Comorbidity prevalence among the urban patients compared to patients from rural areas. About, 30% of patients who belongs to urban area were diagnosed with any comorbidity at baseline and it has increased to 38% by endline. On the other hand, the comorbidity prevalence for rural patients was 20% in baseline and 27% at endline. The patients who were from Maharashtra belonged to rich income tertile had higher prevalence of any comorbidity.

Figure 5.1 shows the prevalence of comorbidities among breast cancer patients at baseline and endline. At the time of baseline, 12% of the patients had diabetes and it has increased to 18% at endline. Similarly, hypertension increased by approximately 6 percentage point between baseline and endline.

Figure 5.1: Prevalence of type of co-morbidity among breast cancer patients at baseline and endline



5.3. Self -rated health of breast cancer patients

The self -rated health status of breast cancer patients is described in this section. The variation in self -rated health at three stages of cancer treatment was large across socio-economic and patient level characteristics. Patients reporting poor self -rated health increased with increase in age. Among patients aged 60 plus, 51% patients reported poor self-rated health compared to 39% of those below 40 years of age. The poor self-reported health decreases with level of education. Among patients who never attended school, about 44% of the reported poor health status at baseline compared to 54% at endline and 22% at follow up. It was relatively lower among

those with higher secondary and above schooling. Patients who came from outside of Maharashtra, belonged to poor income tertile had reported higher percentage of poor health status compared to their respective counterpart. Patient with least one comorbidity reported higher poor health status in baseline (48%) as well as in follow-up (29%) (Table 5.3).

Table 5.2: Prevalence of diabetes, hypertension, lung disease and other morbidity among breast cancer patients.

Comorbidity prevalence	Baseline			Endline		
	Percent	Lower CI	Upper CI	Percent	Lower CI	Upper CI
Diabetes	11.6	8.92	14.73	17.54	14	21.55
Hyper tension	15.2	12.16	18.65	20.91	17.1	25.14
Lung Diseases	1.4	0.56	2.86	0.24	0.006	1.33
Other morbidity	3.6	2.14	5.63	2.64	1.32	4.68

Table 5.3: Prevalence of poor self-rated health among breast cancer patients at baseline, endline and follow-up

Patients' characteristics	Baseline (%)	Endline (%)	Follow -up (%)
Age			
< 40	38.8	41.1	17.9
41 - 59	41.5	43.6	16.8
> 60	50.8	47.8	25
Years of schooling			
Never attended	44.4	53.5	22.2
Up to secondary	42.8	39.6	17.4
Higher secondary and above	37.7	40.8	15.9
Marital status			
Currently married	42.4	42.3	15.9
Other	38.5	49.2	33.3
Health insurance			
Yes	51.1	25	16
No	40.9	45	18.2
Patient category			
Non-chargeable	68	57	15.8
General	40	45	19.5
Private	38	27	10.7
Treatment taken outside before coming to TMC			
Yes	30.2	48.9	15
No	43.4	42.3	18.7
Co-morbidity			
No co-morbidity	40	43.7	15.5
One and more co-morbidity	47.5	41.8	29
Stage of cancer diagnosis			
I-II	41.1	39.6	13.5
III	42.8	46.4	21.9
IV	35.7	25	20
Residence during treatment			
Hotel or rental room	47.6	44.2	14.1
Own house	28	38.8	17.9
Relatives and friends house	49.6	42.1	20
Ashram and others	42.1	54.6	25
Residence			
Urban	37.1	43.2	12.9

Rural	45.9	43.4	22.9
State			
Maharashtra	33.5	44.2	14.6
Outside of Maharashtra	48.7	42.5	21.9
Distance from native place			
< 500 kms	33.5	43.7	16.5
501 - 1500 kms	42.1	40.7	20.6
> 1500 kms	50.2	43.8	18.5
Major source of income			
Agriculture	31.3	34.6	15.4
Labour	57.4	47.5	21
Self-employed	43	44.4	18.5
Service	35.5	43	16.5
Income tertile			
Poor	49.4	44.3	19.2
Middle	37.1	43.1	21.7
Rich	38	42.5	12.5
Total	**41**	**43**	**18**
N	**500**	**429**	**206**

Figure 5.2: Percentage of breast cancer patients reporting poor self-rated health at baseline, endline and follow-up

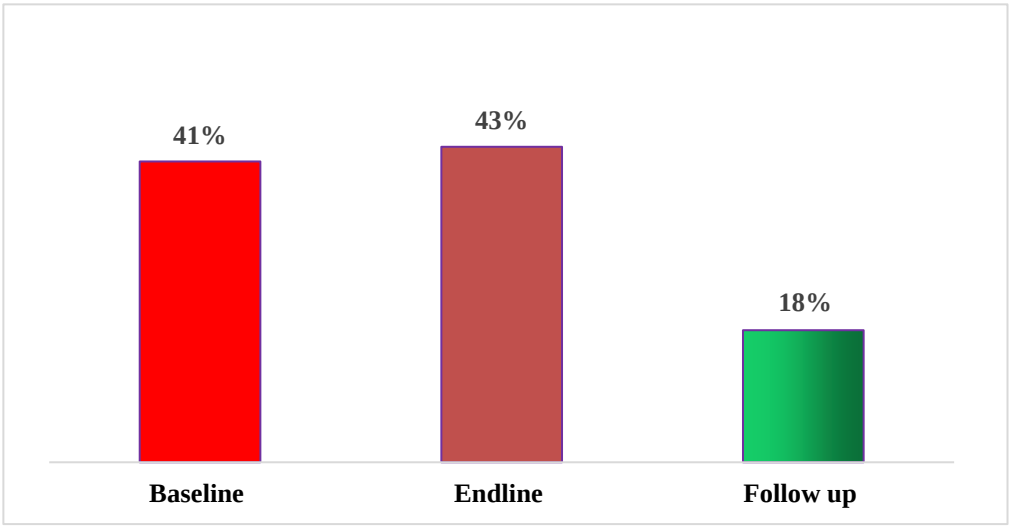


Figure 5.2 presents the poor self-rated health of breast cancer patients. At the time of baseline 41% cancer patients reported poor self -rated health which increased to 43% at endline but decreased to 18% at follow up. This suggests that the cancer treatment has improved the health status of patients.

5.4. Demographic profile of cancer and non-cancer cohort

In the study, 500 cancer patients were compared with the non-cancer cohort of 200 subjects. The non-cancer females who visited the preventive oncology department for their preventive health check-up formed the non-cancer cohort. The baseline demographic details were recorded at the time of accrual for both cancer and heathy (non-cancer) cohort. The comparison of the two cohorts implies that the non-cancer cohort and the cancer cohort are naturally expected to have different epidemiological and socio-

economic backgrounds. predominantly belonged to the Mumbai and sub-urban region thereby resulting in the difference between the demographic variables as shown in Table 5.4. The median time of treatment completion was 9 months.

Table 5.4: Demographic profile of cancer and non-cancer cohort

Socio-demographic characteristics	Cancer (in %)	Non-cancer (in %)	p-value
Age (in years)			
Mean age in years	46.9	41.5	<0.001
Below 40	30.4	46.8	<0.001
41 to 59	57.4	46.8	
60+	12.2	6.5	
Education			
Mean years of schooling	7.0	10.0	<0.001
Illiterate	26.6	13.9	<0.001
Primary	21.2	13.9	
Secondary	25.4	24.4	
Higher secondary and above	26.8	47.8	
Religion			
Hindu	78.8	89.6	0.001
Others	21.2	10.5	
Social group			
Unreserved	51.8	59.2	0.114
Scheduled Caste/Scheduled Tribe	33.8	25.9	
Other Backward Class	14.4	14.9	
Wealth quintile			
Poorest	20.0	20.4	1
Poorer	20.0	19.9	
Middle	20.0	19.9	
Richer	20.0	20.4	
Richest	20.0	19.4	
Household size			
1 to 4	49.6	63.7	0.002
5 to 6	35.8	28.4	
7 and more	14.6	8.0	
Health insurance			
Yes	9.0	28.9	<0.001
No	91	71.1	
Place of residence			
Urban	46.4	76.6	<0.001
Rural	53.6	23.4	
Annual household income			
Less than 50000	22.4	8.0	<0.001
50000- 1lac	23.4	16.1	
1 lac- 2 lac	22.2	25.6	
More than 2 lacs	32.0	50.3	
Clinical stages			
I & II	33.6	NA	NA
III	60.8	NA	
IV	5.6	NA	

5.5. Comparison of EQ-5D-5L of cancer and non-cancer cohort

The EQ-5D-5L is a set of self-assessed, health related quality of life question that measure the quality of life in five domains; mobility, self-care, usual activity, pain/discomfort and anxiety/depression. The 5-point scale considered were; no, slight,

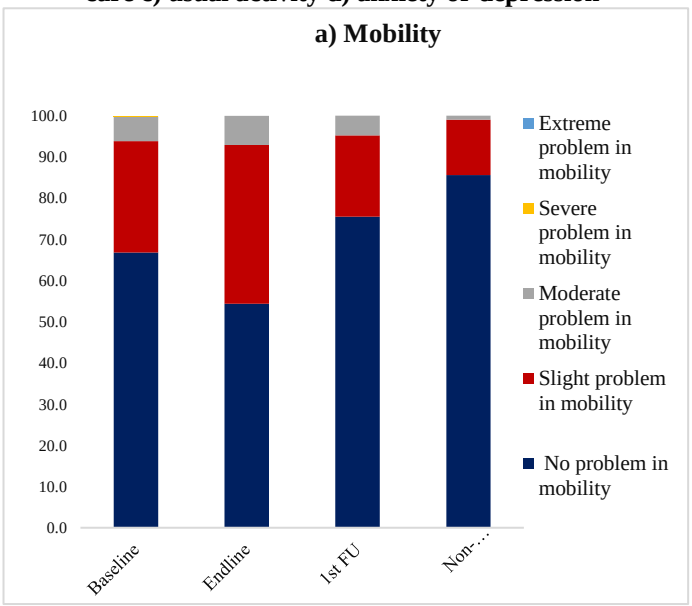
moderate, severe, extreme (Table 5.5). All the three positive health states (mobility, self-care, and usual activity) were reported to a higher extent in the non-cancer cohort while the negative health states (pain/discomfort and anxiety/depression) were more frequent in the cancer cohort. Similarly, the EQ-VAS is a vertical analogous scale that takes a value between 0 and 100, based on self-reporting. Figure 5.3 shows the comparative data between the two cohorts. Figure 5.5 shows the distribution of the baseline EQ-5D-5L and EQ-VAS scores for cancer cohort and non-cancer cohort respectively.

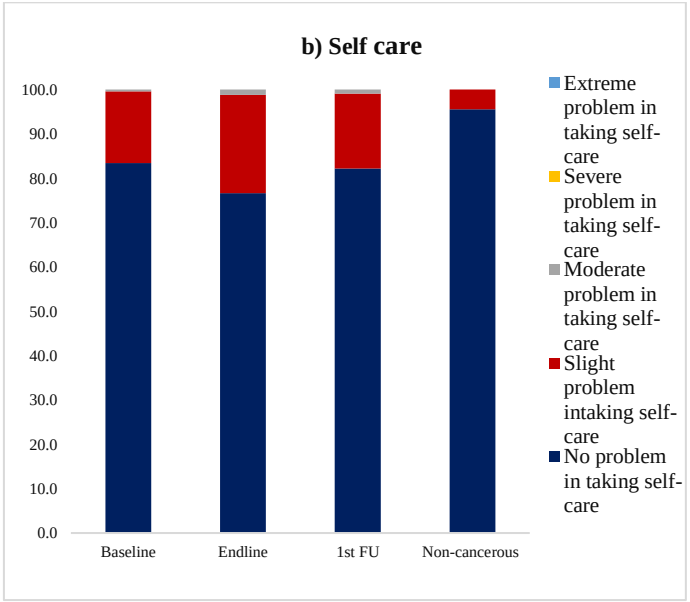
EQ-5D-5L utility scores as per stage for the cancer cohort were 0.88, 0.86 and 0.83 respectively for stage I-II, III and IV. Similarly, the EQ-VAS scores for stage I-II, III and IV were 74.9, 72.6 and 73.2 respectively. The temporal trend with respect to cancer stage is shown in Figure 6.3. While the quality of life improves for stage I-II and III, it reduces for stage IV cancer.

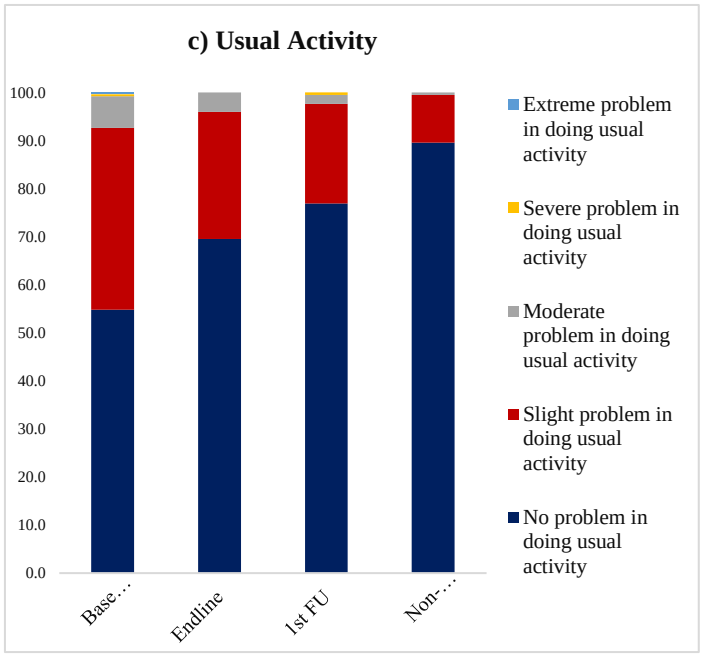
Table 5.5: Comparative EQ-5D-SL data from cancer and non-cancer cohort

	Mobility (%)		Self-care (%)		Usual activity (%)		Pain/Discomfort (%)		Anxiety/ Depression(%)	
Problems	**Cancer**	**Non-cancer**	**Cancer**	**Non-cancer**	**Cancer**	**Non-cancer**	**Cancer**	**Non-cancer**	**Cancer**	**Non-cancer**
No	66.8	85.6	83.4	95.5	54.8	89.6	25.6	52.2	16.6	42.8
Slight	27.0	13.4	16.2	4.5	37.8	10.0	60.6	36.8	66.2	39.3
Moderate	6.0	1.0	0.4	0.0	6.6	0.5	12.4	11.0	15.2	15.4
Severe	0.2	0.0	0.0	0.0	0.4	0.0	1.4	0.0	2.0	2.5
Extreme	0.0	0.0	0.0	0.0	0.4	0.0	0.0	0.0	0.0	0.0

Figure 5.3: Comparative EQ-5Q-5L data from cancer and non-cancer cohort on a) mobility b) self-care c) usual activity d) anxiety or depression







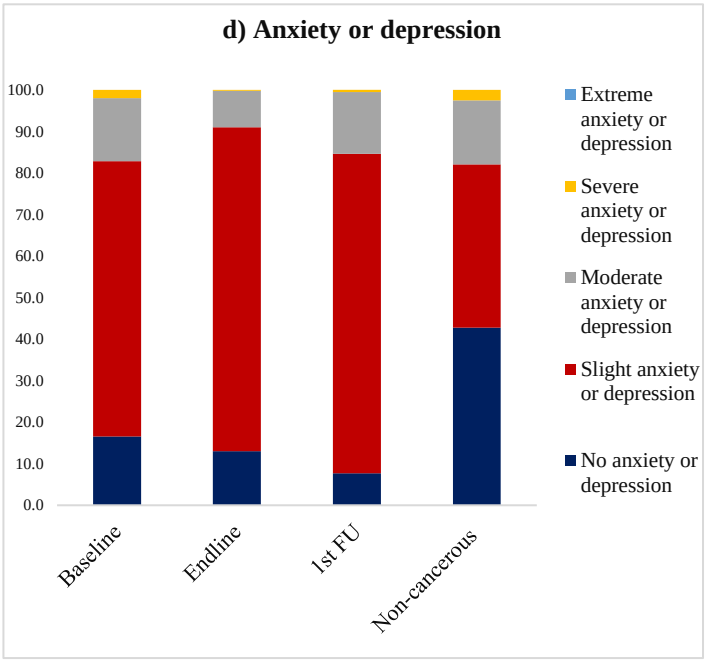
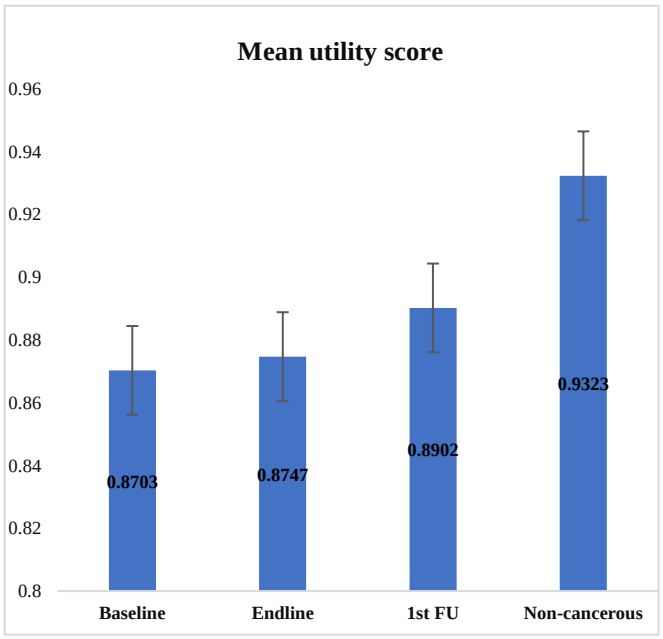


Figure 5.4: Mean utility score and EQ-VAS comparison between cancerous and non-cancerous participants



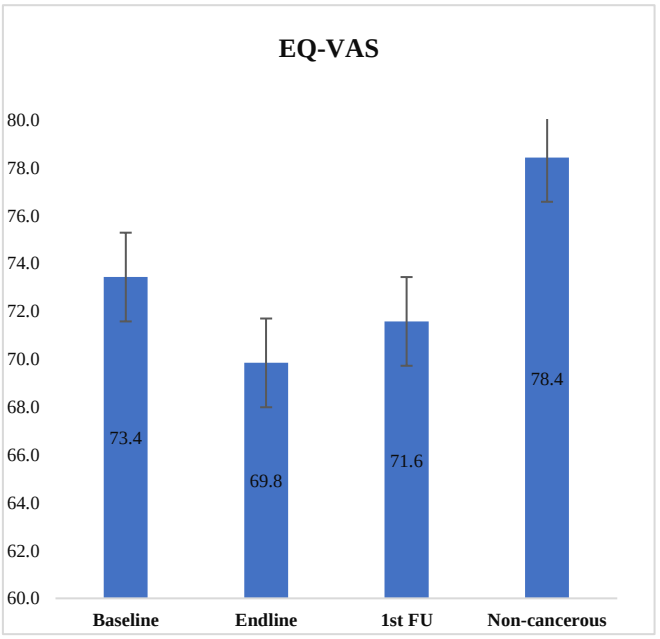
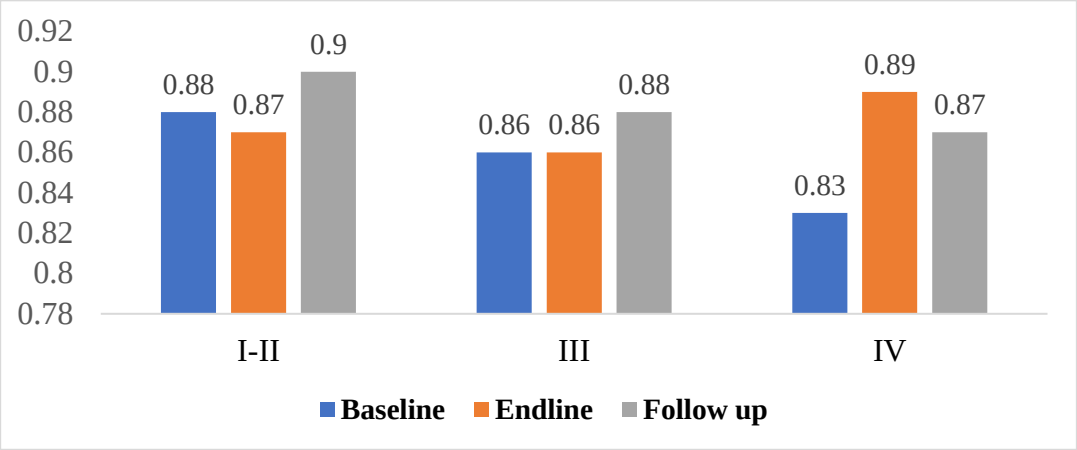


Figure 5.5: Temporal trend of mean utility score by cancer diagnosis



The mean utility value for the baseline, completion and follow up states of cancer cohort and non-cancer cohort have been reported in Table 5.6. The difference in the two cohorts was statistically significant by both the methods of assessment of utility scores. The utility values showed a significant positive trend in the controlled state compared to baseline while the completion values were not statistically significant from baseline as measured by EQ-5D-5L but significantly worse as assessed by VAS. However, there was positive correlations between mean utility score and VAS for each of the time period (for baseline it was 0.5, conclusion it was 0.4 and for follow up it was 0.6).

Table 5.6: Comparative EQ-5D-5L and VAS scores from non-cancer and cancer cohort at different time points.

	Mean utility score		VAS score	
Cancer	**Mean± SD**	**p-value***	**Mean ±SD**	**p-value***
Baseline	0.8703±0.121	NA	73.43 ± 12.66	NA
Completion	0.8745 ± 0.094	0.557	69.81 ± 10.14	0
Follow up	0.8902 ± 0.107	0.043	71.56 ± 10.50	0.063
Non-cancer	0.9323 ± 0.082	0	78.88 ± 13.65	0

*t-test was done using baseline value.

In order to study the effect of various socio-economic variables, we carried out bivariate analysis independently for both the cohorts (baseline data was used in the cancer cohort). Age, religion, social group, educational and marital status, wealth quintile, family type, household size, health insurance, place of residence, annual income and cancer stage were considered for the analyse. The results are shown in Table 5.7. It was observed that

younger age, Hindu religion and higher income had positive impact on the utility values in both the cohorts but the difference was statistically significant only for the religion and income while the association with age showed a decreasing trend for statistical significance in both the cohorts. In addition, cancer stage also impacted utility scores showing a trend towards statistical significance. Multivariate analysis also confirmed the strong association of age, religion, and income with the utility values (Table 5.8).

5.6. Summary

We summarize the main findings of this chapter. First, at the time of registration for treatment, one-fourth of the breast cancer patients had any co-morbidity and at the time of completion of treatment, it has increased to 32%. Second, we found that hypertension and diabetes were the two most prevalent co-morbidities among cancer patients. The prevalence of comorbidity has strong among older age patients, patients who had belonging to primary or secondary education levels and patients who come from urban areas. Third, our finding suggests that about two-fifth of the breast cancer patients reported poor self-rated health at baseline and end line which decrease to 18% during follow-up. Patients who came from outside of Maharashtra, and those who belonged to poor households had reported higher poor self-rated health status. Fourth, it was observed that the EQ-5D-5L values had worsened after diagnosis of cancer as compared to the non-cancer cohort. Cancer affected all domains of the EQ-5D-5L as observed from the lower percentage of cancer patients in the “no problem” category and the difference between cancer and non-cancer ranged from 12 to 35% for this category.

Table 5.7: Socio economic differential of mean EQ-5D-5L score among baseline cancer patients and non-cancer cohort.

	Cancer		Non-cancer	
Socio-economic characteristics	**Mean EQ-5D-5L score**	**p-value**	**Mean EQ-5D-5L score**	**p-value**
Age (in years)				
Below 40	0.882±0.117	0.0642	0.947±0.071	0.0722
41 to 59	0.870±0.121		0.920±0.090	
60+	0.839±0.127		0.918±0.094	
Education				
Illiterate	0.857±0.122	0.3512	0.908±0.103	0.1875
Primary	0.870±0.120		0.922±0.091	
Secondary	0.872±0.113		0.929±0.076	
Higher secondary and above	0.883±0.129		0.944±0.075	
Marital status				
Currently married	0.871±0.123	0.6781	NA	NA
Others	0.865±0.108		NA	
Religion				
Hindu	0.877±0.117	0.0148	0.937±0.083	0.0288
Others	0.845±0.132		0.895±0.072	
Household size				
1 to 4	0.878±0.111	0.3995	0.935±0.080	0.803
5 to 6	0.862±0.133		0.928±0.090	
7 and more	0.866±0.125		0.925±0.077	
Health insurance				
Yes	0.892±0.130	0.2065	0.942±0.076	0.2982
No	0.868±0.120		0.928±0.085	
Place of residence				
Urban	0.872±0.126	0.7276	0.939±0.078	0.0406
Rural	0.869±0.117		0.911±0.093	
Annual household income				
Less than 50000	0.843±0.138	0.0364	0.881±0.091	0.0242
50000- 1lac	0.869±0.101		0.923±0.082	
1 lac- 2 lac	0.877±0.124		0.927±0.090	
More than 2lac	0.886±0.117		0.945±0.075	
Cancer stage				
I & II	0.884±0.093	0.0894	NA	NA
III	0.866±0.126		NA	
IV	0.836±0.187		NA	

p-value: *<0.1, ** <0.05, *** <0.01.

Table 5.8: Socio-economic determinants of EQ-5D-5L score among baseline cancerous and non-cancerous group.

	Cancer		Non-cancer	
	Co-efficient	**Confidence interval (CI)**	**Co-efficient**	**Confidence interval (CI)**
Age (in years)				
Below 40®				
41 to 59	-0.018	[-0.045, 0.008]	-0.049***	[-0.082, -0.015]
60+	-0.053**	[-0.094, -0.013]	-0.032	[-0.1, 0.035]
Education				
Illiterate®				
Primary	0.007	[-0.027, 0.04]	0.011	[-0.049, 0.071]
Secondary	0.005	[-0.028, 0.038]	0.019	[-0.037, 0.075]
HS and above	0.002	[-0.033, 0.037]	0.023	[-0.032, 0.077]
Religion				
Hindu®				
Others	-0.033**	[-0.061, -0.005]	-0.059**	[-0.11, -0.008]
Household size				
1 to 4®				
5 to 6	-0.013	[-0.038, 0.013]	0.011	[-0.025, 0.048]
7 and more	-0.01	[-0.045, 0.026]	-0.001	[-0.065, 0.063]
Health insurance				
Yes®				
No	0.009	[-0.034, 0.052]	-0.005	[-0.045, 0.034]
Place of residence				
Urban®				
Rural	0.001	[-0.023, 0.024]	-0.03	[-0.07, 0.01]
Annual household income				
Less than 50000®				
50000- 1lac	0.022	[-0.011, 0.055]	0.046	[-0.021, 0.113]
1 lac- 2 lac	0.038**	[0.004, 0.073]	0.049	[-0.017, 0.116]
More than 2lac	0.045**	[0.011, 0.079]	0.07**	[0.006, 0.135]
Cancer stage				
I & II®				
III	-0.017	[-0.042, 0.008]	N.A.	
IV	-0.048*	[-0.1, 0.004]	N.A.	
Constant	0.885***	[0.835, 0.934]	0.926***	[0.856, 0.995]

p-value: *<0.1, ** <0.05, *** <0.01.

Summary and Conclusion

Chapter 6

6.1. Introduction

Cancer in India is the fifth leading cause of death (ORGI, 2018). Breast cancer account for one-seventh of the two million cancer cases and has been increasing fast. Among all cancer, breast cancer had the highest share; accounting 21.8% of all cancer cases among women in the country (Kulothungan et al., 2022). Besides high mortality, breast cancer treatment exerts high economic, social and health burden on patients and households during and after treatment.

While the cancer registry provides macro estimates on volume of cancer and death, there are limited information on individual and household characteristics of cancer patients in India. Studies on patient characteristics and household economic condition of breast cancer is very limited in India. Even studies on estimates of cancer estimates based on NSS data draws from cross sectional survey that likely to underestimate the cost, OOP, and CHE (Rajpal et al. 2018). We came across only two small scale unrepresentative studies in last decade, one study in Punjab in 2012-13 and one study in Andhra Pradesh in 2016-17 on breast cancer (Shankar et al.,2018). In this context, the need for collecting data on economic conditions of cancer patients and their household was long felt. To fill the gap, TMC and IIPS jointly carried out this study with funding from an extramural grant provided by the *Women's Cancer Initiative, Nag Foundation* as well as an intramural grant provided by IIPS. The aim of this study was to examine the social,

demographic, economic and health conditions of breast cancer patients during and after treatment from a tertiary cancer hospital.

This is the first ever longitudinal study that collected comprehensive data on socio, demographic, economic and health conditions of breast cancer patients and their households over the course of treatment and follow up visit during June 2019 to March 2022 from Tata Memorial Centre (TMC) Mumbai, a publicly funded tertiary cancer center in India. The study used a longitudinal cohort design and data was collected from a prospective cohort study of 500 breast cancer patients who sought treatment from June 2019 to March 2022 at the country's one of the largest cancer treatment centre, the Tata Memorial Centre (TMC), Mumbai.

Of 500 breast cancer patients interviewed at baseline (first contact), 71 patients discontinued treatment and 429 were interviewed at the end line. A total of 206 patients were interviewed in follow-up visits which was six months after the completion of treatment. Around 200 non-cancerous patients were also interviewed in the study. We estimated the median age of breast cancer diagnosis, socio- demographic characteristics of breast cancer patients, stage of diagnosis, reason for discontinuation of treatment, duration of treatment, number of visits and co-morbidities. The economic conditions were assessed using household income, consumption, loan for cancer treatment and distress financing at baseline, end line and follow-up visit. Out-of-pocket (OOP) payment, reimbursement and catastrophic health expenditure of breast cancer was also calculated.

Our study is unique as we comprehensively collected data on expenditure of breast cancer patients in each time of visit over the stipulated span of treatment (longitudinally). Our sample size is adequate for segregated analyses and we have included patients who were treated at subsidized rate and as private patients. About 54.6% patients of our sample were from other states (other than Maharashtra) and on an average a cancer patient travelled over 1000 kilometers for treatment at TMC.

6.2. Summary

We summarize the main findings and provide possible explanation in support of the findings.

1. **Low Follow up visit:**

We found low follow up visit of breast cancer patients who had completed treatment. Of the 500 breast cancer patients interviewed at baseline (first contact), 14% patients discontinued treatment (5.2% died and 4.8% discontinued due to financial crisis) and only 41% had follow up visit after six months of completion of treatment. The discontinuation due to financial reason was higher among poor and less educated. Our findings suggest that the onset of breast cancer was much lower in country.

2. Low age at onset and late diagnosis:

We estimated the median age of breast cancer diagnosis was 47 years and three-fifths of the patients were under 50 years of age. This suggests that most breast cancer patients were young and in the reproductive age. We also found 5.6% patients with breast cancer who were diagnosed below the age of 30 years. Two-third of breast cancer cases were diagnosed at advanced stage and age at diagnosis was higher among women with lower educational attainment and were poor.

3. High duration of treatment

The mean duration of the treatment for breast cancer patients was 276 days and on an average a breast cancer patient made 49 visits to TMC, Mumbai to complete their treatment. the duration of treatment was higher among patients who were less educated, poor and patients who came from outside the state of Maharashtra. Higher treatment duration among less educated and non-chargeable patients could be owing to their lack of knowledge and understanding about the treatment procedure. Concurrently, patients coming from outside the state of Maharashtra had to stay longer for treatment.

4. Increase in travel and accommodation cost

We found that the travel and accommodation cost increased by five and six times respectively after the diagnosis of cancer. The average consumption expenditure following cancer diagnosis has increased but the average household income has reduced. Reduced income was more among the poor households. Increased medical and non-medical expenditure during treatment and loss of income force breast cancer households to borrow from formal and informal sources.

5. High OOP payment on breast cancer treatment

We estimated high economic burden of breast cancer treatment due to high OOP payment in India. The average cost of treatment of breast cancer was at ₹ 258,095 (for general or non-changeable patients ₹ 219,621 and ₹ 416,198 for private patients) and the average

reimbursement was at INR 78,016. Using these estimates of cost and reimbursement for the breast cancer patients we estimated the OOP payment, which is defined as total cost of treatment net of reimbursement at INR 186,461. These estimates were higher than estimated OOP payment of USA and other high-income countries. The mean monthly OOP payment of treating breast cancer in India was INR 20,419 while it was INR 15,504 in USA and INR 15,278 in other high-income countries (Irragori et al., 2021). The OOP payment and OOP payment as a share of total cost increases linearly with economic well-being of households. The high OOP payment is supported by the fact that 68.9% of breast cancer patients had a loan at the time of concluding treatment and the average amount of loan was ₹ 115,140.

6. High catastrophic health spending

The high OOP payment has led to high CHE. We estimated that 85% cancer households incurred CHE. The CHE was higher among rural patients, poor households, patients who came from outside of Maharashtra and households who primarily depend on agriculture for their livelihood. About 72.4% of patients met the expenses through either selling assets or borrowing. We found a strong association between distress financing (selling assets/borrowing) and CHE. Distress financing was significantly higher among patients who had more than a year of treatment, or with no education or up to higher secondary education and who had only labour or self-employed as income source.

7. Low health insurance coverage

Our findings suggests that the health insurance coverage of breast cancer survivors is low. In the baseline, we observed that a meagre 10% of the patients had any health insurance. However, about three-fourth of breast cancer patients had any form of reimbursement as they might had approached multiple sources but only one-third of the cost of treatment was reimbursed. Private health insurance had lesser coverage but higher reimbursement. Reimbursement was higher from social health insurance schemes (33.1%) followed by charitable trusts (30%) and employee health insurance (5%).

8. Low reimbursement of breast cancer treatment

Reimbursement of breast cancer patients is very low. Reimbursement reduced the CHE incidence by 13.78% only (98.14 to 84.62%) and the reduction was higher among patients who were from Maharashtra, in the early stage of cancer, belonged to urban areas, and were in the poorest wealth quintile.

9. **High loans and debt**

Our findings suggest that the loans and debts of breast cancer households increased from 37.8% at the baseline to 64.6% during endline and 69% after 6 months of treatment. It appears that the breast cancer households are trapped in vicious circle of poverty and debt. Loan as a share of household income was higher among poor, less educated, and rural residents

10. **High co-morbidity of breast cancer**

At the time of registration for treatment, one-fourth of the breast cancer patients had any co-morbidity and at the time of completion of treatment it has increased to 32% following treatment. The most prevalent co-morbidities among breast cancer patients were diabetes and hypertension. The EQ-5D value for cancer patients was significantly lower after diagnosis of cancer as compared to the non-cancer cohort (0.87 vs. 0.93 , p-value <0.001). However, the health status of patients, measured from self-rated health was improved following the completion of cancer treatment

Our findings of low age at onset of breast cancer are consistent with literature. On an average, the age of breast cancer diagnosis in low-and-middle income countries (LMICs) is 40-50 years compared to 60-70 years in western countries (Lim et al 2022; Bidoli, 2019). Studies from developed countries revealed that early detection of malignancy and early start of the treatment could be an essential strategy to improve disease prognosis, lowering the mortality risk and excess healthcare burden (Palència et al., 2010). Cancer treatment facilities in India are limited in number and mostly metro-city centric. The socially and economically disadvantaged population from rural areas face numerous challenges in accessing cancer treatment. Patients from remote and rural areas travel long distances for treatment, which has a significant effect on their economic conditions. This possibly led to high OOP payment, CHE and distress financing.

6.3. Limitations

Although this study is a one of its kind, large study highlighting important factors about the economic, social and health aspects of breast cancer patients, it is not without limitations. First, the study used 500 breast cancer samples from a single centre and hence the results cannot be generalized. Second, estimates of expenditure or cost of treatment prior to TMC might be prone to recall bias and dependent on the recall of the respondents

and their families. Last, the study period also coincided with the Covid-19 pandemic that had delayed the study, impacted the treatment period, and might have increased the cost.

6.4. Conclusions

Breast cancer in India is primarily affecting women in the prime working and reproductive age group. We found early age at onset, late diagnosis, and high indebtedness in treating breast cancer. It is recommended to increase awareness, early diagnosis, multi-disciplinary treatment and increase the coverage of health insurance for breast cancer patients. Though the National Programme on Cancer Screening recommended screening for all women above 30, only less than 1% of the eligible women in 30-49 are ever screened (Sen et al., 2022). The financial catastrophe of breast cancer is very high in India. Though large number of breast cancer patients had some form of reimbursement it did not reduce the CHE burden to a large extent. Long travel distance to avail treatment, low insurance coverage and lack of sufficient treatment facilities are the major contributing factors to the economic and health burden of cancer patients. It is also recommended to build an affordable and accessible medical infrastructure in remote areas along with cancer specific insurance for the existing public or private insurance policies to reduce treatment related financial catastrophe of affected households. It is recommended to make cancer treatment free for all under the PM-JAY programme as cancer is making everybody poor. A mechanism to increase follow up and reduce discontinuation is recommended.

ANNEXURES

References

Alexander, A., Kaluve, R., Prabhu, J. S., Korlimarla, A., Srinath, B. S., Manjunath, S., Patil, S., Gopinath, K. S., & Sridhar, T. S. (2019). The impact of breast cancer on the patient and the family in Indian perspective. *Indian Journal of Palliative Care*, *25*(1), 66-72

Arnold, M., Morgan, E., Rumgay, H., Mafra, A., Singh, D., Laversanne, M., ... & Soerjomataram, I. (2022). Current and future burden of breast cancer: Global statistics for 2020 and 2040. *The Breast*, *66*, 15-23.

Bidoli, E., Virdone, S., Hamdi-Cherif, M., Toffolutti, F., Taborelli, M., Panato, C., &Serraino, D. (2019). Worldwide Age at Onset of Female Breast Cancer: A 25-Year Population-Based Cancer Registry Study. *Scientific reports*, *9*(1), 14111. https://doi.org/10.1038/s41598-019-50680-5

Bose B, Clarke J, Glasbey JC, Haque PD, Jolly, K. K, P. A. ... &, et al. Catastrophic expenditure and treatment attrition in patients seeking comprehensive colorectal cancer treatment in India: A prospective multicentre study. Lancet Reg Heal - Southeast Asia. 2022;6:100058.

Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R. L., Torre, L. A., & Jemal, A. (2018).

Caduff CA, Sullivan R, Pramesh CS, Booth C. India's new health scheme: what does it mean for cancer care? Lancet Oncol. 2019;

Dey, S. (2014). Preventing breast cancer in LMICs via screening and/or early detection: The real and the surreal. *World journal of clinical oncology*, *5*(3), 509.

Dhillon, P. K., Mathur, P., Nandakumar, A., Fitzmaurice, C., Kumar, G. A., Mehrotra, R., ... & Dandona, L. (2018). The burden of cancers and their variations across the states of India: the Global Burden of Disease Study 1990–2016. *The Lancet Oncology*, *19*(10), 1289-1306.

Dracham, C. B., Shankar, A., & Madan, R. (2018). Radiation induced secondary malignancies: a review article. *Radiation oncology journal*, *36*(2), 85.

Ferlay, J., Soerjomataram, I., Dikshit, R., Eser, S., Mathers, C., Rebelo, M., Parkin, D. M., Forman, D., & Bray, F. (2015). Cancer incidence and mortality worldwide: sources, methods and major patterns in GLOBOCAN 2012. *International Journal of Cancer*, *136*(5), E359–E386.

Fitzmaurice, C., Abate, D., Abbasi, N., Abbastabar, H., Abd-Allah, F., Abdel-Rahman, O., Abdelalim, A., Abdoli, A., Abdollahpour, I., & Abdulle, A. S. M. (2019). Global, regional, and national cancer incidence, mortality, years of life lost, years lived with disability, and disability-adjusted life-years for 29 cancer groups, 1990 to 2017: a systematic analysis for the global burden of disease study. *JAMA Oncology*, *5*(12), 1749–1768.

Fowler, H., Belot, A., Ellis, L., Maringe, C., Luque-Fernandez, M. A., Njagi, E. N., Navani,

Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians*, *68*(6), 394–424

Goyanka, R. (2021). Economic and non-economic burden of cancer: A propensity score matched analysis using household health survey data of India. *Cancer Research, Statistics, and Treatment*, *4*(1), 29.

Harbeck, N., & Gnant, M. (2017b). Breast cancer. The Lancet, 389(10074), 1134–1150.

IIPS, ICF. National Family Health Survey (NFHS-5), 2019–21: India. Mumbai: International Institute for Population Sciences 2021.

International Agency for Research on Cancer. IARC handbooks of cancer prevention Weight control and physical activity. [Internet]. 2002 [cited 2022 Sep 22]. p. Vol 6. Available from: https://publications.iarc.fr/Book-And-Report-Series/Iarc-Handbooks-Of-Cancer-Prevention/Weight-Control-And-Physical-Activity-2002

International Agency for Research on Cancer. IARC handbooks of cancer prevention Fruit and vegetables. [Internet]. 2003 [cited 2022 Sep 22]. p. Vol 8. Available from: https://publications.iarc.fr/Book-And-Report-Series/Iarc-Handbooks-Of-Cancer-Prevention/Fruit-And-Vegetables-2003

International Agency for Research on Cancer. IARC monographs on the evaluation of carcinogenic risks to humans Painting, firefighting, and shiftwork. [Internet]. 2010 [cited 2022 Sep 22]. p. Vol 98. Available from: https://publications.iarc.fr/Book-And-Report-Series/Iarc-Monographs-On-The-

Iragorri, N., de Oliveira, C., Fitzgerald, N., & Essue, B. (2021). The out-of-pocket cost burden of cancer care—a systematic literature review. *Current Oncology*, *28*(2), 1216-1248.

Jain, M., & Mukherjee, K. (2016). Economic burden of breast cancer to the households in Punjab, India. *International Journal of Medicine and Public Health*, *6*(1).

Jemal, A., Bray, F., Center, M. M., Ferlay, J., Ward, E., & Forman, D. (2011). Global cancer statistics. *CA: a cancer journal for clinicians*, *61*(2), 69-90.

Jones, C. E., Maben, J., Jack, R. H., Davies, E. A., Forbes, L. J., Lucas, G., & Ream, E. (2014). A systematic review of barriers to early presentation and diagnosis with breast cancer among black women. *BMJ open*, *4*(2), e004076.

Jyani, G., Sharma, A., Prinja, S., Kar, S. S., Trivedi, M., Patro, B. K., ... & Kaur, M. (2022). Development of an EQ-5D Value Set for India Using an Extended Design (DEVINE) Study: The Indian 5-Level Version EQ-5D Value Set. *Value in Health*.

Kastor, A., & Mohanty, S. K. (2018). Disease-specific out-of-pocket and catastrophic health expenditure on hospitalization in India: Do Indian households face distress health financing? PLOS ONE, 13(5), e0196106.

Kulothungan, V., Sathishkumar, K., Leburu, S., Ramamoorthy, T., Stephen, S.,Basavarajappa, D., Tomy, N., Mohan, R., Menon, G. R., & Mathur, P. (2022). Burden of cancers in India - estimates of cancer crude incidence, YLLs, YLDs and DALYs for 2021 and 2025 based on National Cancer Registry Program. BMC Cancer, 22(1), 1–12.

Lawanga, S.k, Lemeshow S. Sample Size Determination in Health Studies : A Practical Manual. Vol. 86. World Health Organization; 1991. p. 1–1149.
Lim, Y. X. ;, Lim, Z. L. ;, Ho, P. J. ;, Li, J., Papi, L., Susini, T., Lim, Y. X., Lim, Z. L., Ho, P. J., & Li, J. (2022) Breast Cancer in Asia: Incidence, Mortality, Early Detection, Mammography Programs, and Risk-Based Screening Initiatives. *Cancers 2022, Vol.14, Page 4218*, *14*(17), 4218. https://doi.org/10.3390/CANCERS14174218
Mahal, A., Karan, A., Fan, V. Y., & Engelgau, M. (2013). The Economic Burden of Cancers on Indian Households. *PLOS ONE*, *8*(8), e71853. https://doi.org/10.1371/JOURNAL.PONE.0071853

N., Sarfati, D., & Rachet, B. (2020). Comorbidity prevalence among cancer patients: A population-based cohort study of four cancers. BMC Cancer, 20(1), 1–15. https://doi.org/10.1186/S12885-019-6472-9/FIGURES/3

Natarajan, A., Mehra, N., & Rajkumar, T. (2020). Economic perspective of cancer treatment in India. *Medical Oncology*, *37*(11), 1–7.

National Cancer for Disease Informatics and Research 2020, Report of National Cancer registry Programme (2012-2016). Retrieved July 18, 2022, from https://ncdirindia.org/All_Reports/Report_2020/resources/Chapter7CancerBreast.pdf

Palència, L., Espelt, A., Rodríguez-Sanz, M., Puigpinós, R., Pons-Vigués, M., Pasarín, M. I., ... & Borrell, C. (2010). Socio-economic inequalities in breast and cervical cancer screening practices in Europe: influence of the type of screening program. *International Journal of Epidemiology*, *39*(3), 757-765.

Pati, S., Hussain, M. A., Chauhan, A. S., Mallick, D., & Nayak, S. (2013). Patient navigation pathway and barriers to treatment seeking in cancer in India: a qualitative inquiry. *Cancer Epidemiology*, *37*(6), 973-978.

Pearlman, P. C., Divi, R., Gwede, M., Tandon, P., Sorg, B. S., Ossandon, M. R., ... & Lash, T. B. (2016). The National Institutes of Health Affordable Cancer Technologies program: Improving access to resource-appropriate technologies for cancer detection, diagnosis, monitoring, and treatment in low-and middle-income countries. *IEEE journal of translational engineering in health and medicine*, *4*, 1-8.

Porta, M. (Ed.). (2014). *A dictionary of epidemiology*. Oxford university press.

Pramesh, C. S., Chaturvedi, H., Reddy, V. A., Saikia, T., Ghoshal, S., Pandit, M., Babu, K. G., Ganpathy, K. v., Savant, D., Mitera, G., Sullivan, R., & Booth, C. M. (2019).Choosing Wisely India: ten low-value or harmful practices that should be avoided in cancer care. The Lancet Oncology, 20(4), e218–e223.

Rajpal, S., Kumar, A., & Joe, W. (2018). Economic burden of cancer in India: Evidence from cross-sectional nationally representative household survey, 2014. *PloS One*, *13*(2), e0193320.

Saha, U. C., & Saha, K. B. (2010). A trend in women's health in India–what has been achieved and what can be done. *Rural and Remote Health*, *10*(2), 296–306.

Sasco, A. J., Kaaks, R., & Little, R. E. (2003). Breast cancer: occurrence, risk factors and hormone metabolism. *Expert review of anticancer therapy*, *3*(4), 546-562.

Sen, S., Khan, P. K., Wadasadawala, T., & Mohanty, S. K. (2022). Socio-economic and regional variation in breast and cervical cancer screening among Indian women of reproductive age: a study from National Family Health Survey, 2019-21. *BMC Cancer*, *22*(1), 1–13. https://doi.org/10.1186/S12885-022-10387-9/FIGURES/1

Smith, R. D., & Mallath, M. K. (2019). History of the growing burden of cancer in India: from antiquity to the 21st century. *Journal of global oncology*, *5*, 1-15.

Sponholtz, T. R., Palmer, J. R., Rosenberg, L., Hatch, E. E., Adams-Campbell, L. L., & Wise, L. A. (2017). Reproductive factors and incidence of endometrial cancer in US black women. *Cancer Causes & Control*, *28*, 579-588.

Sung, H., Ferlay, J., Siegel, R. L., Laversanne, M., Soerjomataram, I., Jemal, A., & Bray, F. (2021). Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: a cancer journal for clinicians*, *71*(3), 209-249.

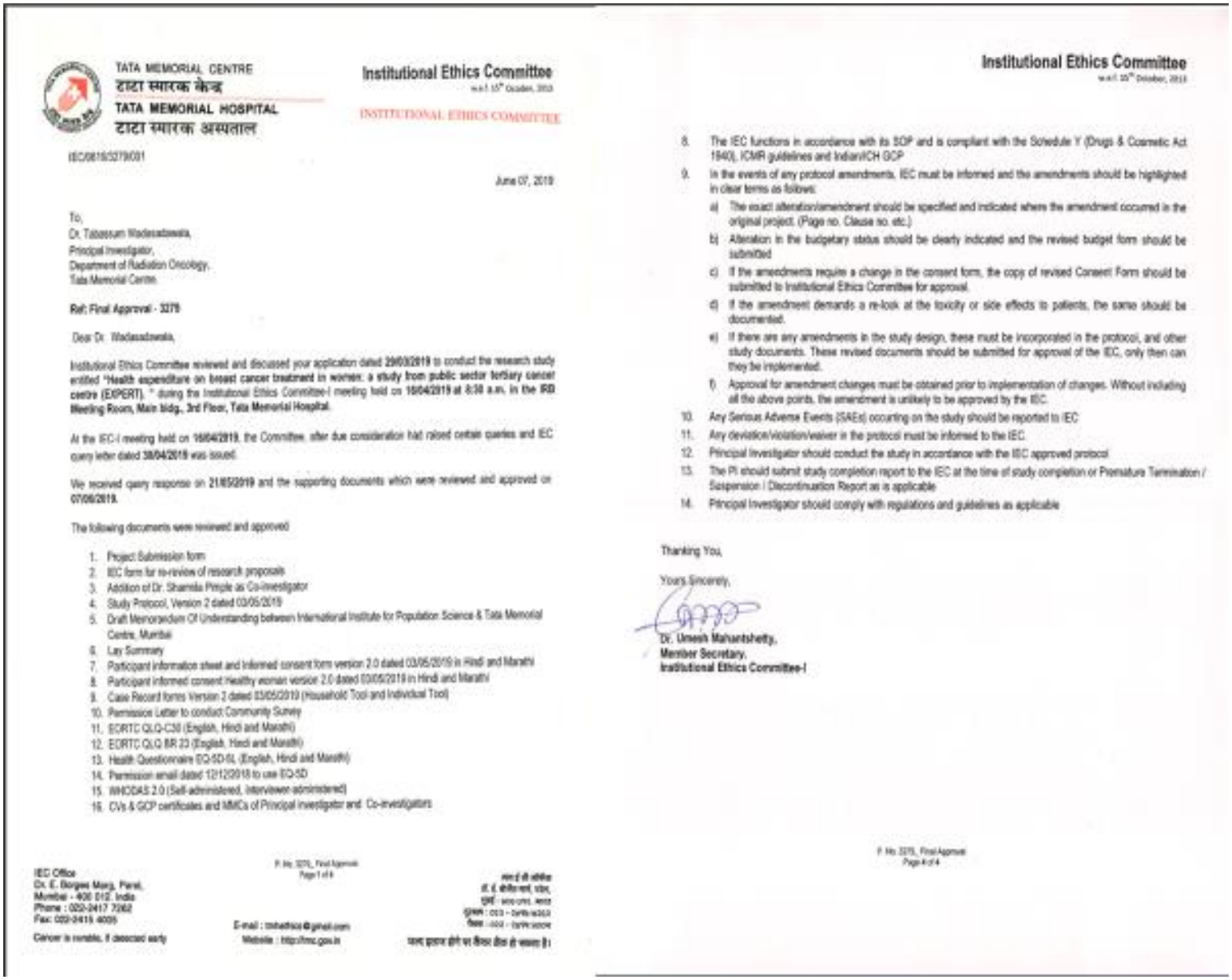
Sung, Hyuna, et al. "Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries." *CA: a cancer journal for clinicians* 71.3 (2021): 209-249.

Thakur, M., Gupta, B., Kumar, R., Mishra, A. K., Gupta, S., & Kar, S. K. (2019). Depression among women diagnosed with breast cancer: A study from North India. *Indian Journal of Medical and Paediatric Oncology*, *40*(03), 347-352.

Weiderpass, E., Meo, M., & Vainio, H. (2011). Risk factors for breast cancer, including occupational exposures. *Safety and health at work*, *2*(1), 1-8.

World Health Organization. (2020). *Cancer India 2020 country profile*. https://www.who.int/publications/m/item/cancer-ind-2020

Ethical Approval



TATA MEMORIAL CENTRE
टाटा स्मारक केन्द्र
TATA MEMORIAL HOSPITAL
टाटा स्मारक अस्पताल

Institutional Ethics Committee
w.e.f. 15th October, 2013

INSTITUTIONAL ETHICS COMMITTEE

IEC/0819/3279/091

June 07, 2019

To,
Dr. Tabassum Wadasadawala,
Principal Investigator,
Department of Radiation Oncology,
Tata Memorial Centre.

Ref: Final Approval - 3279

Dear Dr. Wadasadawala,

Institutional Ethics Committee reviewed and discussed your application dated **29/03/2019** to conduct the research study entitled **"Health expenditure on breast cancer treatment in women: a study from public sector tertiary cancer centre (EXPERT). "** during the Institutional Ethics Committee-I meeting held on **16/04/2019 at 8:30 a.m. in the IRB Meeting Room, Main bldg., 3rd Floor, Tata Memorial Hospital.**

At the IEC-I meeting held on **16/04/2019**, the Committee, after due consideration had raised certain queries and IEC query letter dated **30/04/2019** was issued.

We received query response on **21/05/2019** and the supporting documents which were reviewed and approved on **07/06/2019.**

The following documents were reviewed and approved:

1. Project Submission form
2. IEC form for re-review of research proposals
3. Addition of Dr. Sharmila Pimple as Co-investigator
4. Study Protocol, Version 2 dated 03/05/2019
5. Draft Memorandum Of Understanding between International Institute for Population Science & Tata Memorial Centre, Mumbai
6. Lay Summary
7. Participant information sheet and Informed consent form version 2.0 dated 03/05/2019 in Hindi and Marathi
8. Participant informed consent Healthy woman version 2.0 dated 03/05/2019 in Hindi and Marathi
9. Case Record forms Version 2 dated 03/05/2019 (Household Tool and Individual Tool)
10. Permission Letter to conduct Community Survey
11. EORTC QLQ-C30 (English, Hindi and Marathi)
12. EORTC QLQ BR 23 (English, Hindi and Marathi)
13. Health Questionnaire EQ-5D-5L (English, Hindi and Marathi)
14. Permission email dated 12/12/2018 to use EQ-5D
15. WHODAS 2.0 (Self-administered, Interviewer-administered)
16. CVs & GCP certificates and MMCs of Principal investigator and Co-investigators

IEC Office
Dr. E. Borges Marg, Parel,
Mumbai - 400 012. India
Phone : 022-2417 7282
Fax: 022-2416 4035

Cancer is curable, if detected early

P. No. 3279_ Final Approval
Page 1 of 4

E-mail : iecadhoc@gmail.com
Website : http://tmc.gov.in

Institutional Ethics Committee
w.e.f. 15th October, 2013

8. The IEC functions in accordance with its SOP and is compliant with the Schedule Y (Drugs & Cosmetic Act, 1940), ICMR guidelines and Indian/ICH GCP
9. In the events of any protocol amendments, IEC must be informed and the amendments should be highlighted in clear terms as follows:
   a) The exact alteration/amendment should be specified and indicated where the amendment occurred in the original project. (Page no. Clause no. etc.)
   b) Alteration in the budgetary status should be clearly indicated and the revised budget form should be submitted
   c) If the amendments require a change in the consent form, the copy of revised Consent Form should be submitted to Institutional Ethics Committee for approval.
   d) If the amendment demands a re-look at the toxicity or side effects to patients, the same should be documented.
   e) If there are any amendments in the study design, these must be incorporated in the protocol, and other study documents. These revised documents should be submitted for approval of the IEC, only then can they be implemented.
   f) Approval for amendment changes must be obtained prior to implementation of changes. Without including all the above points, the amendment is unlikely to be approved by the IEC.
10. Any Serious Adverse Events (SAEs) occurring on the study should be reported to IEC
11. Any deviation/violation/waiver in the protocol must be informed to the IEC
12. Principal Investigator should conduct the study in accordance with the IEC approved protocol
13. The PI should submit study completion report to the IEC at the time of study completion or Premature Termination / Suspension / Discontinuation Report as is applicable
14. Principal Investigator should comply with regulations and guidelines as applicable

Thanking You,

Yours Sincerely,

Dr. Umesh Mahantshetty,
Member Secretary,
Institutional Ethics Committee-I

P. No. 3279_ Final Approval
Page 4 of 4

Appendix 1: Household Schedule

PART A: SOCIO-DEMOGRAPHIC PROFILE OF THE HOUSEHOLD

1. Date of interview: | | | | | | | |
2. Interviewer ID: | | | |
3. Place (Circle) TMH……01
   ACTREC……02
4. Respondent: Patient 01 Spouse 02 Other HH member 03 Other, specify _____ 04
5. Status of interview: Completed 01 partially completed 02 Refused 03
6. Mode of interview: Face to face 01 Telephonic 02 Both
7. Language of interview: English 01 Hindi 02 Marathi 03 Others 04

8. Permanent address details

8.1. Place of residence Urban 01 Rural 02

8.2. Dwelling Slum 01 Non slum 02

8.3. Exact postal address (post office name taluka and mohalla)

8.4. PIN

8.5. State

8.6. District name

8.7. District code

8.8. Distance of Mumbai from native in Km.

8.9. Mobile no 1: Household head

8.10. Mobile no 2: Specify _____

9. Temporary address details at Mumbai:

9.1. Type of temporary residence: Hotel……01 Ashram……02
Rented room…….03 Others……..04

9.2. Exact Postal address (post office name taluka and mohalla):

9.3. PIN

9.4. Distance of current accommodation from TMC in Km:

9.5. Local contact number 1 (friend/relative):

9.6. Local contact number 2

10. Household roster: Please give me details information on each member of your household (list all members first then fill other details)

10.1. Number of usual family members in household: | | |

S N. (10.1)	Name (10.2) **Start with patient**	Age (10.3)	Sex (10.4)	Relation to HH (10.5)	Marital status 10+ years (10.6)	Usual Resident (10.7)	Educational level (10.8)	Years of schooling (10.9)	Insurance/reimbursement (10.10)	Type of HI (10.11)	Financial Dependent (10.12)
1	Patient Name:										
2											
3											
4											
5											

Codes for Item 10:

10.4: Male-01 Female-02 Others- 03

10.5: Head- 01 Spouse- 02 Children- 03 Son/Daughter in law- 04 Grand-children- 05 Parent- 06
Sibling- 07 Father-in-law- 08 Nephew/Niece- 09 Brother/Sister in law- 10 Other relative- 11 Friend- 12 Servant/Other- 13

10.6: Never married- 01 Currently Married- 02 Widow- 03 Divorced/Separated- 04 Married no gauna- 05 Deserted- 06

10.7 No- 00 Yes- 01

10.8 Illiterate 01 Primary I-V 02 Upper primary VI-VIII 03 Secondary IX-XII 04 Graduate (first degree/diploma) 05
Post graduate (second degree/diploma) 06 Literate without formal schooling 07 Attending school/college 08

10.10: No- 00 Yes- 01

10.11: ESIS- 01 CGHS- 02 SHIS- 03 AB- 04 Medical-reimbursement - 05 Other employer based HI - 06 Private or commercial HI- 07
RGJY 08 Others- 09 _____
ESIS: Employees State Insurance Scheme, CGHS: Central Government Health Scheme, SHIS: State Health Insurance Scheme
AB: Ayushman Bharat RGJY: Rajiv Gandhi Jeevandayi Yojna

10.12 No- 00 Yes- 01

10.13 Relationship of accompanying person:

11 Specify total number dependent members of the household ☐☐

12 Has anybody in the family died in last two years? No- 00 Yes- 01

12.1	12.2	12.3	12.4	12.5
Name	Age in yrs	Sex	Relation with current household head	Cause of death

12.3 Male 01 Female 02

12.4 Husband/Wife 01 Son/Daughter 02 Parent 03 Parent-in-law 04 Brother or sister 05 Grand-child 06 Son or daughter in law 07 Brother or sister in law 08 Other relative 09 Other/servant 10 Self 11

12.5 Cardiovascular 01 Ill-defined/ All other symptoms, signs and abnormal clinical and laboratory findings 02 Respiratory diseases 03 Malignant and other Neoplasms 04 Perinatal conditions 05 Diarrhoeal diseases 06 Digestive diseases 07 Unintentional injuries: Other Than Motor Vehicle Accidents 08 Respiratory infections 09 Tuberculosis 10 Accident 11 Old age 12 Others, specify _____13

13. What is your religion? Hindu- 01 Muslim- 02 Christian- 03 Sikh- 04 Buddhist- 05 Jain- 06 None- 07 Others- 08

14. What is your caste? General- 01 OBC- 02 SC- 03 ST- 04 Others- 05

14.1 What is your type of family: Alone- 01 Spouse only- 02 Spouse and children- 03 Extended family/non-nuclear family- 04 Children only 05 Others- 06

15. Ration card and other programs:

15.1 What type of ration card does your household has BPL- 01 APL- 02 Kesari- 03 No card- 04 ☐

15.2 How many members are listed on it?

15.3. Did your household avail any benefit from Govt. in last one year? NO- 00 Yes- 01 (If YES answer 15.4)

15.4 Please list the benefits your household acquire in last one year

1 _____ 2 _____ 3 _____

16. Living conditions

16.1 Type of house you are living in: Pucca- 01 Semi-pucca- 02 kutcha- 03 No structure- 04

16.2 Do you own your own house (you are currently living)? No 00 Yes 01

16.4 How many rooms does your house has? ☐☐

16.5 What is the approximate area of the house? Sqft. ☐☐☐☐☐

16.6 Do you own house other than you live No- 00 Yes- 01

16.7 What is the source of light in your house? Electricity-01 Kerosene/feul-02 Petromax/gas- 03
Solar-04 Specify others _____

16.8 Type of toilet facility available Open Field- 01 Shared pit toilet- 02 Own pit toilet- 03 Own flush toilet- 04 Public toilet- 05

16.9 Source of drinking water River/lake- 01 Dam/Public well- 02 Private well/bore- 03 Piped water- 04 Bottled water- 05 Tankers- 06

16.10 Where is the water source located? Own dwelling- 01 Own plot- 02 Elsewhere- 03

16.11 What type of fuel is used for cooking? Gas- 01 Kerosene- 02 Wood- 03 Waste- 04 Dung- 05 Electricity-06 Specify others _____

16.12 Cooking is done on: Stove- 01 Chulha- 02 Gas stove- 03 Open fire -04 Electricity- 05

17. List out items owned by the household	NO	YES
a) ELECTRICITY	00	01
b) MATTRESS	00	01
c) PRESSURE COOKER	00	01
d) CHAIR	00	01
e) COT/BED	00	01
f) TABLE	00	01
g) ELECTRIC FAN	00	01
h) RADIO/TRANSISTOR	00	01

i) B & W TELEVISION 00 01

j) COLOUR TELEVISION 00 01

k) SEWING MACHINE 00 01

l) MOBILE TELEPHONE 00 01

m) LAND LINE TELEPHONE 00 01

n) INTERNET 00 01

o) COMPUTER/LAPTOP 00 01

p) REFRIGERATOR 00 01

q) AIR CONDITIONER/COOLER. 00 01

r) WASHING MACHINE 00 01

s) WATCH/CLOCK 00 01

t) BICYCLE 00 01

u) MOTORCYCLE/SCOOTER 00 01

v) ANIMAL-DRAWN CART 00 01

w) CAR 00 01

x) WATER PUMP 00 01

y) THRESHER 00 01

z) TRACTOR 00 01

PART B: CONSUMPTION EXPENDITURE OF THE HOUSEHOLD

Please provide me detail of consumption (value) before and after diagnosis of cancer of **usual members only.** Include your home grown and market purchased for consumption. If consumption is from home production, then ask quantity and take approximate price. Take market value of actual consumed products (excluding stored goods). In case of local patient, column B also includes patient expenditure.

18.0 How long you have been staying in Mumbai for seeking treating at days ☐☐ TMC

18.0 How long you have been diagnosed with cancer ☐☐ days

Sr. No.	**A. USUAL EXPENDITURE IN LAST 30 DAYS**	Month after diagnosis of cancer (for patient and attendant) (A)	Month after diagnosis (for other HH members) (B)	Month before diagnosis of cancer (for all household member) (C)
18.1	Consumption on Food items (staple food, grocery, oil, vegetables, fruits, dairy, oil, egg, meat, etc.)			
18.2	Expenditure on Utility bills (mobile, electricity, water, cooking fuel etc.)			
18.3	Expenditure on Travel (car fuel or public transport)			
18.4	Expenditure on Entertainment (recreation, hobbies, sports)			
18.5	Habits (smoking, alcohol etc..)			
18.6	Consumer services (maid, cook, laundry, car wash, newspaper)			
18.6.1	Rentals (house only)			
18.6.2	Total monthly expenditure			
18.6.3	If yes have received subsidized food, accommodation or any other facility, please give equivalent amount of subsidized facility			
18.6.4	Total monthly usual expenditure			
	B. USUAL EXPENDITURE IN LAST ONE YEAR			
18.7	Education (books, fees) in last one year			
18.8	Clothes in last one year			
18.9	Insurance premium (life) in last one year			
18.10	Insurance premiums (health) in last one year			

18.11	Total usual expenditure in last one year			
	C. NON-USUAL EXPENDITURE IN LAST ONE YEAR			
18.12	Others (non-usual expenditure in last one month)			

18.13. Did your household reduce usual consumption of household members other than cancer patient (to meet the health care cost of cancer after diagnosis of cancer? 01. Yes 02 No

19. I want to know the detail of medical expenditure and reimbursemnet of your **household (for all usual members) on out-patient and inpatient** visits. **IN CASE MORE THAN ONE PERSON HOSPITALISED/HAD OUTPATIENT VISIT TAKE SUM OF ALL MEMBER AND WRITE**

19.1a Outpatient visit in last 365 days

	1	2	3	4	5	6	7	8	9	10	Total
Date of visit											
Type of hospital											
Reason											
HH member suffering (patient/others)											
Fees											
Tests											
Medication											
Travel cost (return total) per visit											
Food cost (total) per visit											
Self medication or test											
Outside investigation/medicine											
Accommodation cost per visit											
Total cost per visit											

19.1b Inpatient visit in last 365 days

	1	2	3	4	5	6	7	8	9	10	Total
Date of admission											
Date of discharge*											
Type of hospital											
Reason^											
HH member suffering											
Fees											
Tests											
Medication											

Blood/oxygen											
Transportation for patient (ambulance)											
Admission charges											
Outside test or medication											
Travel cost (return total) per day including patient											
Food cost (total) per day including patient											
Accommodation cost per day											
Expenditure not elsewhere reported (others)											
Total cost per admission											
Total expenditure if details cannot be obtained											
Duration of hospital stay (auto)											

* Code for Type of Hospital

1. Government hospital
2. Private hospital /Nursing home
3. NGO/Charity/Trust/Church-run hospital
4. Private (partial) and /Government (partial)/NGO (partial)

^ Code for reason of your last hospitalization?

A. Cancer
b. Chronic pain in your joints/arthritis/rheumatism/osteoporosis (joints, back, neck)
c. Dengue or other vector-born disease (Chikungunya, Filariasis)

d. Depression or anxiety/tension/sleep problem
e. Diabetes or related complications

f. Fever/Pyrexia of unknown reason
g. Fracture/Muscle rupture
h. Gastroenteritis or other diarrheal illness

i. High blood pressure (hypertension)
j. HIV/AIDS
k. Injury/accident (non-occupational)
l. Liver diseases (hepatitis, alcoholic liver disease, cirrhosis)

m. Malaria
n. Maternal or Prenatal Conditions (pregnancy-related problem or gynecological problems)

o. Occupation/work-related accident/injury
p. Other acute/chronic communicable diseases
q. Problems with your breathing (asthma/chronic obstructive pulmonary disease [COPD])
r. Problems with your heart, including unexplained pain in chest (angina, myocardial infarction [M.I.] heart-related surgery)
s. Stroke/sudden paralysis of one side of body
t. Surgery for abdominal causes (appendix, hernia, gall bladder, kidney)
u. Surgery for genitourinary (prostate, piles, incontinence)
v. Surgery for ophthalmic cause (cataract, glaucoma, retina, cornea)

19.2 How much your HH pay for outpatient care in last 365 days: Rs. _____

19.3 Specify the amount spent on episode of hospitalization

19.3a Last hospitalization in Rs. _____

19.3b Last but one hospitalization in Rs. _____

19.3c All other hospitalization in Rs. _____

20. What were the sources through which your household met the expenses for health care in last 365 days? (Please tell me whether you have used from any or all of the sources to meet the treatment of medical ailments)

	Sources		**Amount for non-cancer ailments**	**Amount for cancer treatment**	**Un-utilized amount**
1.	Personal Income of patient	1. Yes 2. No			
2.	House hold income excluding personal income	1. Yes 2. No			
3.	Household saving	1. Yes 2. No			
4.	Selling assets/property/jewelry	1. Yes 1. No			
5.	Loans/Borrowing (bank/friends/relatives)	1. Yes 2. No			
6.	Contribution from friends/relatives	1. Yes 1. No			
7.	Insurance coverage	1. Yes 1. No			
8.	Reimbursement from employer	1. Yes 1. No			
9.	Other (work more hours, additional member started earning etc…) please specify……..	1. Yes 2. No			
10.	Total (auto sum)				

21. Tell me the **debt** your household has currently:

21.1 How many loans your household had in total (more than 10,000 rupees)

21.2 Tell me detail of the three largest loans your household had now?

	What was the main purpose of loan (21.3)	Source of borrowing (21.4)	Rate of interest per annum (21.5)	Amount of loan (21.6)	Year of loan (21.7)	Amount to be repaid (21.8)
1st largest loan	1. Treating cancer 2. Education 3. Marriage 4. Buying/constructing home 5. Others	1. Bank 2. Employer 3. Money lender 4. Family and Friends 5. Others				
2nd largest loan						
3rd largest loan						

21.3 Important notes:

_____

_____

_____

PART C: INCOME DETAILS OF THE HOUSEHOLD AND PATIENT

22. What is income source of the Household **(circle all that applies):** Agriculture own farm-01 Agriculture by rent-02
Wage labour-03 Artisan/independent work-04
Petty shop /other trade-05 Organized trade/business-06
Service in public sector-07 Service in non-government sector-08
Pension/rent/dividend-09 Job in Private Sector-10
Others (specify)-11_____

23. How has cancer diagnosis impacted your household with respect to family earning?

23.1 Number of earning members in the household: Before cancer diagnosis ☐ After cancer diagnosis ☐

23.2 Did any member loose job because of cancer? Yes 01 No 02

23.3 Did any member change job because of cancer? Yes 01 No 02

23.4 **Monthly** loss/gain of income from above due to cancer Rs. ☐☐☐☐☐☐ (use negative for loss and positive for gain)

23.5 How many days were members on paid leave? ☐

23.6 How many days were members on unpaid leave? ☐

23.7 Did any member of HH work for more hours after cancer diagnosis: Yes 01 No 02

23.8 Did any member start working after cancer diagnosis (if not working earlier)? Yes 01 No 02

23.9 Did your HH reduce food expenditure after cancer diagnosis? Yes 01 No 02

23.10 Did your HH reduce non-food expenditure after cancer diagnosis? Yes 01 No 02

23.9. How do you rate the financial condition of the household before diagnosis of cancer? Very good-01 Good-02

Moderate-03 Poor-04 Very poor-05

23.10 How do you rate the financial condition of the household now after diagnosis of cancer? Very good-01 Good-02

Moderate-03 Poor-04 Very poor-05

23.11 Was your household financially independent before cancer was diagnosed? No- 00 Yes- 01

23.12 Is your household financially independent after cancer diagnosis? No- 00 Yes- 01

24. What is the estimated household income of all the members?

24.1 Estimted annual income before cancer diagnosis (numbers): Rs. ---------

24.2 Estimted monthly income after cancer diagnosis (numbers): Rs. ---------

24.1 Estimted annual income before cancer diagnosis (words): Rs. ---------

24.2 Estimted monthly income after cancer diagnosis (words): Rs. ---------

PART D: HEALTH SEEKING BEHAVIOUR OF THE HOUSEHOLD

25. When members of your household get sick, where do they mainly go for treatment? (**circle only one)**
Municipal hospital/dispensary 01 PHC/RH 02
AYUSH 03 NGO/Trust hospital 04
Private hospital/clinic 05 Traditional healer 06
Pharmacy or drug store 07 Home remedy 08
Others 09 Specify _____

26. If not 1-4, Why don't members of your household visit government facility when they are sick? No nearby facility 01 Facility timing inconvenient 02
Staff often absent 03 Waiting time too long 04
Poor quality of care 05 Others 06 Specify_____

27. Do you have cancer facility within 30 Km? No 00 Yes 01

28. Nearest cancer facility Distance from your residence: ☐☐ Km

29. What is the reason for not seeking or continuing treatment locally? (**tick all that apply**) No nearby facility 01 Facility timing inconvenient 02
Staff often absent 03 Waiting time too long 04
Poor quality of care 05 Belief system 06
Financial difficulties 07 Others 08 Specify_____

30. Where did you consult for cancer treatment? Municipal hospital/dispensary 01 PHC/RH 02
AYUSH 03 NGO/Trust hospital 04
Private hospital/clinic 05 Traditional healer 06
Pharmacy or drug store 07 Home remedy 08
Others 09 ___

31. How many members in the household are suffering from chronic medical ailments? ☐

32. How many members are on active non-cancer medical treatment? ☐

33. Type of chronic medical ailment for which active treatment ongoing: **(tick all that apply**) HT a DM b Thyroid disorder c Arthritis d Psychiatric e Cardiac f Pulmonary g Surgical 08 Cancer h Others i ____

34. How much would you pay for prevention of cancer? Under Rs. _----------_01 _Rs. ---------- to ---------- 02 Over Rs. ---------- 03 Others ----------_____

35. If government could provide you with **one** service to ease financial burden of cancer on you and your family, what would you prefer to have?

Transport vouchers 01 Accommodation vouchers 02
Food vouchers 03 Cover cost of treatment 04 Cashless facility 05 Others 06

INDIVIDUAL SECTION

PART A: Demographic

D001. HHID (To be taken from HH Part A 9.7 | | |

D002. Serial number (To be taken from HH Part A 10) | | |

D003. TMC Case number

D004. Date of registration

D005. Type of case file 01 NC 02 General 03 Private

D006. Date of interview:

D007. Interviewer ID: | | |

D008. Status of interview: Completed 01 partially completed 02 Refused 03

D009. Language of interview: English 01 Hindi 02 Marathi 03 Others 04

D010. In which day, month, and year you were born (DD/MM/YR):

D011 Age in completed years | | |

D012. Place of birth (State code)

D013. Which state you are currently residing (use state code of census of India) | | |

D014. What is your mother tongue?

1. Assamese
2. Bengali
3. Gujarati
4. Hindi
5. Kannada
6. Kashmiri
7. Konkani
8. Malayalam
9. Manipuri
10. Marathi
11. Nepali
12. Oriya
13. Punjabi
14. Rajasthani
15. Sindhi
16. Tamil
17. Telugu
18. Urdu
19. English
20. Other, please Specify

D015. How many years have you been living (continuously) in this area?

[Instruction for the interviewer: If less than 1 year, enter '0']

D016. What is your **current (latest)** marital status?

1. Currently married
2. Widowed
3. Divorced
4. Separated
5. Deserted
6. Live-in relationship
7. Never married

D017. [ask If 2 to 5 in Q 17] When did you get widowed/divorced/separated/deserted (with respect to your most recent marriage?) Number of YEARS Number of MONTHS:

Instruments served: Yes / No

Instruments collected: Yes/No

PART B: MEDICAL HISTORY

MH001. Date, month and year of symptom presentation:

MH002. Date, month and year of first diagnosis of cancer

MH003. Date of first consultation outside TMC:

MH 004 Did you start treatment locally (outside TMC)?

1 Yes
2 No

MH005. How many places did you consult before coming to TMC?

MH006. Who referred you to TMC?

1. Self
2. Company or sponsor (TMC on panel)
3. Local physician in private sector within Mumbai
4. Local physician in public sector outside Mumbai
5. Local physician in private sector outside Mumbai
6. Local physician in private sector within Mumbai

MH007. Types of intervention if evaluation started outside (Circle all that apply):

			Date of investigation
1	Biopsy	1. Yes 2. No	
2	X-ray/Mammography	1. Yes 2. No	
3	Other imaging	1. Yes 2. No	
4	Other tests	1. Yes 2. No	

MH008 Who accompanied you and for how many days? Code: _____

a. Husband 1. Yes 2. No _____days
b. Sister/Brother 1. Yes 2. No _____days

c. Parents 1. Yes 2. No _____days

d. In-laws 1. Yes 2. No _____days

e. Relative/Friend 1. Yes 2. No _____days

f. others (specify) _____ _____days

MH009. Type of accommodation you are currently using for stay:

1. Lodge/dormitory
2. Guest house
3. Charitable accommodation
4. Hospital facility
5. Rented house
6. Relatives
7. No accommodation
8. Others _____

MH010. Do you have cooking facility at the accommodation? 1. Yes 2. No

MH011. Provide details of the direct and indirect cost of evaluation for cancer diagnosis and treatment which was done outside TMC.

MH011.1. Direct Cost: Treatment (verify medical records and bills, ask HH, telephonic if needed)

	Last	Second last	Third last	Fourth last	Fifth last	Sixth last	Seventh last	Eight last and more	Total (auto-sum)
Date of visit									
Type of health centre 1. Public 2. Private									
Service Provider 1.Sx 2.CT 3.RT									
Travel time (in hours)									
Waiting time in days for evaluation									
Registration fees for registration									
Consultation fees									
Admission fees									
Investigation cost (blood, radiological, tissue diagnosis, others)									
Consumable/ medicine cost/cross referral									
Total cost per visit (auto-sum)									
Reimbursement amount if applicable									

MH011.2. Indirect cost of outside interventions

	Last	Second last	Third last	Fourth last	Fifth last	Sixth last	Seventh last	Eight last and more	Total (aut sum)
No of assistants									
Mode of travel (Train 01, bus 02, flight 03)									
Travel cost (return total) per visit									
Food cost (total) per visit									
Accommodation cost per stay period if applicable									
Total cost per stay period (autosum)									
No of days patient was absent from work since diagnosis									
Wage loss of patient since cancer diagnosis									
No of days accompanying person was absent from work since diagnosis									
Wage loss of accompanying person since cancer diagnosis									

MH012. Height in cm. | | |

MH013. Weight in kg | | |

MH014. BMI | | |

MH015. WHO Performance status

1 00
2 01
3 02
4 03
5 04

MH016. Laterality

1. Right
2. Left
3. Bilateral

MH017. Clinical Stage of cancer T _____ N_____ M _____

MH018. Do you have medical illness other than cancer?

1. Yes
2. No

MH019. Age at menarche in years | | |

MH020. Age at menopause in years | | | (99 for not applicable)

MH021. Number of children born | | |

MH022. Breast feeding

1. Yes
2. No

MH023. Duration of breast feeding

1. < 6 months
2. 6-12 months
3. >12 months

MH024. Use of hormone pills (contraception or replacement)

1. Yes
2. No
3.

MH025 Menopausal status 01 Premenopausal 02 Post-menopausal 03 Per-menopausal

MH026 Type of accommodation you are currently staying:

PART C: TREATMENT HISTORY AT TMH

TH001.1 Surgery and systemic therapy details

Treatment (Quote as many relevant options for each intervention)	Type OF TREATMENT	Others	No of cycles	Start date	End date	Postponed No-00 Yes-01	Reason Waiting-01 Financial 02 Logistics 03 Others 04	Complications No-00 Yes-01	Deferred any intervention No-00 Yes-01
Surgery 1 (MRM 01 /BCT 02 / biopsy 03 / revision 04 /re-suturing 04)									
Surgery 2 MRM 01 /BCT 02 / biopsy 03 / revision 04 /re-suturing 04)									
Surgery 3 (MRM 01 /BCT 02 / biopsy 03 / revision 04 /re-suturing 04)									
Chemo regimen 1 cycles (anthra 01/ taxanes 02 /others 03)									
Chemo regimen 2 cycles (anthra 01/ taxanes 02 /others 03)									
Chemo regimen 2 cycles (anthra 01/ taxanes 02 /others 03)									
Targeted therapy regimen 1 cycles (trastuzumab 01 / others 02/ none 03)									

Targeted therapy regimen 2 cycles (trastuzumab 01 / others 02/ none 03)									
Hormone therapy agent 1 (Tamoxifen 01 / Letrozole02 /None 03)									
Hormone therapy agent 1 (Tamoxifen 01 / Letrozole02 /None 03)									

TH001.2 Table for radiotherapy details

	Regimen 1 (latest first)	Regimen 2	Regimen 3	Regimen 4
Type of radiation				
Dose				
Fractions				
Type of technique				
Start date				
End date				

TH002. Pathological stage of cancer T _____ N_____ M _____

TH003. Histologic grade

1. Grade 1
2. Grade 2
3. Grade 3

TH004. ER status

1. Positive
2. Negative
3. Not known

TH005. PR status

1. Positive
2. Negative
3. Not known

TH006. Her2neu status

1. Positive
2. Negative
3. Equivocal
4. Not known

TH010. Provide details of the direct and indirect cost of treatment you received at TMC

TH010.1. Direct cost

	1	2	3	4	5	6	7	8	9	10	Total	Date of visit	Date of next visit
Date of visit													
Date of next visit													
Change in treatment category (Yes/No)													
Rx: Sx/CT/RT													
Travel time in minutes													
Waiting time in hospital in hours													
Registration fees													
Consultation fees													
Admission fees													
Investigation cost (blood, radiological, tissue diagnosis, others)													
Consumable/ medicine cost/cross referral													
Treatment cost: surgery													
Treatment cost: chemo													

Treatment cost: RT													
Outside test/medication													
Referred out (Yes/No)													
Total cost per visit (autosum)													
Total cost verified from DIS													
Reimbursement amount if applicable													
Reimbursement source if applicable													
	11	12	13	14	15	16	17	18	19	20	Total	Date of visit	Date of next visit
Date of visit													
Date of next visit													
Change in treatment category (Yes/No)													
Rx: Sx/CT/RT													
Travel time in minutes													
Waiting time in hospital in hours													
Registration fees													

Consultation fees													
Admission fees													
Investigation cost (blood, radiological, tissue diagnosis, others)													
Consumable/ medicine cost/cross referral													
Treatment cost: surgery													
Treatment cost: chemo													
Treatment cost: RT													
Outside test/medication													
Referred out (Yes/No)													
Reimbursement amount if applicable													
Reimbursement source if applicable													

TH010.2. Indirect cost

	1	2	3	4	5	6	7	8	9	10	Total	Date of visit	Date of next visit
Date from													
Date to													

Duration of treatment in days													
No of assistants													
Travel cost (return total) per person per visit													
Mode of travel (Train, bus, flight) per visit													
Food cost (total) per day per person													
Accommodation cost per stay period													
Outside test/medication													
Total cost per stay period													
Reimbursement amount													
No of days patient was absent from work since diagnosis													
Wage loss of patient since cancer diagnosis													
No of days accompanying person was absent from work since diagnosis													
Wage loss of accompanying person since cancer diagnosis													
	11	12	13	14	15	16	17	18	19	20	Total	Date of visit	Date of next visit

Date from													
Date to													
Duration of treatment in days													
No of assistants													
Travel cost (return total) per person per visit													
Mode of travel (Train, bus, flight) per person per visit													
Food cost (total) per day per person													
Accommodation cost per stay period													
Outside cost or medication													
Total cost per stay period													
Reimbursement amount													
No of days patient was absent from work since diagnosis													
Wage loss of patient since cancer diagnosis													
No of days accompanying person was absent from work since diagnosis													
Wage loss of accompanying													

person since cancer diagnosis													

10.6. Did you get an estimate of medical expenditure from your doctor? Yes 01 No 02 Did not seek 03

If yes, Give amount (in Rs.) ……. Surgery, …….(in Rs.) Chemotherapy ……in (Rs.) Radiotherapy ……..(in Rs.) Hormone therapy ……(in Rs.) Targeted therapy

PART D: Socio Economic and Work

SE001. Have you ever attended school?

1. Yes
2. No

SE002. Can you read and write?

1. Can read only
2. Can write only
3. Can both read and write
4. Cannot read or write

SE003. How many years of education have you completed? [Instruction for the Interviewer: Enter **'0'** if completed less than 1 year of schooling]? _____ Years

SE004. What was your medium of instruction and type of school?

Level of Education	Medium of schooling	Type of School
a. Secondary	1. English 2. Hindi 3. Regional 4. Not Available	1. Public 2. Private 3. Charity 4. Other (Specify)
b. Higher Secondary	1. English 2. Hindi 3. Regional 4. Not Available	1. Public 2. Private 3. Charity 4. Other (Specify)
c. Primary	1. English 2. Hindi 3. Regional 4. Not Available	1. Public 2. Private 3. Charity 4. Other (Specify)

SE005. Stream of your education

a. General
   1. Arts
   2. Commerce
   3. Science
   4. Other (specify)

b. Professional
   1. Medical
   2. Engineering
   3. Management
   4. Other (Specify)

C. Vocational (Specify)…..

SE006. What was your highest educational attainment?

1. No education
2. Below Primary
3. Primary completed
4. Middle Completed
5. Secondary
6. Higher Secondary
7. Graduation
8. Post-Graduation
9. M.Phil./Ph.D./ PDF
10. Other (Specify)

SE007. Has your partner ever attended school? Yes/No

SE007.1 What is the years of schooling of your partner?

SE008. Stream of your education of your Husband/partner (for married only)

a. General

1. Arts
2. Commerce
3. Science
4. Other (specify)

b. Professional
1. Medical
2. Engineering
3. Management
4. Other (Specify)

c. Vocational (Specify)….

SE009. Now, I am going to ask you some questions about your work and employment. **Have you ever worked for at least 3 months during your lifetime?** Work includes agricultural work, wage work, self-employed activities, and unpaid family business work. Work also includes all kinds of labor, excluding doing your own housework, whether you earn wages or not.

1. Yes
2. No

SE010. [Ask only if SE009=2] What is the **main reason** for you not to have worked in your lifetime?

1. Unemployed: interested in working but unable to find a job
2. Disabled and unable to work
3. Homemaker
4. Other, please specify _____

SE011 [Ask only if SE009=1] Have you ever stopped working for one year or more at a time due to reasons of Family. health, education, economic recession, natural disasters, etc.?

1. Yes
2. No

SE012. . [Ask if SE009=1 and SE011 =2] Why did you **mainly** stop working? Would any of the following apply to you?

1. Temporarily laid off
2. Cancer only
3. Health problem other than cancer
2. Low payment
3. Did not like the job
4. Long working hours
5. Family related issues
5. Other, please specify_____

SE013. Now I want to ask how your health affects paid work activities. Do you have any impairment or health problem that limits the kind or amount of paid work you can do?

1. Yes
2. No
3. Too old to work

PART E: SALARY AND WAGE

SW001. Please provide details of the wage or salary of the patient (make more than one entry if a person is involved in more than one occupation) in the table below: To be filled if SE009 = 01

1.1	1.2	1.3	1.4 (refer to 22 HH)	1.5	1.6	1.7	1.8	1.9	1.10	1.11	1.12
S NO	Are you currently working? No=00 Yes=01 **If no go to after cancer diagnosis section**	Description of work (see below)	Occupation code	Days/ week	Type of employer (see below)	Pay/Earnings per month (inclusive of salary, DA, HRA & any other allowances)	Sick leaves (availed per year in days)	Casual leaves (availed per year in days)	Unpaid leaves (availed per year in days)	Was on leave because of cancer diagnosis No=00 Yes=01	Permanent or casual job SE 012 Permanent=01 Contractual=02
Before cancer diagnosis											
After cancer diagnosis	No=00 Yes=01 **If no go to next section**										

1.3: 1. Regularly 2. Contract-based 3. Performance-based 4. Other, please specify

1.4: 1. Agriculture own farm 2. Agriculture by rent 3. Wage labour 4. Artisan/independent work 5. Petty shop /other trade 6. Organized trade/business
7. Service in public sector 8. Service in non-government sector 9. Pension/rent/dividend 10. Job in Private Sector 11. Others (specify)_____

1.6: 1. Government sector 2. Private sector/organization/entrepreneur 3. Cooperatives 4. NGO/Trust 5. Individual household 6. Other, please specify _____

SW002.How would you rate your work (professional) productivity on a scale of 0 to 10 before you were diagnosed with cancer? replace simple word to productivity

Health problems completely prevented me from working — Health problems had no effect on my work

0 1 2 3 4 5 6 7 8 9 10

SW003. How would you rate your work (professional) productivity on a scale of 0 to 10 now (after you were diagnosed with cancer?

Health problems completely prevented me from working — Health problems had no effect on my work

0 1 2 3 4 5 6 7 8 9 10

PART F: Health

H001. Now I want to ask you about your health. In general, would you say your health is excellent, very good, good, fair, or poor?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

H002. Has any health professional ever diagnosed you with the following **chronic conditions or diseases**?

	Has any health professional **ever** told you that you have	Diagnosed by a physician	Age of first Diagnosis in completed years	Are you currently taking any medicine?
1	Hypertension or high blood pressure	1. Yes 2. No		1. Yes 2. No
2	Diabetes or high blood sugar	1. Yes 2. No		1. Yes 2. No (Diet control)
3	Chronic lung disease such as asthma, chronic obstructive pulmonary disease/chronic bronchitis or other chronic lung problems	1. Yes 2. No		1. Yes 2. No
4	Chronic heart disease such as coronary heart disease (heart attack or myocardial infarction): History of definite or probable MI (EKG changes and/or enzyme changes) congestive heart failure, other chronic heart problem: Exertional or paroxysmal nocturnal dyspnea and has responded to digitalis, diuretics, or afterload reducing agents	1. Yes 2. No		1. Yes 2. No
5	Stroke (CVA or TIA)	1. Yes 2. No		1. Yes 2. No
6	Arthritis or rheumatism, osteoporosis, or other bone/joint disease	1. Yes 2. No		1. Yes 2. No
7	Any neurological, or psychiatric problems such as depression, Alzheimer's/ Dementia, unipolar/bipolar disorders, convulsions, Parkinson's etc.	1. Yes 2. No		1. Yes 2. No
8	High cholesterol	1. Yes 2. No		1. Yes 2. No
9	Solid tumor (localized/metastatic)	1. Yes 2. No		1. Yes 2. No
10	Hematological disease (Non-malignant/Lymphoma/ Leukemia)	1. Yes 2. No		1. Yes 2. No

11	Physical or mental impairment	1. Yes 2. No		1. Yes 2. No
12	Peripheral vascular disease: Intermittent claudication or past bypass for chronic arterial insufficiency, history of gangrene or acute arterial insufficiency, or untreated thoracic or abdominal aneurysm (≥6 cm)	1. Yes 2. No		1. Yes 2. No
13	Connective tissue disease If yes, mention type _____	1. Yes 2. No		1. Yes 2. No
14	Peptic ulcer disease: Any history of treatment for ulcer disease or history of ulcer bleeding	1. Yes 2. No		1. Yes 2. No
15	Liver disease: Severe = on dialysis, status post kidney transplant, uremia, moderate = creatinine >3 mg/dL (0.27 mmol/L) If yes, mention mild/mod/severe _____	1. Yes 2. No		1. Yes 2. No
16	Hemiplegia	1. Yes 2. No		1. Yes 2. No
17	Moderate to severe CKD: Severe = on dialysis, status post kidney transplant, uremia, moderate = creatinine >3 mg/dL (0.27 mmol/L), mild = creatinine <3 mg/dL If yes, mention mild/mod/severe _____	1. Yes 2. No		1. Yes 2. No
18	AIDS	1. Yes 2. No		1. Yes 2. No

H003. I am now going to ask you about other **acute diseases** that are common in India. In the past 2 years, have you had any of the following disease/ please identify all diseases you suffered from in past 2 years [disease diagnosed by health professional]?

		In past 1 year have you had?...	[Ask if Q3=1] Was this disease treated by a health professional?
1	Jaundice/Hepatitis	1. Yes 2. No	1. Yes 2. No
2	Tuberculosis (TB)	1. Yes 2. No	1. Yes 2. No
3	Malaria	1. Yes 2. No	1. Yes 2. No
4	Diarrhea/ Gastroenteritis	1. Yes 2. No	1. Yes 2. No
5	Thyroid	1. Yes 2. No	1. Yes 2. No
6	Urinary Tract Infection	1. Yes 2. No	1. Yes 2. No
7	Anemia	1. Yes 2. No	1. Yes 2. No
8	Chikungunya	1. Yes 2. No	1. Yes 2. No
9	Dengue	1. Yes 2. No	1. Yes 2. No
10	Other, Please specify…..	1. Yes 2. No	1. Yes 2. No

H004. Here are a few aids/instruments listed. Please tell me which of the following device(s), you have been using to assist you in the activities of daily living?

1	Hearing aid	1. Yes 2. No
2	Spectacles/contact lens	1. Yes 2. No
3	Denture	1. Yes 2. No
4	Walker/walking sticks	1. Yes 2. No
5	Wheel chair	1. Yes 2. No
6	Adjustable shower stools /Commodes	1. Yes 2. No
7	Back/ neck collar	1. Yes 2. No
8	Orthesis and prosthesis	1. Yes 2. No
9	Other, Please specify…..	1. Yes 2. No

H005. We would like to know about the medical history of your family. Could you tell me if your father, mother, brother, sister, children, grandchildren, has ever been diagnosed with the following diseases? Please only refer to blood-related family members-

		a. Father Yes 01 No 02	b. Mother Yes 01 No 02	c. Brother Yes 01 No 02	d. Sister Yes 01 No 02	e. Children Yes 01 No 02	f. Spouse Yes 01 No 02
1	Cancer						
2	Diabetes						
3	Hypertension						
4	Hypercholesterolemia						
5	Stroke						
6	Arthrits						
7	Asthma or pulmonary ailment						
8	Neurological or psychiatric problem						
9	Physical or mental impairment						

PART G: IMPACT OF CANCER ON ADL/IADL

DL001. Now, I will ask you about a few everyday activities. Please tell me if you have any difficulty with these because of a physical, mental, emotional, or memory problem **resulting from cancer**. Exclude any difficulties that you expect to last less than three months.

1	Getting in or out of bed (IADL)	1. Yes 2. No
2	Walking across a room (ADL)	1. Yes 2. No
3	Walking 100 yards	1. Yes 2. No
4	Sitting for two hours and more	1. Yes 2. No
5	Getting up from a chair after sitting for long period	1. Yes 2. No
6	Climbing one flight of stairs without resting	1. Yes 2. No
7	Stooping, kneeling or crouching	1. Yes 2. No
8	Reaching or extending arms above shoulder level (either arm)	1. Yes 2. No
9	Pulling or pushing large objects	1. Yes 2. No
10	Lifting or carrying weight over 5 kilos, like a heavy bag of groceries	1. Yes 2. No
11	Picking up a coin from table	1. Yes 2. No
12	Using the toilet, including getting up and down (IADL)	1. Yes 2. No
13	Bathing (ADL)	1. Yes 2. No
14	Eating difficulties (ADL)	1. Yes 2. No
15	Dressing, including putting on chapels, shoes, etc. (ADL)	1. Yes 2. No
16	Making telephone calls (IADL)	1. Yes 2. No
17	Taking medications (IADL)	1. Yes 2. No
18	Preparing a hot meal (cooking and serving) (IADL)	1. Yes 2. No

19	Doing work around the house or garden (IADL)	1. Yes 2. No
21	Managing money, such as paying bills and keeping track of expenses (IADL)	1. Yes 2. No
22	Shopping for groceries (IADL)	1. Yes 2. No

DL002. How would you rate your work ADL related productivity on a scale of 0 to 10 before you were diagnosed with cancer?

Health problems completely prevented me from working — Health problems had no effect on my work

0 1 2 3 4 5 6 7 8 9 10

DL003. How would you rate your activity if daily living related productivity on a scale of 0 to 10 after you were diagnosed with cancer?

Health problems completely prevented me from working — Health problems had no effect on my work

0 1 2 3 4 5 6 7 8 9 10

DL004.

4.1 Did cancer affect schooling/college of your children? 1. Yes 2. No
4.2 Did anyone take a permanent drop out from school or college? 1. Yes 2. No
4.3 Has cancer diagnosis affected your personal life? 1. Yes 2. No

DL005. How has cancer affected your personal life? (Ask each one of these)

5.1 MARRIAGE (Divorce/ Separated) 1. Yes 2. No
5.2 Social taboo 1. Yes 2. No
5.3 Sexual life disrupted 1. Yes 2. No
5.4 Ill health of other family members 1. Yes 2. No
5.5 Financial constraints 1. Yes 2. No
5.6 Others 1. Yes 2. No
5.7 Discontinuation of education 1. Yes 2. No
5.8 Seeking job 1. Yes 2. No
5.9 Leisure activity 1. Yes 2. No
5.10 Social/voluntary work 1. Yes 2. No
5.11 Ambulation/mobility 1. Yes 2. No

DL006. Please provide details of the change in your ADL due to cancer diagnosis

	Before cancer diagnosis HOW FREQUENTLY YOU WERE DOING	**After cancer diagnosis HOW FREQUENTLY YOU WERE DOING**
Activity	1. Daily 2. Weekly 3. Monthly 4. Never	1. Daily 2. Weekly 3. Monthly 4. Never

Household Activities	1. Daily 3. Monthly	2. Weekly 4. Never	1. Daily 3. Monthly	2. Weekly 4. Never
Child Care Activities	1. Daily 3. Monthly	2. Weekly 4. Never	1. Daily 3. Monthly	2. Weekly 4. Never
Professional Work	1. Daily 3. Monthly	2. Weekly 4. Never	1. Daily 3. Monthly	2. Weekly 4. Never
Voluntary work	1. Daily 3. Monthly	2. Weekly 4. Never	1. Daily 3. Monthly	2. Weekly 4. Never
Leisure activities (yoga, pranayama etc..)	1. Daily 3. Monthly	2. Weekly 4. Never	1. Daily 3. Monthly	2. Weekly 4. Never
Attending school/university	1. Daily 3. Monthly	2. Weekly 4. Never	1. Daily 3. Monthly	2. Weekly 4. Never
Seeking job	1. Daily 3. Monthly	2. Weekly 4. Never	1. Daily 3. Monthly	2. Weekly 4. Never
Social work	1. Daily 3. Monthly	2. Weekly 4. Never	1. Daily 3. Monthly	2. Weekly 4. Never
Rigorous physical work	1. Daily 3. Monthly	2. Weekly 4. Never	1. Daily 3. Monthly	2. Weekly 4. Never
Moderate intensity physical work	1. Daily 3. Monthly	2. Weekly 4. Never	1. Daily 3. Monthly	2. Weekly 4. Never
Others (specify)	1. Daily 3. Monthly	2. Weekly 4. Never	1. Daily 3. Monthly	2. Weekly 4. Never

DL007. Provide details of the spending due to need of assistance for various activities of living in tabulated form as below:

Activity	**Yes 01** **No 02**	**Is this assistance because of cancer**	**Number of assistants needed**	**Assistant** **(DL008 below)**	**Hours per day**	**Days per week**	**Paid** **Yes 01** **No 02**	**Rate amount**	**Total monthly amount**
Household Activities									

Child Care Activities (divide the cost if single person doing both duties)									
Professional Work									
Others (specify)									
Total									

DL008. Who helps you with that most often, select person if helper is a household member (Name if helper is not a household member)?

1. Spouse or partner
2. Son
3. Daughter
4. Grandchild
5. Father
6. Father of spouse or partner
7. Mother
8. Mother of spouse or partner
9. Brother
10. Brother-in-law
11. Sister
12. Sister-in-law
13. Other relative
14. Non-professional, paid helper
15. Professional (paid or non-paid)
16. Ex-spouse or partner
17. Other, please Specify_____

DL009. How often did the respondent receive assistance in answering this section?

1. Never
2. A few times
3. Most or all of the time

PART I: Health Behavior

HB001. Have you ever smoked tobacco (cigarette, bidi, cigar, hookah, cheroot) or used smokeless tobacco (such as chewing tobacco, gutka, pan masala, etc.)? 1. Yes 2. No

HB002. [Ask only if Q1=1] How old were you when you first started smoking or using smokeless tobacco?

Age _____

HB003. [Ask only if Q1= 1] What type of tobacco product have you used or consumed?

1. Smoke tobacco
2. Smokeless tobacco (such as chewing tobacco, gutka, pan masala, etc.)
3. Both Smoke and smokeless tobacco
4. Passive smoker

HB004. [Ask if Q1=1 and Q3=1 or 3] Do you currently smoke any tobacco products (cigarettes, bidis, cigars, hookah, cheroot)? 1. Yes 2. No, I have quitted

HB005. [Ask if Q3=1 or 3] How many cigarettes, bidis, cigars, cheroot do you usually smoke in a day?

_____ Number of cigarettes/bidis/cigars/ cheroo

HB006. Have you ever consumed any alcoholic beverages such as beer, wine, liquor, country liquor etc.?
1. Yes 2. No, never

HB007. [Ask only if Q5=1] At what age did you first consume alcoholic beverages?

Age-------

HB008. [Ask only if Q1=1] What type of drinks do you usually drink?

1. Beer

2. Wine

3. Distilled spirits/liquor/Arrack
4. Toddy/ Tadi (Palm wine)
5. Country Liquor/ Desi Sharab
6. Other, please specify _____

HB009. How frequently you drink

1. Daily
2. 3-5 day in a week
3. 1-2 days in a week
4. 1-2 day in month
5. Occasionally
6. Never

PART K: Insurance

I001.Introduction: I am going to ask you some questions on how you would pay for expenses incurred for health care if you were to fall ill or sustain an injury.

I002. Are you covered by health insurance? [Instruction for the interviewer: Interviewer should explain about health insurance as a type of insurance coverage that pays for medical and surgical expenses that are incurred by the insured. Health insurance can either reimburse the insured for expenses incurred from illness or injury or pay the care provider directly.] 1. Yes 2. No

I003. [Ask only if Q2=1] What types of health insurance are you covered by? [Multiple answers are allowed]

a. Employees State Insurance Scheme (ESIS) 1 YES 2 NO
b. Central Government Health Scheme (CGHS) 1 YES 2 NO
c State health government health insurance schemes, please specify 1 YES 2 NO
d. Ayushman Bharat 1 YES 2 NO
e. Medical reimbursement from an employer 1 YES 2 NO
f. Other employer based health insurance 1 YES 2 NO
g Private or commercial health insurance 1 YES 2 NO
h. Others, please specify _____

I004. [Ask only if Q2=1] What does this health insurance cover? [Instruction to the Interviewer: If more than one insurance, record the insurance that has the **largest cover**]

	Covered?
A. Surgery	1. Yes 2. No
b. Tests (e.g. X-Rays, MRI, CT scan, lab tests)	1. Yes 2. No
c. Doctor visits	1. Yes 2. No
d. Medicines	1. Yes 2. No
e. Dental care	1. Yes 2. No
f. In-home care	1. Yes 2. No
g. Hospitalization charges	1. Yes

	2. No
h. Other, please specify	1. Yes 2. No

I005. [Ask only if Q2=1] In which month and year did you first purchase/enrol in the health insurance policy which provides? _____Month _____Year

I006. [Ask only if Q2=1] When did this health insurance benefit begin? _____Month _____Year

I007. [Ask only if Q2=1] What was the amount of last premium (per year) paid for this policy (In rupees)? [Instruction for the interviewer: Enter '**0**' if no premium paid per year] _____Rs/year

I008. [Ask only if Q2=1] What is the maximum amount of insurance coverage (in rupees)? [Instruction for the interviewer: Enter '**9**' if total amount will be reimbursed by the organization/company where he/she works] _____Rs./year

I009. Did this insurance cover for cancer 1. Yes 2. No

I010. [Ask only if Q2=2] What is the **main reason** for not having health insurance?

1. I am not aware about health insurance
2. I cannot afford it
3. I do not need it
4. I do not know where to purchase it
5. I tried to get health insurance but was denied it
6. My family decided not to purchase it
7. Other, please specify _____

PART L: Hospitalization in the past 12 months (Treatment Seeking)

TS001. Who took care of you most of the time when you were admitted in the hospital?

1. Spouse
2. Son
3. Daughter
4. Son-in-law
5. Daughter-in-law
6. Grandchild
7. Parent
8. Parent-in-law
9. Brother
10. Sister
11. Grandparent
12. Other relative
13. Friends
14. Caregivers
15. Other, please specify
16. No one

_____

TS002. Overall, how satisfied were you with healthcare you received during the hospital stay?

1. Very satisfied
2. Satisfied
3. Neither satisfied nor dissatisfied
4. Dissatisfied

5. Very dissatisfied

TS003: Quality of care questions

I would like to ask you about your impressions of your last overnight stay. I would like you to rate your experiences using the following questions.						
For your **last hospitalization** or stay at long-term care facility, how would you rate the following:		VERY GOOD	GOOD	MODERATE	BAD	VERY BAD
HC224	….your experience about the length of the time you **waited** before being attended to	1	2	3	4	5
HC225	...your experience of **being treated respectfully**	1	2	3	4	5
HC226	…your experience of how **clearly** health care providers **explained** things to you	1	2	3	4	5
HC227	...your experience the way the health care staff ensured that you could **talk privately** to providers	1	2	3	4	5
HC228	...your experience of seeing a health care provider **of your choice**	1	2	3	4	5
HC229	...your experience of the **cleanliness** in the health facility	1	2	3	4	5

PART M: Outpatient Visit

OV001. Who took care of you most of the time when you had gone for outpatient visit? Same as TS003

OV002. Overall, how satisfied were you with healthcare you received in your last outpatient visit?

1. Very satisfied
2. Satisfied
3. Neither satisfied nor dissatisfied
4. Dissatisfied
5. Very dissatisfied

OV003: Quality of care questions

I would like to ask you about your impressions of your last outpatient visit. I would like you to rate your experiences using the following questions.						
For your **last visit** to a hospital or health care facility, how would you rate the following:		VERY GOOD	GOOD	MODERATE	BAD	VERY BAD
HC318	...your experience about the length of time you **waited** before being attended to	1	2	3	4	5
HC319	...your experience of **being treated respectfully**	1	2	3	4	5
HC320	…your experience how **clearly** health care providers **explained** things to you	1	2	3	4	5
HC321	...your experience of the way the health care staff is ensured that you could **talk privately** to providers	1	2	3	4	5

HC322	…your experience of getting a **health care provider of your choice**	1	2	3	4	5
HC323	...your experience about the **cleanliness** in the health facility	1	2	3	4	5

Appendix 3. **Follow-up schedule**

1. Record id:
2. Name of the patient:
3. How is your health today? 01 Excellent 02 Very Good 03Good 04Fair 05Poor
4. How would you rate your daily activity after completion of the treatment at TMC on a scale of 0 to 10, where 0 indicates worst state and 10 indicates best state?

Health problems completely prevented me from working — Health problems had no effect on my work

0 1 2 3 4 5 6 7 8 9 10

How would you rate your daily activity in post treatment of cancer on a scale of 0 to 10, where 0 indicates worst state and 10 indicates best state? (only after 6 months FU)

Health problems completely prevented me from working — Health problems had no effect on my work

0 1 2 3 4 5 6 7 8 9 10

Are you currently suffering from the followings:

	Has any health professional **ever** told you that you have	Diagnosed by a physician (1. Yes/No)	Year and month of diagnosis	Are you currently taking any medicine?
1	Hypertension or high blood pressure	1. Yes 2. No	MM YYYY	3. Yes 4. No
2	Diabetes or high blood sugar		1.	2. Yes 3. No (Diet control)
3	Chronic lung disease such as asthma, chronic obstructive pulmonary disease/chronic bronchitis or other chronic lung problems		1.	2. Yes 3. No
4	Chronic heart disease such as coronary heart disease (heart attack or myocardial infarction): History of definite or probable MI (EKG changes and/or enzyme changes) congestive heart failure, other chronic heart problem: Exertional or paroxysmal nocturnal dyspnea and has responded to digitalis, diuretics, or afterload reducing agents		1.	2. Yes 3. No
5	Stroke (CVA or TIA)		1.	2. Yes 3. No
6	Arthritis or rheumatism, osteoporosis, or other bone/joint disease	1. Yes 2. No	1.	2. Yes 3. No
7	Any neurological, or psychiatric problems such as depression, Alzheimer's/ Dementia, unipolar/bipolar disorders, convulsions, Parkinson's etc.	1. Yes 2. No	1.	2. Yes 3. No
8	High cholesterol	1. Yes 2. No	1.	2. Yes 3. No

9	Solid tumor (localized/metastatic)	1. Yes 2. No	1.	2. Yes 3. No
10	Hematological disease (Non-malignant/Lymphoma/ Leukemia)	1. Yes 2. No	1.	2. Yes 3. No
11	Physical or mental impairment	1. Yes 2. No	1.	2. Yes 3. No
12	Peripheral vascular disease: Intermittent claudication or past bypass for chronic arterial insufficiency, history of gangrene or acute arterial insufficiency, or untreated thoracic or abdominal aneurysm (≥6 cm)	1. Yes 2. No	1.	2. Yes 3. No
13	Connective tissue disease If yes, mention type _____	1. Yes 2. No	1.	2. Yes 3. No
14	Peptic ulcer disease: Any history of treatment for ulcer disease or history of ulcer bleeding	1. Yes 2. No	1.	2. Yes 3. No
15	Liver disease: Severe = on dialysis, status post kidney transplant, uremia, moderate = creatinine >3 mg/dL (0.27 mmol/L) If yes, mention mild/mod/severe _____	1. Yes 2. No	1.	2. Yes 3. No
16	Hemiplegia	1. Yes 2. No	1.	2. Yes 3. No
17	Moderate to severe CKD: Severe = on dialysis, status post kidney transplant, uremia, moderate = creatinine >3 mg/dL (0.27 mmol/L), mild = creatinine <3 mg/dL If yes, mention mild/mod/severe _____	1. Yes 2. No	1.	2. Yes 3. No
18	AIDS	1. Yes 2. No	1.	2. Yes 3. No

6. Here are a few aids/instruments listed. Please tell me which of the following device(s), you have been currently using to assist you in the activities of daily living?

1	Hearing aid	1. Yes 2. No
2	Spectacles/contact lens	1. Yes 2. No
3	Denture	1. Yes 2. No
4	Walker/walking sticks	1. Yes 2. No
5	Wheel chair	1. Yes 2. No
6	Adjustable shower stools /Commodes	1. Yes 2. No
7	Back/ neck collar	1. Yes 2. No
8	Orthesis and prosthesis	1. Yes 2. No
9	Other, Please specify…..	1. Yes 2. No

7. How much did you spend for cancer treatment (during 6-8 months of treatment) at TMC?

7.1. How much did you spend for cancer treatment outside of TMC?

7.2. How much reimbursement did you receive for cancer treatment?

8. What were the sources through which your household met the expenses of cancer treatment at TMC? (Please tell me whether you have used from any or all of the sources to meet the treatment of medical ailments)

	Sources		**Amount spent for cancer treatment**
1.	Personal Income of patient	1. Yes 2. No	

2.	House hold income excluding personal income	1. Yes 2. No	
3.	Household saving	1. Yes 2. No	
4.	Selling assets/property/jewelry	1. Yes 1. No	
5.	Loans/Borrowing (bank/friends/relatives)	1. Yes 2. No	
6.	Contribution from friends/relatives	1. Yes 1. No	
7.	Insurance coverage	1. Yes 1. No	
8.	Reimbursement from employer	1. Yes 1. No	
9.	Other (work more hours, additional member started earning etc…) please specify……..	1. Yes 2. No	
10.	Total (auto sum)		

9. How many loans your household had in total (more than 10,000 rupees) ? 1 Yes 2 No

10. Can you tell me detail of the three largest loans your household had now?

	What was the main purpose of loan (10.1)	Source of borrowing (10.2)	Rate of interest per annum (10.3)	Amount of loan (10.4)	Year of loan (10.5)	Amount to be repaid (10.6)
1st largest loan	1. Treating cancer 2. Education 3. Marriage 4. Buying/constructing home 5. Others	1. Bank 2. Employer 3. Money lender 4. Family and Friends 5. Others				
2nd largest loan						
3rd largest loan						

Appendix 4: **Quality of Life Schedule (EQ-5D-5L instrument)**

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about ❑

I have slight problems in walking about ❑

I have moderate problems in walking about ❑

I have severe problems in walking about ❑

I am unable to walk about ❑

SELF-CARE

I have no problems washing or dressing myself ❑

I have slight problems washing or dressing myself ❑

I have moderate problems washing or dressing myself ❑

I have severe problems washing or dressing myself ❑

I am unable to wash or dress myself ❑

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ❑

I have slight problems doing my usual activities ❑

I have moderate problems doing my usual activities ❑

I have severe problems doing my usual activities ❑

I am unable to do my usual activities ❑

PAIN / DISCOMFORT

I have no pain or discomfort ❑

I have slight pain or discomfort ❑

I have moderate pain or discomfort ❑

I have severe pain or discomfort ❑

I have extreme pain or discomfort ❑

ANXIETY / DEPRESSION

I am not anxious or depressed ❑

I am slightly anxious or depressed ❑

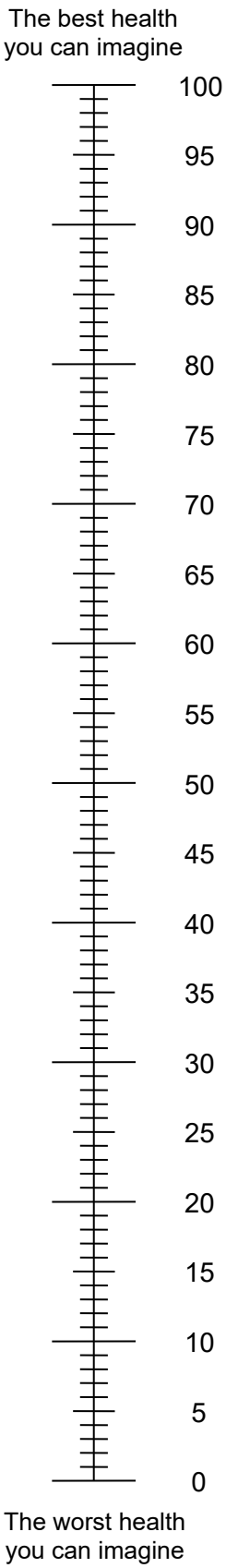
I am moderately anxious or depressed ❑

I am severely anxious or depressed ❑

I am extremely anxious or depressed ❑

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
  0 means the <u>worst</u> health you can imagine.
- Please mark an X on the scale to indicate how your health is TODAY.
- Now, write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



Appendix 5: **Non-cancerous schedule**

1. **Record id:**
2. **TMC case id:**
3. **Date of interview:** | | | | | | | |
4. **Respondent:**

   Patient 01 Spouse 02 Other HH member 03 Other, specify _____ 04

5. **Mode of interview:** 01 Face to face 02 Telephonic
6. **Language of interview:** 01 English 02 Hindi 03 Marathi 04 Others
7. **Patient name:**
8. **Patient age (in completed years):** | | |
9. **Religion:** 01 Hindu 02 Muslim 03 Christian 04 Other
10. **Caste:** 01 General 02 OBC 03 SC 04 ST 05 Others
11. **Years of schooling completed in complete years.** | | |
12. **Do you have any degree in technical education?** 01 No 02 Engineering 03 IT Diploma
13. **Number of usual household members:** | | |
14. **Permanent address details**
    a. Place of residence Urban 01 Rural 02
    b. Dwelling Slum 01 Non slum 02
    c. State
    d. District
    e. Mobile no
    f. Mobile no _____
15. **Temporary address details at Mumbai:**
    a. Type of temporary residence: Hotel……01 Ashram……02 Rented room…….03 Others……..04
16. **Reason for screening:**
    a. Referred by doctor
    b. Faced health problem
    c. (Open ended questions)

17. **Do you have any health insurance?** 01 Yes 02 No

17.1 [Ask if 17= 01 Yes] Type of Insurance 01 ESIS 02 CGHS 03SHIS 04 Pvt HI 05 AB 06 Other employee based HI 07 RGJY 08 Other

State of Health and Healthcare Expenditure

In this section I am going to ask you about status of your physical, functional and mental health in current days.

18. **In general, how do you rate your current health?** 1 Excellent 2 Very Good 3 Good 4 Fair 5 Poor
19. **How is your health today in a scale of 0 to 100 where 0 means worst health and 100 means best health?**
20. **Are you currently suffering from any of the following?**

	Has any health professional **ever** told you that you have	Diagnosed by a physician (1. Yes/No)	Year and month of diagnosis	Are you currently taking any medicine?
1	Hypertension or high blood pressure	5. Yes 6. No	MM YYYY	7. Yes 8. No
2	Diabetes or high blood sugar		MM YYYY	4. Yes 5. No (Diet control)
3	Chronic lung disease such as asthma, chronic obstructive pulmonary disease/chronic bronchitis or other chronic lung problems		MM YYYY	4. Yes 5. No
4	Chronic heart disease such as coronary heart disease (heart attack or myocardial infarction): History of definite or probable MI (EKG changes and/or enzyme changes) congestive heart failure, other chronic heart problem: Exertional or paroxysmal nocturnal dyspnea and has responded to digitalis, diuretics, or afterload reducing agents		MM YYYY	4. Yes 5. No
5	Stroke (CVA or TIA)		MM YYYY	4. Yes 5. No
6	Arthritis or rheumatism,	3. Yes	MM	4. Yes

	osteoporosis, or other bone/joint disease	4. No	YYYY	5. No
7	Any neurological, or psychiatric problems such as depression, Alzheimer's/ Dementia, unipolar/bipolar disorders, convulsions, Parkinson's etc.	3. Yes 4. No	MM YYYY	4. Yes 5. No
8	High cholesterol	3. Yes 4. No	MM YYYY	4. Yes 5. No
9	Solid tumor (localized/metastatic)	3. Yes 4. No	MM YYYY	4. Yes 5. No
10	Hematological disease (Non-malignant/Lymphoma/ Leukemia)	3. Yes 4. No	MM YYYY	4. Yes 5. No
11	Physical or mental impairment	3. Yes 4. No	MM YYYY	4. Yes 5. No
12	Peripheral vascular disease: Intermittent claudication or past bypass for chronic arterial insufficiency, history of gangrene or acute arterial insufficiency, or untreated thoracic or abdominal aneurysm (≥6 cm)	3. Yes 4. No	MM YYYY	4. Yes 5. No
13	Connective tissue disease If yes, mention type _____	3. Yes 4. No	MM YYYY	4. Yes 5. No
14	Peptic ulcer disease: Any history of treatment for ulcer disease or history of ulcer bleeding	3. Yes 4. No	MM YYYY	4. Yes 5. No
15	Liver disease: Severe = on dialysis, status post kidney transplant, uremia, moderate = creatinine >3 mg/dL (0.27 mmol/L) If yes, mention mild/mod/severe _____	3. Yes 4. No	MM YYYY	4. Yes 5. No
16	Hemiplegia	3. Yes 4. No	MM YYYY	4. Yes 5. No
17	Moderate to severe CKD: Severe = on dialysis, status post kidney transplant, uremia, moderate = creatinine >3 mg/dL (0.27 mmol/L), mild = creatinine <3 mg/dL If yes, mention mild/mod/severe _____	3. Yes 4. No	MM YYYY	4. Yes 5. No

18	AIDS	3. Yes 4. No	MM YYYY	4. Yes 5. No

21. **Apart from the above-mentioned conditions, do you have any other health abnormalities?** (Please specify if any)

22. Kindly tick the suitable option.

	Domain	**Scale**
	Do you currently have any problem in Mobility?	1. No problem 2. Slight problem 3. Moderate problem 4. Severe problem 5. Unable to do
	Do you currently face any problem in self-care?	1. No problem 2. Slight problem 3. Moderate problem 4. Severe problem 5. Unable to do
	Do you currently face any problem in doing your usual activity?	1. No problem 2. Slight problem 3. Moderate problem 4. Severe problem 5. Unable to do
	Do you currently have any discomfort or pain in your body?	1. No pain 2. Slight pain 3. Moderate pain 4. Severe pain 5. Extreme pain
	Do you currently have anxiety or depression?	1. No anxiety or depression 2. Slight anxiety or depression 3. Moderate anxiety or depression 4. Severe anxiety or depression 5. Extreme anxiety or depression

Economic condition of household

23. How do you rate your household current financial condition? 01 Excellent 02 Very good 03 Good 04 Fair 05 Poor

24. Does covid-19 have any impact on your household financial condition? 01 Yes 02 No

24.1 [Ask if 24= 01 Yes] Type of impact 01 Income reduced 02 Expenditure increased 03 Had to dependent on savings/ borrowed money/ loans etc. 04 Only 1 & 2 05 all of the above

24.2 **[Ask if 24.1= 01 or 04 or 05] To what extent your household income reduced due to COVID 19?** 01 less than 10% 02 10 to 20% 03 20 to 30% 04 30 to 40% 05 40 to 50% 06 More than 50%

25. No. of earning members of your household? ☐☐

26. What is the monthly income of your household?

27. Could you please tell me whether your household possess the following items?

a) ELECTRICITY	00	01
b) MATTRESS	00	01
c) PRESSURE COOKER	00	01
d) CHAIR	00	01
e) COT/BED	00	01
f) TABLE	00	01
g) ELECTRIC FAN	00	01
h) RADIO/TRANSISTOR	00	01
i) B & W TELEVISION	00	01
j) COLOUR TELEVISION	00	01
k) SEWING MACHINE	00	01
l) SMART PHONE…..	00	01
m) BASIC PHONE…….	00	01
n) LAND LINE TELEPHONE	00	01
o) INTERNET	00	01
p) COMPUTER/LAPTOP	00	01
q) REFRIGERATOR	00	01
r) AIR CONDITIONER/COOLER. .	00	01
s) WASHING MACHINE	00	01
t) WATCH/CLOCK	00	01
u) BICYCLE	00	01
v) MOTORCYCLE/SCOOTER	00	01
w) ANIMAL-DRAWN CART	00	01

x) CAR 00 01

y) WATER PUMP 00 01

z) THRESHER 00 01

aa) TRACTOR 00 01

Now I want to ask you about you and your household's medical expenditure.

28. Outpatient visit in last 30 days.

		For patient	**For other household members**
1.	Number of visits		
2.	Medical cost of all visits (total)		
3.	Non-medical cost of all visits		
4.	Reimbursement amount if any		

29. Inpatient visit in last 365 days.

		For patient	**For other household members**
1.	Number of visits		
2.	Medical cost of all visits (total)		
3.	Non-medical cost of all visits		
4.	Reimbursement amount if any		


Comorbidities
Cost of Treatment
Financial Protection
Capacity to pay
Trust
Financial Toxicity
Quality of Life
Out of pocket expenditure
Catastrophic health expenditure
Financial Burden
Reimbursement
Distress Financing
Longitudinal
Breast cancer
Cost of Treatment
Health expenditure
Cancer Survivor
Treatment Duration
MPCE