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**March, 2023**

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# Financial Catastrophe of Breast Cancer Treatment: Evidences from a Longitudinal Cohort study in India

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# Abstract

## *Background*

Breast cancer accounts for one-seventh of the two million cancer cases in India. It exerts a high economic, social and health burden on patients and households during and after treatment. The aim of this study is to examine the financial catastrophe of breast cancer treatment in India.

## *Data and Method*

The study used data of 500 new invasive breast cancer patients seeking treatment at one of the oldest and largest cancer treatment centres in the country, the Tata Memorial Centre (TMC), Mumbai. Data was collected from June, 2019 to March, 2022 using a longitudinal study design. Financial catastrophe was measured using household income, consumption and loan before and during cancer treatment, cost of treatment, out-of-pocket (OOP) payment, catastrophic health expenditure (CHE) and distress financing. Descriptive statistics, bivariate analysis and logistic regression was used in the analysis.

## *Results*

Half of the breast cancer patients diagnosed were under the age of 47 years. The average income of the households reduced by 14% during cancer treatment. The average expenditure on travel and accommodation increased by four and five times, respectively, during cancer treatment. The average cost of breast cancer treatment was ₹ 219,621 for non-chargeable or general category patients, and ₹ 416,198 for private patients. Less than 10% of the breast cancer patients had any form of health insurance at the time of registration although 73.2% had some form of financial assistance. The mean out-of-pocket expenditure was ₹149,315 for general and non-chargeable patients and ₹414,910 for private patients. The average loan of a breast cancer patient was ₹ 108,179. Overall, 84.6% of the households incurred CHE and 55% of households were facing impoverishment. The significant predictors of distress financing for cancer treatment are high OOP payment, poorer households and those who came from outside the state of Maharashtra for treatment.

*Conclusion*

Breast cancer in India primarily affects women in the prime working and reproductive age group. We found high OOP payment, CHE and indebtedness while treating breast cancer. It is recommended to increase awareness, early diagnosis, multi-disciplinary treatment, health insurance coverage and subsidise breast cancer treatment to reduce the financial distress of breast cancer patients in India.

**Keywords:** Breast cancer, loans, catastrophic health expenditure, distress financing, India.

# Highlights

1. From a cohort of 500 breast cancer patients registered for treatment at Tata memorial Center (TMC), 86% (429) patients successfully completed treatment and were interviewed at the end of treatment completion. Among those completed treatment, about 48% (206) of them received follow up treatment at TMC and were interviewed again in 6 months. The study was conducted over a period of 34 months; from June, 2019 to March, 2022. Data using structure schedule was collected at baseline, endline and follow up visit and cost expenditure on cancer treatment was collected at each visit of treatment to TMC.
2. The median age of breast cancer patients at diagnosis was 47 years, suggesting that the majority of patients were young and in the reproductive age group
3. Over two-third of the breast cancer patients were diagnosed at an advanced stage of cancer
4. Late diagnosis and longer duration of treatment was higher among less educated and poorer women
5. 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

6. Among all the patients, 5.2% discontinued their treatment due to death and 4.8% due to financial hardships

7. Less than 10% of the breast cancer patients had insurance coverage

8. 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%

9. 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

10. 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. These estimates were higher than estimated cost of treatment from previous studies

11. 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

12. 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

13. At the time of beginning cancer treatment, 38% had loans for treatment and it has increased to 65% during treatment at TMC

14. About two-fifth of the breast cancer patients reported poor self-rated health at baseline and end-line which decreased to 18% during follow-up

15. The chance of incurring loans, selling assets and loans and borrowings was higher among patients who incurred higher out-of-pocket (more than ₹150,000), who were poor and who came from outside of Maharashtra to seek treatment

# 1.    Introduction

Globally, cancer accounts for 9.6 million deaths annually and an estimated 234 million disability adjusted life years (DALYs) in 2018 (Bray et al., 2018; Fitzmaurice et al., 2019). Majority of the cancer deaths (70%) occurred in low-and-middle income countries (Forouzanfar et al., 2016). Of all the cancer deaths, 7% are due to breast cancer, the second leading cause of all oncological deaths (Bray et al., 2018). Unlike other cancers, breast cancer largely affects women in the prime working age (Ginsburg et al., 2017). About two million new cases of breast cancer are diagnosed annually, which is nearly 25% of all oncological diagnoses among women (Ginsburg et al., 2017; Ferlay et al., 2015). The incidence of breast cancer increased by 30% in both developed and developing countries in the last three decades (Herback & Grant,2017). In the recent decades, while there has been a decline in stomach, cervical and penile cancer, the incidence of colorectal, prostate and breast cancer, has been increasing (Smith et al., 2019). The major risk factors of breast cancer are changing fertility pattern (early age at menarche, later menopause, childlessness, late childbearing, reduced breast feeding), changing life style (drinking alcohol, smoking), increasing obesity, physical inactivity and family history (Economic Intelligence Unit, 2016; Ginsburg et al., 2017; Youn and Han 2020).

India accounts for 6.4% of the global cancer patients and cancer is the fifth leading cause of death. Of all the cancer cases, 21.8% were diagnosed with breast cancer in India where the mortality of breast cancer patient is higher than the global average (Kulothungan et al., 2022). Presently, breast cancer is the most common cancer among women globally, and has also become the most common cancer in India. Late diagnosis, non-availability of cancer treatment facilities in rural areas, familial negligence, social stigma, low standard of living and lack of social safety nets are some of the probable causes of high cancer mortality.

Compared to any other disease, cancer has adverse short and long-term consequences on the health of survivors and socio-economic condition of households. Cancer introduces sudden shock and fear into Indian households mainly because of poor survival and the high economic burden of treatment (Brown et al., 2001). Treatment of cancer is of long duration and most

expensive among all diseases. The cost of treatment of cancer is rising at an unparalleled rate which varies considerably within different treatment settings (Natarajan et al., 2020). Breast cancer treatment cost adversely affects the economic well-being of households, directly and indirectly. Households resort to borrowing and selling assets and absenteeism from work (direct) . The indirect cost includes the loss of wages and salaries of patients and accompanying persons, along with loss of productivity and time (Zheng et al., 2016; Ekwueme et al., 2014). In 2018, the mean out-of-pocket (OOP) payment for any cancer treatment on hospitalisation in India was estimated at ₹85,595; ₹38,859 at public and ₹115,771 at private hospitals (Goyanka et al., 2021). Medicine and hospitalization accounted for 60% of the total cost of breast cancer treatment (Jain & Mukherjee, 2016). Most of the OOP payment was spent for medication, transportation, and physician visits (Arozullah et al 2004). The direct medical cost of breast cancer patients treated in a private hospital was almost three times higher than that at a public hospital (Afkar et al., 2021). Studies have found that cancer is the leading cause of high catastrophic health spending and distress financing in India (Rajpal et al., 2018; Kastor & Mohanty, 2018). A study in the state of Punjab showed that 84% of the households with breast cancer patients experienced catastrophic health expenditure (CHE) and 51% of those faced distress financing (Jain & Mukherjee, 2016). Distance, type of work and insurance coverage are the major factors that increase CHE (Bose et al., 2022). Besides, cancer treatment increases hospital service utilization and patients who had received surgery, radiation therapy and chemotherapy had higher CHE (Zhao et al., 2020; Zhao et al., 2022). The probability of incurring CHE is high for those who undergo surgery, female-headed households, longer duration of stay, type of health insurance, poor households, and household size (Azzani et al., 2017; Zheng et al., 2018; Sun et al., 2021; Kim & Kwon, 2015). Incidence of CHE on cancer is higher among the poor and those who seek treatment in private hospitals (Rajpal et al., 2018; Singh et al., 2020).

Though cancer statistics are increasingly available in recent years, there are limited studies on economic adversity of breast cancer treatment in India. The economic burden of cancer on households and individuals is enormous. Existing studies estimated the overall cost of cancer treatment based on cross-sectional household data which is likely to underestimate the true cost of treatment (Mahal et al., 2013; Rajpal et al., 2018; Goyanka 2021). As cancer

treatment is prolonged, lasting over a year, reliable treatment cost is difficult to estimate at a point of time. Besides, there is no study that estimated debt due to cancer treatment. Against this background, this paper provides a comprehensive estimate of the financial catastrophe of breast cancer treatment India.

## 2. Data & Methods

### 2.1. Study Design

We used a longitudinal study design and collected data from a tertiary public sector cancer center in India. Data was collected under a project entitled "Health Expenditure on Breast Cancer Treatment in Women: A Study from Public Sector Tertiary Cancer Centre" (EXPERT), conducted by the Tata Memorial Centre (TMC), Mumbai and the International Institute for Population Sciences (IIPS), Mumbai, Maharashtra, India. The study had obtained prior approval from the institutional ethics committee of the TMC and is registered on the Clinical Trial Registry of India (CTRI/2019/07/020142).

### 2.2. Data collection and follow-up surveys

All the participants of the study were female breast cancer patients who sought treatment at TMC between June 2019 and March 2022. The current study was restricted to new invasive breast cancer patients treated with curative intent undergoing a multi-modality therapy consisting of surgery, chemotherapy, and radiotherapy. Considering the non-response rate, permissible error, and sufficient power, a maximum of 500 non-metastatic female breast cancer cases was considered for inclusion in the study. The inclusion criteria were:

i. Pathologically confirmed new invasive breast cancer case
ii. Non-metastatic invasive breast cancer (AJCC 8th edition)
iii. Intention to receive the entire treatment at TMC
iv. Multi-modal treatment comprising surgery, chemotherapy, and radiotherapy with or without hormone therapy or targeted therapy
v. Age > 18 years
vi. Willingness to provide all estimates of expenditure before and after coming to the tertiary hospital
vii. Willingness to share relevant socio-demographic information
viii. Willingness to fill out or respond to QoL instruments

The exclusion criteria were:
  i.   Inability or unwillingness to give written informed consent
  ii.  Inability to follow up after treatment completion
  iii. Unwillingness to follow up for two years
  iv.  Recurrent or progressive disease

After carefully considering the inclusion criteria, each participant was assigned a unique identification number (record id) that was used as key identifier. Written informed consent was taken from the participants and their accompanying person before conducting the interviews.

## 2.3. Stage of Data Collection

The study collected comprehensive socio-economic and health data at three time points viz., baseline, endline and follow up and expenditure on treatment during each visit to TMC during a period of 34 months from 26th June, 2019 till 31st March, 2022. The base line survey began on 26th June, 2019 and continued till 1st July, 2021. On an average, patients made 49 visits for treatment at TMC and expenditure on each episode of visit was collected.

The baseline survey is the first contact of the patient with the survey team at the time of registration. During the baseline survey, data was collected for the socio-demographic, health and medical history of the patients and economic condition of the households. Of the 500 patients registered at baseline, 71 patients discontinued treatment therefore, 429 patients could be interviewed successfully at endline. Endline survey began as soon as a patient completed her treatment. The endline survey began on 7th February, 2020 and continued till 31st March, 2022. Six months after completion of treatment, the patient visited for follow-up after a follow up schedule was canvassed. The follow up survey began on 18th January 2021 and was completed on 17th March, 2022. Data on household expenditure and quality of life was collected till the first follow-up visit, i.e., six months after concluding the treatment. In the follow up, a total of 206 patients were interviewed successfully. A large number of patients did not come for follow up services within the stipulated time. It was difficult to get follow up patients as many of them did not visit even after one year of completion of treatment due to COVID restrictions.

The data collection took 34 months against an estimated time of 24 months. The delay in survey was primarily due to the COVID-19 pandemic and need to minimize the risk of COVID exposure in cancer patients by minimizing the time spent in the hospital. Fewer patients visited during lockdown due to travel restrictions and this increased the time span for data collection. Some patients had stopped treatment due to financial crisis during the lockdown period and hence, their treatment got delayed. Many patients had missed follow-up after completing the treatment due to travel restrictions. Sometimes patients did not allow the medical social workers to conduct the interview out of fear of contracting COVID-19. Project staff and principal investigators also suffered from Covid-19. During the treatment period, social workers interviewed each patient for each of their visits to the hospital and only expenditure related information was collected.

## 2.4. Study questionnaire

The household questionnaire covered demographic and socio-economic characteristics of a participant's household including income, consumption pattern, health expenditure in the last one year, health-seeking behaviour, and loans and debts of the household at the time of registration at TMC. The individual questionnaire collected information on treatment history about current breast cancer diagnosis, treatment history at TMC, detailed record of the direct and in-direct health expenditure per hospital visit during the entire course of treatment, commodities and self-rated health status of patients. Both the household and individual questionnaires were canvassed at baseline. A total of four instruments pertaining to the quality of life were canvassed to the patients at the baseline, endline and follow-up period. These are the quality of life developed by European Organization for Research and Treatment of Cancer (EORTC): QLQ-C30 and BR23, World Health Organization Disability Assessment schedule (WHODAS) developed by WHO and EQ-5D-5L developed by EuroQol group. A shorter version of the questionnaire (baseline) was canvassed at the endline and follow up. Follow-up and end-line surveys collected information on self-reported health, comorbidities, health financing, insurance and reimbursement, loans and debts due to cancer treatment. All these questionnaires were canvassed in English/ Hindi / Marathi, based on the

preference of respondents. The medical terminologies were explained to the participants at the time of the interview, and no difficulties in understanding was reported. The questionnaires were validated by a panel of experts comprised of oncologists, health economists, demographers, and university professors.

The data collection process was executed by three trained medical social workers who captured every single visit made by the patient or attendant during the entire period of treatment that generally lasted for 6-12 months depending upon the modalities of treatment appropriate as per the stage of cancer. Various data quality measures like regular monitoring of data collection and re-validation were undertaken. Inconsistency and irrelevant data were identified and corrected regularly by principal investigators and researchers of the project.

## 2.5. Socio-demographic, economic and health variables

A set of socio-economic and health variables were used in the analyses. These were broadly categorised as patient related characteristics, health characteristics and household characteristics. The patient related characteristics included age (<30, 31-40, 41-50, 51-60, 60+ years), education (never attended /up to secondary /higher secondary and above), marital status (currently married/other), health insurance (yes/no), type of patient (non-chargeable or general/private). The health-related characteristics included treatment taken outside before coming to TMC (yes/no), co- morbidity (no co-morbidity/one or more co-morbidity) and stage of cancer diagnosis (stage I-II/stage III/ stage IV). The household related characteristics include residence at the time of treatment (hotel or rental room /own house/relatives and friends house/ ashram and other), religion (Hindu/ Muslim/ Other), social group (general /OBC/ SC,ST or other), residence (urban/rural), state (Maharashtra/Outside Maharashtra), major source of income (agriculture/labour/self-employed/service), distance from native place to Mumbai(<500kms, 500- 2000kms, >2000kms), duration of the treatment (<9 Months, 9-12 Months , >12Months), place of treatment (TMC / at least one outside TMC), income tertile (poor/middle/rich).

At TMC, the patients are classified as a) general b) non-chargeable and c) private. During registration, a patient is registered either as a general or as a private patient depending on their ability to pay for the treatment. Private

patients paid for the treatment as per the market rates while general patients were charged at subsidized rates. The cost of treatment for private patients' category was higher while the waiting time for availing treatment is relatively lower than for general or non-chargeable category patients. After careful scrutiny of the general patients by social workers, treatment is made available for extremely marginalized patients at very low cost or almost negligible cost which have been categorized as non-chargeable.

## 2.6. Outcome variable

A set of outcome variables were used in the analyses. These include, monthly per capita expenditure (MPCE), average monthly income of household, total cost and OOP payment incurred for treatment, source of reimbursement received by patients. The MPCE is defined as the total consumption expenditure divided by household size. The total consumption expenditure did not include health expenditure. The OOP is defined as total expenditure of the household excluding the reimbursement. The catastrophic health spending was estimated using capacity to pay approach (Xu et al.,2003). Many of these outcome variables were assessed at baseline, endline and follow up. A variable on distress financing, defined as those patients who either sold their jewellery or assets or took loans or borrowed money from any other sources to finance their cost of treatment, was computed and used in analyses.

## 2.7. Statistical analysis
Descriptive statistics, and multivariate logistic regression model was used in the analyses. The statistical analysis was carried out using STATA 17.

## 3. Results

**Socio-demographic profile**

### 3.1. Socio-demographic characteristics of breast cancer patients

Table 1 presents the profile of 500 breast cancer patients registered for treatment at TMC, Mumbai. Of all the patients registered for treatment 429 completed their treatment while 71 had discontinued. Of the 429 patients who sought treatment and had been successfully interviewed at the time of

conclusion (henceforth termed as endline), 206 patients were interviewed during their follow up visit after six months.

**Table 1: Duration of survey and completion rate of baseline, endline and follow up visit**

| No | Subjects | Starting date of interview | Ending date of interview | Duration of survey in months | Target | Achieved | Completion rate (in %) |
|----|----------|---------------------------|--------------------------|------------------------------|--------|----------|------------------------|
| 1 | Number of patients accrual (Baseline) | 26-06-2019 | 01-07-2021 | 25 | 500 | 500 | 100 |
| 2 | Number of concluded patients (Endline) | 07-02-2020 | 31-03-2022 | 25 | 500 | 429 | 85.8 |
| 3 | Number of follow-up patients | 18-01-2021 | 17-03-2022 | 14 | 429 | 206 | 48.0 |
| 4 | Number of non-cancerous women | 22-09-2021 | 19-11-2021 | 2 | 200 | 200 | 100 |
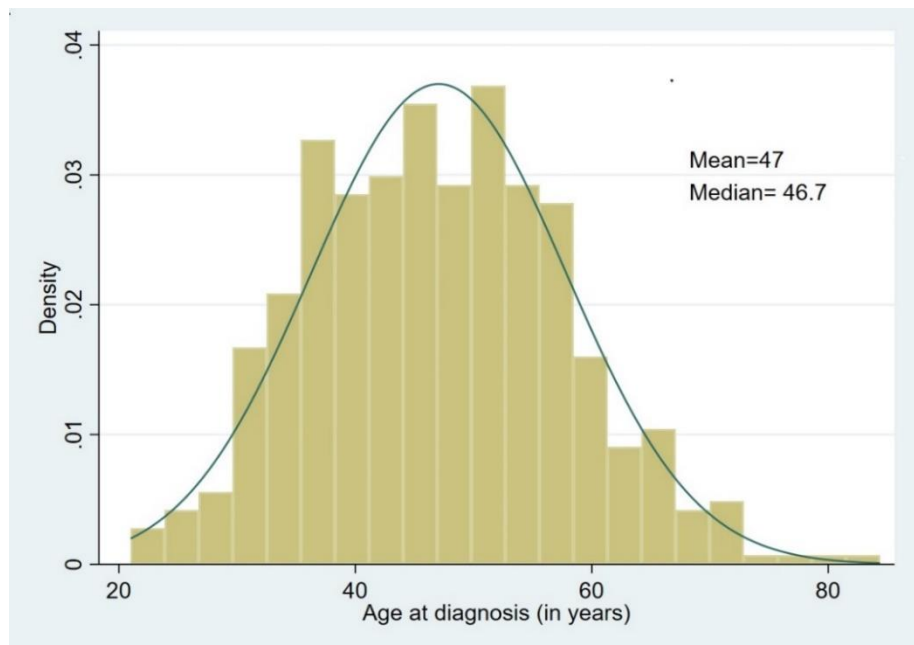


**Figure 1**: **Distribution of age at diagnosis of breast cancer patients**

The age distribution of the patients at the time of cancer diagnosis is shown in figure 1. The mean/median age of breast cancer diagnosis was 47 years. The youngest age at breast cancer diagnosis was 21 years and the oldest age at diagnosis was 84 years. Most of the cancer patients diagnosed were between 40 to 60 years.

**Table 2: Socio-demographic profile of 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 (years)** | | | | | | |
| < 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 | 34.0 | 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 | 9.0 | 45 | 8.9 | 38 | 12.6 | 26 |
| No | 91.0 | 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 | 13.0 | 65 | 13.9 | 60 | 13.6 | 28 |
| **Co-morbidity** | | | | | | |
| No co-morbidity | 75.6 | 378 | 69.0 | 296 | 74.3 | 153 |
| One or more co-morbidity | 24.4 | 122 | 32.0 | 133 | 25.7 | 53 |
| **Household characteristics** | | | | | | |
| **Residence during treatment** | | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| Hotel or rental room | 37.0 | 185 | 38.2 | 164 | 34.5 | 71 |
| Own house | 28.6 | 143 | 28.2 | 121 | 27.2 | 56 |
| Relatives' and friends' house | 23.0 | 115 | 22.6 | 97 | 26.7 | 55 |
| Ashram and others | 11.4 | 57 | 11.0 | 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 | 4.0 | 20 | 4.0 | 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 | 16.0 | 33 |
| **Residence** | | | | | | |
| Urban | 46.4 | 232 | 45.7 | 196 | 49.0 | 101 |
| Rural | 53.6 | 268 | 54.3 | 233 | 51.0 | 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 | 16.0 | 33 |
| **Major source of income** | | | | | | |
| Agriculture | 12.8 | 64 | 12.6 | 54 | 12.6 | 26 |
| Labour | 25.8 | 129 | 24.0 | 103 | 30.1 | 62 |
| Self-employed | 15.8 | 79 | 15.4 | 66 | 13.1 | 27 |
| Service | 45.6 | 228 | 48.0 | 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 | 34.0 | 146 | 31.1 | 64 |
| **Total** | **100** | **500** | **100** | **429** | **100** | **206** |

Table 2 shows the sample characteristics of breast cancer patients undergoing treatment at TMC at various stages of data collection. The basic demographic and social characteristics did not change 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 or older. The distribution remains similar at the endline. Almost half of the patients in the baseline/endline had completed

only secondary schooling (46%), and the mean years of schooling was 7 years. More than four-fifths of the patients were married at the time of the baseline and endline survey. Only 9% of the patients were covered by any health insurance scheme in the baseline and endline each and this was 13% at follow-up. During baseline, about 86% of the patients were registered for treatment at TMC under the general category and this was 81% at the time of endline. The proportion of non-chargeable patients increased from 1.2% at baseline to 5.4% at the time of endline. Only 13% of the patients were registered under the private category, and their numbers remained similar at the baseline and endline. A majority of the patients belonged to the Hindu religion (78%). More than half of the patients were from outside the state of Maharashtra. About two-third of the breast cancer patients were diagnosed at an advanced stage (stage III& IV), only 33% of the breast cancer patients were diagnosed at stage II while very few patients were diagnosed at stage I.

**Table 3: Average number of visits and duration of treatment of breast cancer in TMC, Mumbai, 2019-22**

| Patients' characteristics | Average number of visits | | Mean duration of treatment (Days) | |
|---|---|---|---|---|
| | Mean | SD | Mean | SD |
| **Age (years)** | | | | |
| < 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 3 shows the average duration of treatment and the average number of visits for breast cancer patients at TMC. On an average, a patient made 49 visits to TMC and received treatment for an average of 276 days. Both, the 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 patients staying in a relative's or friend's house (303 days) during treatment. Patients who came from outside Maharashtra had longer duration of treatment (288 days) compared to those from Maharashtra (262days).

**Economic profile**

*3.2. Consumption and income details of breast cancer patients*

Table 4 presents the monthly per capita expenditure (MPCE) of breast cancer patients before and after their breast cancer diagnosis. The components of MPCE are expenditure related to food, non-food items and other expenditure. The average 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 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 increased almost five folds following cancer diagnosis while the rent increased six times. The overall MPCE increased by 69.7%, from ₹ 2,900 to ₹ 4,921.

**Table 4: Monthly per capita expenditure of breast cancer patients (in ₹) before and after diagnosis of breast cancer**

| Variable | Before cancer diagnosis | | After cancer diagnosis | | Percentage change |
|---|---|---|---|---|---|
| | MPCE (in ₹) | SD | MPCE (in ₹) | SD | |
| Food | 1345 | 1407 | 1788 | 1143 | 33.0 |
| Utility | 393 | 298 | 387 | 334 | -1.4 |
| Travel | 201 | 313 | 1024 | 1420 | 408.7 |
| Entertainment | 62 | 131 | 60 | 143 | -4.0 |

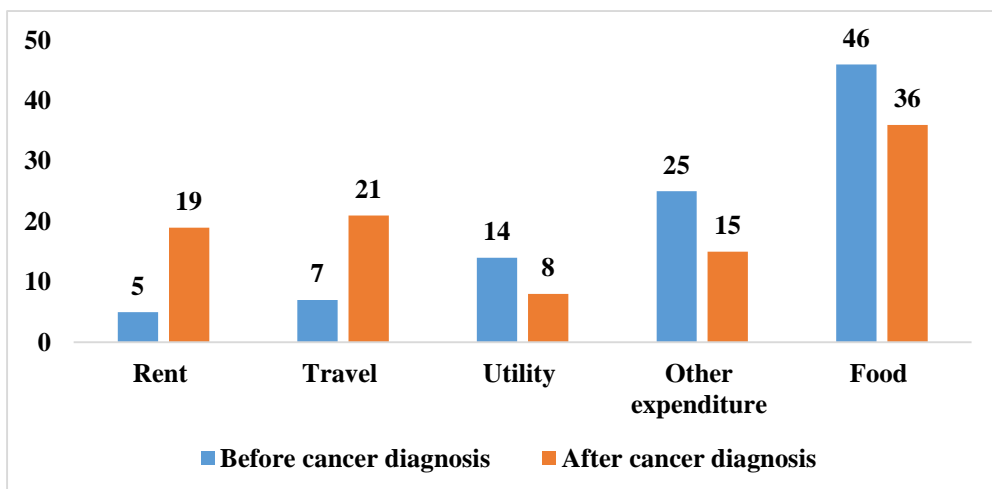| | | | | | |
|---|---|---|---|---|---|
| Maid, cook, laundry etc | 17 | 104 | 17 | 110 | 0 |
| Rent | 156 | 633 | 919 | 1780 | 489.5 |
| Non-food | 1555 | 3683 | 3133 | 5002 | 101.5 |
| **MPCE** | **2900** | **4094** | **4921** | **5553** | **69.7** |



**Figure 2: Percentage share of rent, travel, utility, and food expenditure to MPCE before and after breast cancer diagnosis**

Figure 2 represents the percentage share of specific consumption to the MPCE of breast cancer patients before and after cancer diagnosis. Following cancer diagnosis, the relative share of expenditure on rent to MPCE increased by about 3 times while that of travel increased by 2 times. The relative share of food, utility and other expenditure to MPCE declined during cancer treatment.

**Table 5: Variation in monthly average household income (in ₹) before and after cancer diagnosis**

| Patient's characteristics | Baseline | | | | Percentage difference |
|---|---|---|---|---|---|
| | Before cancer diagnosis | | After cancer diagnosis | | |
| | Median | IQR | Median | IQR | |
| **Age (years)** | | | | | |
| < 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 |

20

| | | | | | |
|---|---|---|---|---|---|
| **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 |

Table 5 presents the variation of monthly median household income before and after diagnosis of cancer, collected during baseline survey. 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 declined by 31.9%, 5.8% and, 20.0%, respectively. Patients who never attended school recorded higher decrease in income. The median monthly income before cancer diagnosis of rural patients was ₹9,000 and it decreased to ₹7,000 after diagnosis of cancer. Households that earned their income through labour showed a drastic reduction in income, by 64%, post cancer diagnosis.

### 3.3 Cost of breast cancer treatment

In Figure 3, the average cost of treatment, reimbursement and OOP payment of breast cancer patients' at TMC is shown. The average cost of treatment was ₹258, 095 and the mean OOP payment for the patients was ₹186, 461.
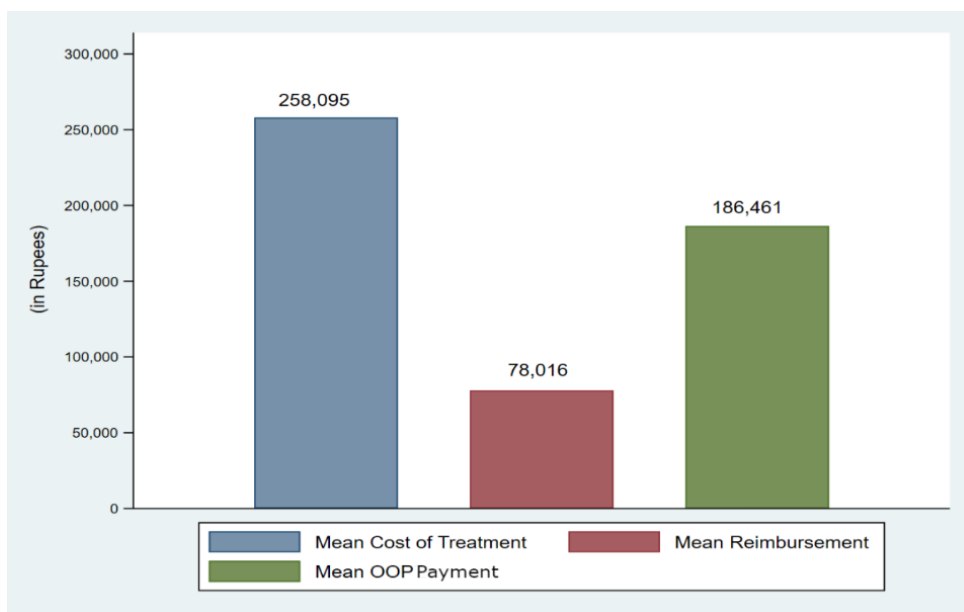
**Figure 3: Average cost of treatment, mean reimbursement and OOP payment for treatment of breast cancer**
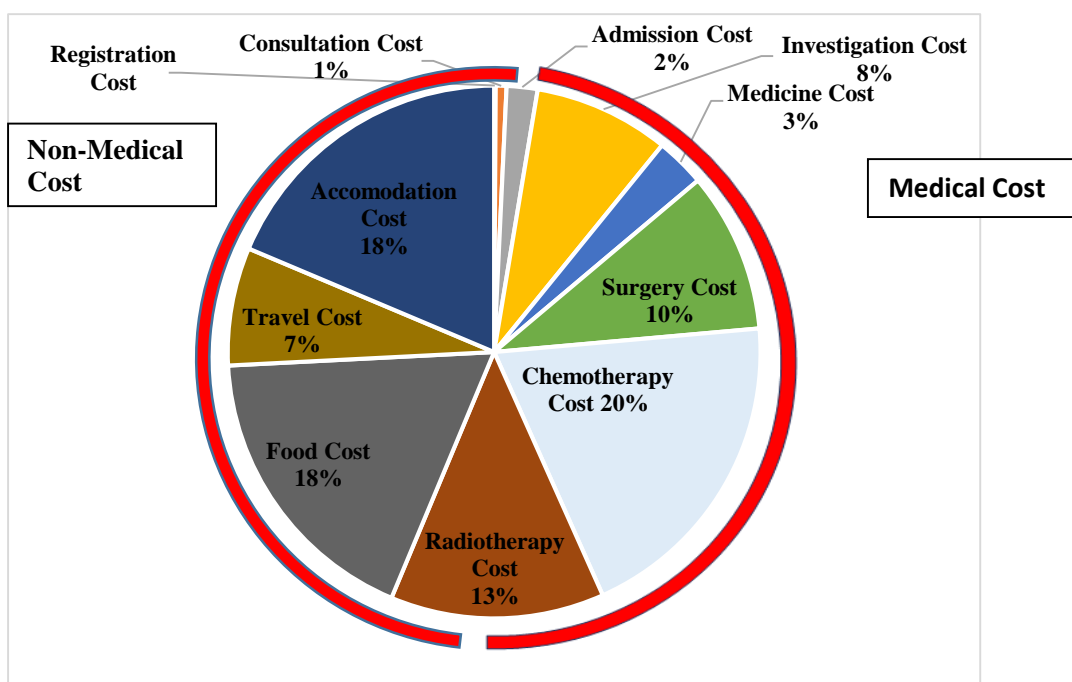


**Figure 4: Percent distribution of treatment cost of breast cancer by component at TMC, Mumbai**

Of the total cost of treatment at TMC, direct medical cost accounted for 56% while 44% was the non-medical cost (Figure 4). The distribution of total cost further suggests that chemotherapy accounted for the largest share (20%) followed by food, accommodation (18% each) and radiotherapy (13%). The largest share of medical cost of treatment was due to chemotherapy (35%), followed by radiotherapy (23%) and surgery (17%).

**Table 6: Socio-economic differentials in the total cost and OOP payment (in ₹) for breast cancer treatment, and share of OOP payment to total cost at TMC, Mumbai**

| SES Variables | N | Cost of treatment (in ₹) | | | OOP payment (in ₹) | | | OOP payment as a share of total cost | |
|---|---|---|---|---|---|---|---|---|---|
| | | 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 quintile** | | | | | | | | | |
| 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** |

Table 6 shows the socio-economic differentials in total treatment cost at TMC, total OOP payment and share of OOP payment to the total cost. The total cost of treatment/OOP payment at TMC was higher for patients who were younger, belonged to rural areas, had comorbidity, were diagnosed at later stage and sought at least one treatment outside TMC. The mean OOP payment was ₹ 186,461, accounting for 72% of the total cost.

On an average, the mean OOP payment for the richest quintile was three times higher than that of the poorest quintile. Further, the share of OOP payment to the total cost varied from 61% in the poorest quintile to 78% in the richest quintile. Similarly, the OOP payment for patients in stage I/II was ₹ 164,721, accounting for 64% of the total cost compared to ₹ 256,848 for stage IV patients, accounting for 74% of the total cost of treatment. The OOP payment also increased with the duration of treatment. Patients with less than 9 months of treatment incurred about half the OOP payment compared to patients treated for more than one year (₹ 156,628 vs ₹ 303,018).
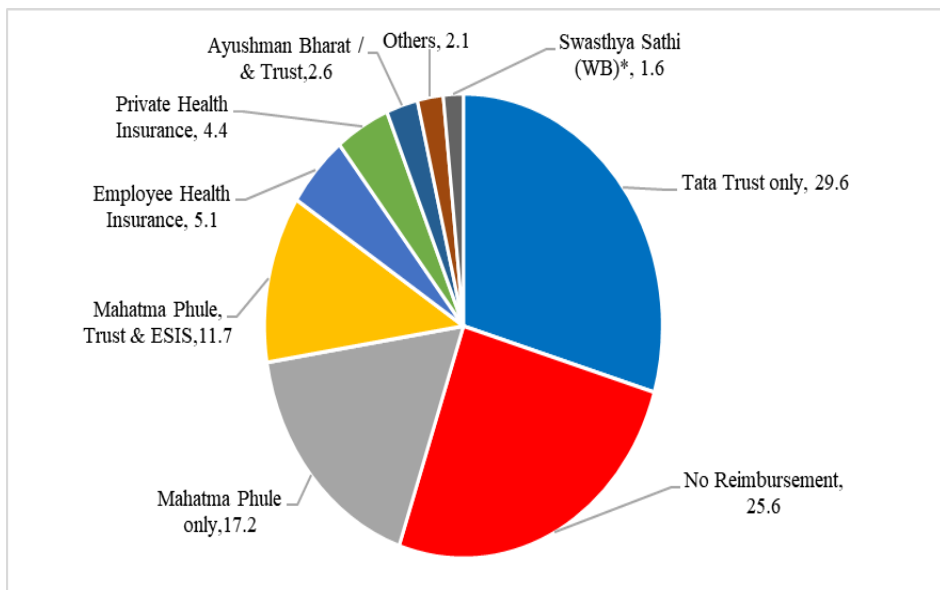


**Figure 5: Percent distribution of source of reimbursement received by patients at TMC.**

Figure 5 presents the percent distribution of source of reimbursement received by the breast cancer patients. The highest reimbursement was received from Tata trust (30%) followed by Mahatma Phule health insurance schemes (17%). Almost, one-fourth of the patients did not receive any reimbursement.

### 3.4. Loan and Debt of Breast cancer patients

Figure 6 presents the percentage of patients who had taken loan for treatment. At the baseline, only 38% of the patients had taken a loan, which increased to 65% at the endline and 69% at the follow-up period.
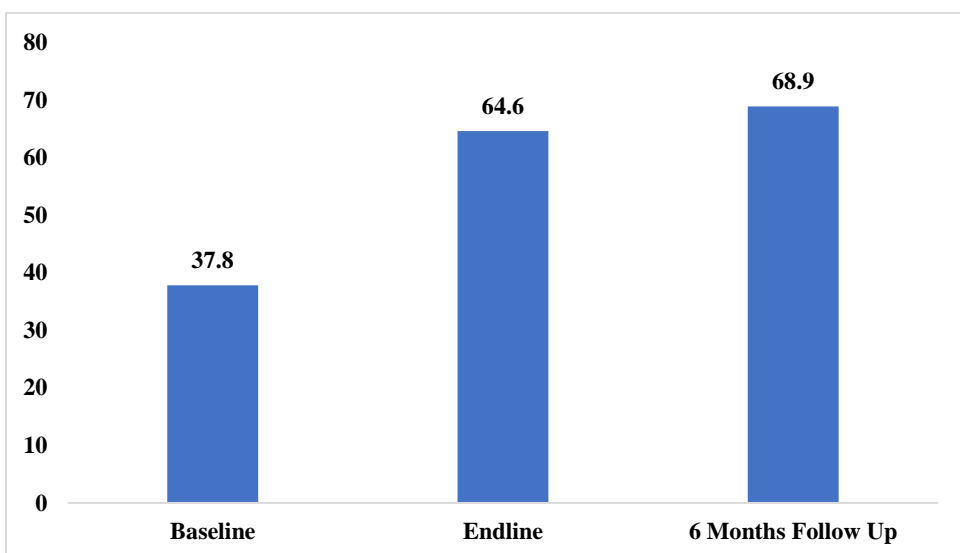
**Figure 6: Percentage of patients taking loan for treatment at baseline, endline and follow up**

**Table 8: Incidence and intensity of CHE and impoverishment by socio-demographic and economic characteristics among breast cancer patients**

| Variables | | Incidence of CHE | | Intensity of CHE | | Impoverishment | |
|---|---|---|---|---|---|---|---|
| Age | n | % | 95% CI | Mean | 95% CI | % | 95% CI |
| Up to 45 years | 202 | 85.2 | [79.5, 89.8] | 1.27 | [1.0, 1.6] | 53.5 | [46.3, 60.5] |
| Over 45 years | 227 | 84.1 | [78.7. 88.6] | 2.56 | [-0.1, 5.2] | 56.4 | [49.7, 62.9] |
| **Marital Status** | | | | | | | |
| Other | 63 | 84.1 | [72.7, 92.1] | 0.95 | [-0.2, 2.1] | 41.3 | [29.0, 54.4] |
| Currently Married | 366 | 84.7 | [80.6, 88.2] | 2.1 | [4.9, 3.7] | 57.4 | [52.1, 62.5] |
| **MPCE quintile** | | | | | | | |
| Poorest | 83 | 84.3 | [74.7, 91.4] | 5.4 | [-1.9, 12.7] | 63.9 | [52.6, 74.1] |
| Poorer | 78 | 83.3 | [73.2, 90.8] | 1.59 | [1.1, 2.1] | 56.4 | [44.7, 67.6] |
| Middle | 89 | 84.3 | [75.1, 91.1] | 1.26 | [0.9, 1.6] | 55.1 | [44.1, 65.6] |
| Richer | 89 | 85.4 | [76.3, 92.0] | 0.93 | [0.7, 1.1] | 48.3 | [37.6, 59.2] |
| Richest | 90 | 85.6 | [76.6, 92.1] | 0.79 | [0.7, 0.9] | 52.2 | [41.4, 62.9] |
| **Place of residence** | | | | | | | |
| Urban | 196 | 78.1 | [71.6, 83.6] | 2.04 | [-0.2, 4.3] | 43.9 | [36.8, 51.1] |
| Rural | 233 | 90.1 | [75.6, 93.6] | 1.89 | [0.8, 3.7] | 64.4 | [57.9, 70.5] |
| **Level of Education** | | | | | | | |
| Never Attended | 99 | 89.9 | [82.2, 95.0] | 0 | [-2.2, 2.2] | 60.6 | [50.3, 70.3] |
| Primary | 36 | 83.3 | [67.2, 93.7] | 6.92 | [-4.1, 18.0] | 55.6 | [38.1, 72.1] |
| Secondary | 167 | 82 | [75.4, 87.5] | 2.6 | [0.8, 5.1] | 47.9 | [40.1, 55.8] |
| Higher Secondary | 50 | 90 | [78.2, 96.7] | 1.23 | [3.9, 8.5] | 62 | [47.2, 75.3] |
| Above HS | 77 | 80.5 | [69.9,88.7] | 1.49 | [1.1, 1.8] | 58.4 | [46.7, 69.6] |
| **Religion** | | | | | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Hindu | 332 | 85.2 | [81.0, 88.9] | 2.1 | [0.3, 3.9]] | 55.7 | [50.2, 61.1] |
| Muslim | 80 | 82.5 | [72.4, 90.1] | 1.42 | [0.9, 1.9] | 56.3 | [44.7, 67.3] |
| Other | 17 | 82.4 | [56.6, 96.2] | 1.7 | [-0.2, 3.6] | 35.3 | [14.2, 61.7] |
| **Caste** | | | | | | | |
| General | 226 | 84.1 | [78.6, 88.6] | 2.11 | [0.42, 3.80] | 55.8 | [49.0, 62.3] |
| OBC | 145 | 86.9 | [80.3, 91.9] | 1.87 | [-1.2, 5.0] | 53.1 | [44.7, 61.4] |
| SC/ST/Other | 58 | 81 | [68.6, 90.1] | 1.5 | [0.8, 2.2] | 56.9 | [43.2, 69.8] |
| **Occupation** | | | | | | | |
| Agriculture | 54 | 98.1 | [90.1, 99.9] | 4.04 | [-2.2, 10.3] | 66.7 | [52.5, 78.9] |
| Labour | 103 | 86.4 | [78.2, 92.4] | 0.4 | [-1.7, 2.5] | 56.3 | [46.2, 66.1] |
| Self-employed | 66 | 80.3 | [68.7, 89.1] | 0.98 | [-0.1, 2.1] | 57.6 | [44.8, 69.7] |
| Service | 206 | 81.6 | [75.6, 86.6] | 2.41 | [0.4, 4.5] | 50.5 | [43.5, 57.5] |
| **Type of patient** | | | | | | | |
| General | 369 | 85.1 | [81.0, 88.6] | 2.05 | [0.44, 3.7] | 54 | [48.7, 59.1] |
| Private | 60 | 81.7 | [69.6, 90.5] | 1.26 | [0.99, 1.5] | 61.7 | [48.2, 73.9] |
| **Stage of Cancer** | | | | | | | |
| Early Stage | 155 | 81.3 | [74.2, 87.1] | 1.3 | [0.78, 1.82] | 52.3 | [44.1, 60.3] |
| Advanced Stage | 274 | 86.5 | [81.9, 90.3] | 2.42 | [0.71, 4.13] | 56.6 | [50.5, 62.5] |
| **Duration of Treatment** | | | | | | | |
| <9 M | 214 | 81.3 | [75.4, 86.3] | 2.04 | [0.41, 3.68] | 53.3 | [46.4, 60.1] |
| 9 M-12M | 174 | 87.4 | [81.5, 91.9] | 2.06 | [0.16, 3.96] | 54 | [46.3, 61.6] |
| >12 M | 41 | 90.2 | [76.9, 97.3] | 1.77 | [1.11, 2.43] | 68.3 | [51.9, 81.9] |
| **State** | | | | | | | |
| Maharashtra | 145 | 75.5 | [68.8, 81.4] | 2.3 | [-0.1, 4.8] | 41.1 | [34.1, 48.5] |
| West Bengal | 74 | 89.2 | [80.4, 94.9] | 1.6 | [1.2, 1.9] | 71.1 | [60.1, 80.5] |
| Bihar | 48 | 92.3 | [81.5, 97.9] | 4.7 | [-2.1, 11.5] | 59.6 | [45.1, 73.0] |
| Uttar Pradesh | 39 | 97.5 | [86.9, 99.9] | -1.1 | [-5.8, 3.6] | 67.5 | [50.8, 81.4] |
| Other | 57 | 91.9 | [82.2, 97.3] | 1.2 | [0.96, 1.5] | 64.5 | [51.3, 76.3] |
| **Total** | **429** | **84.6** | **[80.8, 87.9]** | **1.95** | **[0.55, 3.3]** | **55** | **[51.3, 76.3]** |

Table 8 presents the estimates of incidence and intensity of CHE and impoverishment by socio-economic and demographic characteristics of the breast cancer patients. The socio-economic gradient of CHE and impoverishment is strong. 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 difference 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 by type of income source showed a lower prevalence in self-employed and service households but high prevalence in households with labour and agriculture as the source of income. Households without any education had higher prevalence of CHE and impoverishment than households

with some level of educational attainment. 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. On an average, households incurring CHE incurred 195% more than their capacity to pay.

## 3.7 Distress financing

Treatment cost of breast cancer was financed through various sources as shown in Table 9. 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 borrowed to finance the cost of treatment. The share of total cost of treatment was mainly covered by either selling assets or borrowing (78.9%) followed by contribution from friends (63.4%) and insurance (52.6%).

**Table 9: Source of treatment financing and share to total cost of treatment.**

| Source of financing | % | N | 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 |

Table 10 presents the results of logistic regression analyses with odds ratio and 95% CI of breast cancer patients incurring distress financing. Patients who had OOP payment of more than ₹150,000 for cancer treatment were twice more likely to incur distress financing than patients with OOP payment less than ₹60,000. The odds of incurring distress financing were significantly higher among patients who belonged to poor (OR:3.25; 95% CI: 1.79, 5.90) or middle (OR:2.86; 95% CI: 1.60, 5.09)

income tertile, patients who were from outside Maharashtra (OR: 2.25; 95% CI: 1.26, 4.02) and lived in urban areas (OR: 1.82; 95% CI:1.05, 3.16).

**Table 10: Odds ratio and 95% CI of distress financing of cancer treatment**

| Distress Financing | Odds ratio | 95% CI |
|---|---|---|
| **OOP payment (₹)** | | |
| <60,000 | 1 | |
| 60,000-150,000 | 1.26 | [0.70, 2.25] |
| >150,000 | 2.71** | [1.45, 5.08] |
| **Age in Years** | | |
| <40 | 1 | |
| 41-50 | 1.37 | [0.79, 2.38] |
| 51-60 | 1.00 | [0.55, 1.83] |
| 60 and above | 0.56 | [0.23, 1.39] |
| **Marital status** | | |
| Other | 1 | |
| Currently married | 1.79 | [0.93, 3.42] |
| **Residence** | | |
| Rural | 1 | |
| Urban | 1.82* | [1.05, 3.16] |
| **Income tertile** | | |
| Poor | 3.25*** | [1.79, 5.90] |
| Middle | 2.86*** | [1.60, 5.09] |
| Rich | 1 | |
| **Years of schooling** | | |
| Never attended | 0.76 | [0.42, 1.37] |
| Up to secondary | 0.73 | [0.37, 1.47] |
| Higher secondary and above | 1 | |
| **Religion** | | |
| Hindu | 1 | |
| Muslim | 1.06 | [0.60, 1.86] |
| Other | 1.83 | [0.60, 5.54] |
| **Social group** | | |
| General | 1 | |
| OBC | 1.30 | [0.79, 2.15] |
| SC/ ST / Others | 0.91 | [0.46, 1.77] |
| **Stage of Cancer** | | |
| I/II | 1 | |
| III/IV | 0.75 | [0.47, 1.18] |
| **State** | | |
| Maharashtra | 1 | |
| Outside of Maharashtra | 2.25** | [1.26, 4.02] |
| **Patient category** | | |
| General | 1.66 | [0.78, 3.52] |
| Private | 1 | |
| **Health insurance** | | |
| Yes | 1.45 | [0.63, 3.38] |

| No | 1 | |
| **Duration of Treatment** | | |
| <9 Month | 1 | |
| 9Month -1Year | 1.01 | [0.64, 1.61] |
| > 1Year | 2.33 | [0.92, 5.89] |

(R): reference category; *, **, *** refers to <0.05, <0.01 and <0.001 level of significance respectively.

## 4. Discussion

Cancer has been increasing in India and is the fifth leading cause of death (ICMR-NCDIR-NCRP; 2020). Among all cancer types, breast cancer had the highest share, accounting for 21.8% of all cancer cases among women in the country (Kulothungan et al., 2022). While cancer registry provides macro estimates on the volume of cancer and death, there is limited information on individual and household characteristics of cancer patients in India. This is a comprehensive longitudinal study from a sample of 500 breast cancer patients who were registered for treatment at TMC. We present the financial catastrophe of breast cancer patients using OOP, CHE, distress financing, loans, loss of income and expenditure pattern. Following are the salient findings of the study.

Firstly, it was observed that the per capita household income of breast cancer households declined during the treatment period. The reduction in income was higher among households having labourers. Reduction in income was possibly due to absence from work by the bread winner of the family as well as of the cancer patient. Since a majority of the households were nuclear households comprising labourers, it is likely that they lost jobs due to having to accompany the patients for treatment. Secondly, the average food expenditure increased from ₹ 1345 before cancer diagnosis to ₹ 1788 after cancer diagnosis but the food expenditure as a share of MPCE declined from 46% to 36% during this period. Thirdly, 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. Fourthly, it was estimated the average cost of treatment was ₹ 258,095 and the OOP payment was ₹ 186,461 during cancer treatment. The average treatment cost for general or non-chargeable patients was ₹219,621 while it was ₹416,198 for private patients. Fifthly,

the high OOP payment was supported by the fact that 34% of the patients had taken a loan at the time of registration, 65% had loan at the time of completion of treatment and 68.9% had a loan at the time of concluding treatment. Loan as a share of household income was higher among the poor, less educated and rural residents. Seventhly, it was estimated that 85% of the patients had incurred CHE and that reimbursement from multiple sources reduced the CHE by only 13%. The odds of incurring distress financing were higher among patients incurring higher OOP payment, belonging to poor or middle-income group, coming from outside Maharashtra and living in urban areas.

We provide some plausible explanation of our results. The increase in food expenditure during treatment may be due to the cost of living in Mumbai since, before diagnosis of cancer food expenditure was at the native place, but during treatment it was at TMC. In addition, certain foods might have been prescribed as supplements, thereby, increasing food expenditure. However, food expenditure as a share of consumption expenditure declined after cancer diagnosis as the major contributor to increased expenditure became travel and accommodation. The effect was more prominent for patients coming from rural areas. Cancer treatment facilities in India are limited in number and mostly metro-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 and health status. Our estimates of OOP payment for treatment were much higher than previous estimates (Mahal et al., 2013; Rajpal et al., 2018; Goyanka,2021). One of the probable causes of high OOP payments is low insurance coverage among cancer patients. According to a recent study, there are 1,575 hospitals in India where cancer treatment costs can be reimbursed through this scheme; however, only 438 hospitals, including TMC, have multimodality treatment facilities. These public schemes included 86.2% of the patients in the present cohort and covered approximately 31% of their treatment expenses.

One of our recent papers estimated that the median age of breast cancer patients was 47 years and found that 15% of the patients discontinued treatment (Mohanty et al. 2023). This average age is higher than the average age of Indian women above 20 years estimated to be 33 years by the recently conducted NFHS 5. The average duration of schooling was similar as observed from our survey and the national

population aged above 20 years. The present study indicated that 46% of the urban patients were registered for treatment compared to 34% urban population estimated from NFHS-5. This suggests that while the breast cancer patients were a little older than the overall population, their socio-economic conditions were similar. However, the low median age of breast cancer patients in India compared to that in developed countries could be due to genetic, behavioural and life style factors.

In 2018, the Government of India launched a comprehensive cashless health insurance scheme, *Ayushman Bharat*, for the bottom 40% of the population, providing ₹500,000 per family per year for health care expenditure. This scheme has the potential to deliver quality health care for cancer by linking reimbursement directly to the evidence-based management guidelines recommended by India's National Cancer Grid, which is important for cancer treatment where affordability of treatment is a big issue (Caduff et al., 2019; Pramesh et al., 2019).

Although this study is one of its kind, being a large study highlighting important factors about the economic, social and health aspects of breast cancer patients, it is not without limitations. The study used 500 breast cancer patients as samples from a single centre, hence the results cannot be generalized. Secondly, 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. Finally, the study period also coincided with the Covid-19 pandemic which delayed the study, impacted the treatment period and might have increased the cost.

## 5.Conclusions

Majority of the women with breast cancer are in the working and reproductive age group. We found early age at onset of breast cancer, 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. Though the National Programme on Cancer Screening recommended screening for all women above 30 years, less than 1% of the eligible women in the 30-49 years age group are ever screened (Sen et al., 2022). It is suggested to effectively implement the recommendation of the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) that would diagnose patients at the right time and save lives. 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.

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**Appendix 1: Brief overview of baseline, end line and follow up schedules**

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

# International Institute for Population Sciences

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