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Catastrophic expenditure and treatment attrition in patients seeking comprehensive colorectal cancer treatment in India: A prospective multicentre study



*CROCODILE study group*¹

Summary

Background Although colorectal cancer is increasing in India, the cost of comprehensive treatment and its consequences for patients and households are unknown. This study aimed to describe catastrophic expenditure and treatment attrition in patients with a treatment plan for colorectal cancer.

Methods A prospective, multicentre, cohort study was conducted in five tertiary hospitals in India from December 2020 to March 2022. Consecutive patients with a new treatment plan for colorectal cancer were followed-up for six months. The total cost of treatment was reported, including out-of-pocket payments (OOPP, paid by patients at the time-of-service use) and covered by third parties (insurance, public funds). The primary outcome was catastrophic expenditure, defined as OOPPs greater than 25% of patient's annual household income and the secondary outcome was treatment attrition, defined as unplanned interruption of the treatment course not recommended by the clinical team.

Findings Of 226 patients included, 20 died within six months of being offered a treatment plan and four were lost to follow-up. The median total cost of colorectal cancer treatment was 407,508 Indian Rupees (INR/5340 USD), to which the biggest contributor was the patient's OOPP (median 330,277 INR/4328 USD). Surgery and anaesthesia costs (median 85,944 INR/1126 USD) were higher than radiotherapy (median 55,525 INR/728 USD) and chemotherapy (median 14,780 INR/194 USD). The overall catastrophic expenditure rate was 90.1% (182/202) and the treatment attrition rate was 9.4% (19/202). Patients with treatment attrition made lower OOPPs than those who completed treatment (median 205,926 vs 349,398 INR, $p < 0.01$) but had a similar risk of catastrophic expenditure (OR 0.23, 95%CI 0.03-2.28, $p = 0.186$).

Interpretation Most treatment costs for colorectal cancer were paid out-of-pocket by patients and catastrophic expenditure was common. Treatment attrition rates at tertiary centres were low, suggesting greater attrition at previous stages of care. Better financial protection may allow more patients to receive comprehensive cancer treatment while avoiding household financial catastrophe.

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Keywords: Catastrophic expenditure; Cancer; Colorectal cancer; Treatment attrition; India

Introduction

Colorectal cancer is currently the 7th most common cancer in India with 65 358 new cases in 2021.¹ The incidence of colorectal cancer has been increasing worldwide currently being 19.5 per 100 000 population globally and 15.2 in India.^{1,2} From 2004 to 2014, the age-sex adjusted rates of colorectal cancer in India have raised by 20.6%, with a steeper increase in adults aged

under 50 years.²⁻⁴ Although not yet included in early detection programs, colorectal cancer is the 6th type of cancer contributing to disability-adjusted life years loss in India.⁵

Treatment for cancer is one of the most expensive among non-communicable diseases, with catastrophic expenditure rates reported between 34% and 84%.⁶⁻¹⁷ Reducing catastrophic health spending is a Sustainable

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Research in context

Evidence before this study

A search on PubMed, Embase and Google Scholar on April 30th, 2022 was conducted using the terms “catastrophic expenditure”, “financial toxicity”, “cost of illness” or “health expenditure” and “cancer”, “neoplasm”, in combination with “colorectal cancer” or “India”. We identified 28 studies reporting the financial burden of cancer on Indian households, 18 of them including various types of cancer and 10 focusing on one type of cancer (4 in breast cancer, 2 head and neck, 1 cervical, 1 oral, 1 brain and 1 pancreatic). Only two studies on catastrophic expenditure in colorectal cancer patients were found, reporting rates in Malaysia (17.8%) and China (75%).

Added value of this study

This study included 226 patients from 5 tertiary hospitals in India. Among the 202 who were alive at six months after a decision for treatment, the catastrophic expenditure rates were high (90.1%). The median cost of treatment was 407,508 INR (5340 USD) and most of it was paid out-of-pocket by patients (330,277 INR/4328 USD). Surgical fees were the most expensive and patients who had advanced disease or required surgery had higher risk of catastrophic expenditure. Treatment attrition was low (8.9%) in tertiary care, suggesting that attrition might be higher in previous stages of care.

Implications of all the available evidence

To our knowledge, this study is the first to report the cost and catastrophic expenditure rates in patients undergoing colorectal cancer treatment in India. An expansion of funds for cancer care is needed in India, with efficient reimbursements or pre-paid mechanisms, to avoid high out-of-pocket expenditure. Cancer funding needs to account for the complexity of the disease and treatment options, providing additional support to patients who require surgery or have advanced disease. More research is needed on reasons for cancer treatment attrition at all levels of care.

Development Goal (3.8.2) and the latest WHO report on financial protection states that 996 million people were undergoing catastrophic expenditure in 2017 and 70 million being pushed into poverty due to healthcare costs.¹⁸ Patients from low- and middle-income countries are particularly vulnerable due to low governmental spending on healthcare, insufficient insurance coverage and high out-of-pocket payments.^{7,19,20} India’s public health expenditure is less than 2% of the GDP, resulting in high out-of-pocket payments and 6.53% of the whole population experiencing catastrophic healthcare spending (7th highest in the world).^{13,21} Cancer care in India is funded by public funds, private or employer-

provided insurances, out-of-pocket payments, non-profit organisations, and other funds (grants or loans).²² It is estimated that government funds only cover a quarter to a third of cancer treatment cost, forcing patients to make out-of-pocket payments ranging from 19,494 to 295,679 Indian Rupees (INR) depending on the type of cancer.^{13,23} To date, no data exists on absolute costs nor out-of-pocket payments for colorectal cancer in India.

Healthcare funding systems in India fail to account for the complexity of cancer and catastrophic spending is more likely when multiple treatment modalities are required, which is often the case in colorectal cancer.²³ Catastrophic expenditure for colorectal cancer has been reported in Malaysia and China, with very different rates of 17.8% and 75% respectively, but there are no studies reporting financial toxicity in colorectal cancer in India.^{24,25} The current costs of colorectal cancer treatment in India and its consequences to patients’ treatment courses and their household financial stability are unknown. This study aimed to describe catastrophic expenditure and treatment attrition in patients with a diagnosis and a treatment plan for colorectal cancer.

Methods

Study design and setting

A prospective cohort study of patients with a new treatment plan for colorectal cancer was conducted in five tertiary care hospitals in India, in four different states. Patients were enrolled from December 2020 to August 2021, with the last follow-up date being in March 2022. The study was registered (ClinicalTrials.gov 04517032; Central Trials Registry of India CTRI/2020/09/027896) and the protocol was published.²⁶ Health Ministry Screening Committee approval was obtained from the Indian Council of Medical Research and hospital level ethical review boards. Individual patient consent was collected for all patients, as per local regulations. Hospitals started enrolling patients after local approvals were granted and recruitment was closed when the pre-planned sample size was achieved. The sample size was previously defined in the study protocol as 200 patients, according to the WHO recommendations on sample sizes for health studies.²⁷ Assuming a baseline rate of catastrophic expenditure of 45% based on previous studies in India and Asia^{17,28} and a confidence level of 95%, 389 participants would be required to estimate the proportion of the population with catastrophic expenditure with a prespecified precision of 5% (confidence interval 40% to 50%). A precision of 10% would require 95 participants (confidence interval 35% to 55%). The final sample size falls between these and was considered feasible by the local principal investigators. This study followed the STROBE reporting guidelines for observational studies.

Patient inclusion and follow-up

Consecutive patients with a new treatment plan (curative or palliative) for colorectal cancer made at the participating hospitals were included. Hospitals identified patients for inclusion from multidisciplinary meetings whenever possible or through alternative pathways at hospitals where routine multidisciplinary decisions are not held for all patients (dedicated outpatient clinics and colorectal surgery wards). After identification, patients were included in the study during their following visit to the hospital, where informed consent and baseline data were collected. Patients could receive the whole treatment course at the index hospital or prefer to undergo parts of the treatment at other facilities, but follow-up data was collected regardless. The study outcomes were assessed at six months after the baseline assessment, with two interim follow-up timepoints being conducted at six weeks and three months, to prevent recall bias and mitigate against loss to follow-up.

Costs of colorectal cancer treatment

The total costs of colorectal cancer treatment, paid by patients as OOPP (patient perspective) or covered by any third parties (healthcare system perspective) were reported. Out-of-pocket payments were defined as payments made by patients at the time of cancer service use that were not covered by any other third party (details below). Costs covered by third parties included insurance companies (pre-paid by the patient or their employer), central or state government funding schemes (e.g. Aayushman Bharat, Swastha Sathi) or covered by hospitals at free cost for patients (concessions or discounts). These data were collected from hospital bills and from patient-reported expenses.

Study outcomes

The primary outcome was catastrophic expenditure at six months after a new treatment plan, defined as out-of-pocket payments (OOPP) for colorectal cancer being higher than 25% of patient's annual household income. Cancer care expenses covered by third parties were not included in catastrophic expenditure calculations as they were not incurred by patients. Although there is no consensus on the ideal threshold for the definition of catastrophic expenditure, the cut-off of 25% was chosen based on the most used definition by the World Health Organisation (Sustainable Development Goal 3.8.2).²⁹ Patients' annual household income was defined as the total amount of money earned by all the earning members of the household over one year, in Indian Rupees (INR). OOPP payments included medical, non-medical and indirect expenses. Medical OOPP included payments made at the participating hospitals (collected from hospital bills, confirmed with patients), at other healthcare facilities if patients received part of the

treatment elsewhere (reported by patients) and for other healthcare services (e.g. pharmacy, nursing services, dressings, colostomy bags). Non-medical OOPP included travel, accommodation and food expenses necessary to receive treatment at the participating hospitals. Indirect OOPP reflect patient income loss while being absent of work due to receiving treatment. Full details on how OOPP were collected are available in Appendix A. The average proportion of medical, non-medical and indirect expenses from the total OOPP for colorectal cancer was reported. Distress financing strategies used by households to pay for colorectal cancer care were described, including money loans, property selling and donations from relatives or friends.

The second main outcome of this study was treatment attrition at six months after a treatment plan was made, defined as an unplanned interruption of the treatment course that was not recommended by the clinical team. Treatment interruption due to clinical decisions to change the treatment plan, side effects, complications of treatment or other clinical events were not included in treatment attrition. Reasons for treatment attrition were sought from patients at follow-up and were reported.

Data collection, handling and analysis

Baseline data on demographics, disease characteristics, treatment plan and household income was collected through a face-to-face assessment at the point of inclusion in the study. Follow-up data was collected from clinical record files (treatment attrition), hospital bills (medical costs at the index hospital) and via a telephone call with patients (remaining costs and reasons for treatment attrition). See Appendix A for further details.

Demographic variables included age, sex, patient education (highest completed level: graduate, secondary, primary or none), household size (number of adult and children sharing the same house unit), employment status (categorized into employed, non-employed [housewives/students/other] and retired) and distance from the patient's house to the hospital (in kilometres). Cancer stage was defined according to the TMN classification (8th edition of the AJCC guidelines),³⁰ being categorised into local (T1-3 without nodal or metastatic invasion) or advanced (T4 or with positive nodes or with metastatic spread). Treatment intent was defined as curative or palliative at the time where the treatment plan was made. Treatment status at follow-up was collected, including at least one of the following: surgical resection, chemotherapy, radiotherapy, diverting stoma and targeted therapy. The treatment status was categorised into surgical resection and no surgical resection for the analysis, as this was expected to be a key determinant of oncological and study outcomes. Hospital types reflect the funding system of the hospital where the

patients were recruited, being defined as public if funded by the government and private if privately owned (profit or non-profit).

The analysis was performed using the R statistical software (version 4.1.1, packages *tidyverse*, *gmodels*, *finalfit*, *ggplot2*). Categorical variables were described with frequency tables and percentages. Continuous variables were summarised with appropriate metrics: mean and standard deviation when normally distributed or with median and interquartile range when non-normally distributed. Chi-square tests were used to report unadjusted results of patients with and without catastrophic expenditure or treatment attrition. A multivariable regression model was used to identify variables associated with catastrophic expenditure, using treatment attrition as the main explanatory variable and adjusting for patient, tumour and treatment variables. A multivariate model with Firth’s correction was performed, given the small sample size. Continuous outcomes (absolute costs) were compared between groups using T-student tests for normally distributed variables and Kruskal-Wallis tests for skewed data. Patients who died before the study outcomes could be assessed (six months after a treatment plan) or who were lost to follow-up were not included in the main analysis. Missing data was reported in all tables and figures.

Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

Patients and households

Of 226 patients included, twenty died within six months of being offered a treatment plan and four were lost to follow-up. A detailed description of deaths and patients lost to follow-up at each follow-up timepoint is given in [Figure 1](#). Patients receiving treatment with palliative intent and who had primary/no education were more likely to die within six months of a treatment decision, but the remaining features were similar across groups (full details in Supplementary Table 1). The study period and number of patients included from each hospital are described in Supplementary Table 2.

From the 202 patients included in the main analysis, 48.0% (97/202) had colon cancer and 52.0% (105/202) had rectal cancer; 64.4% (130/202) of the patients were male, and the mean age was 52 years (standard

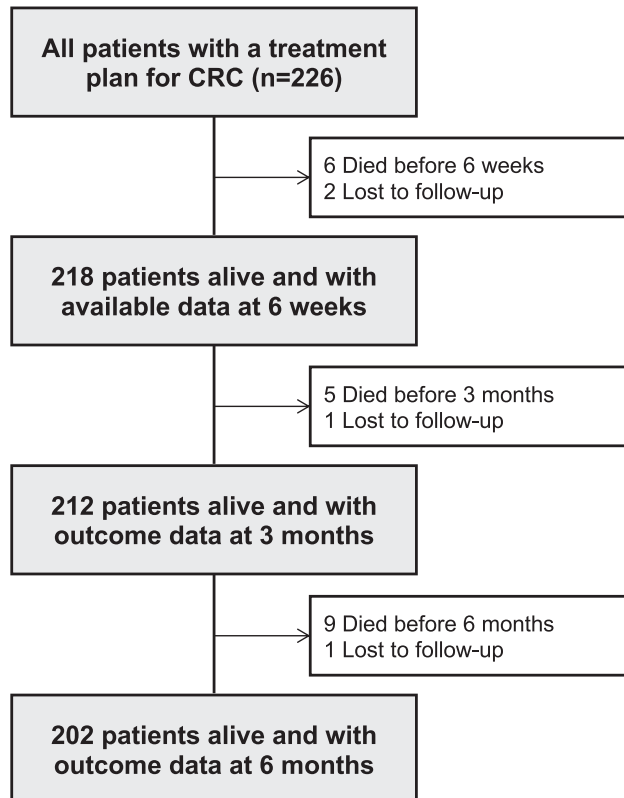


Figure 1. Flowchart of included patients, reporting deaths and losses to follow-up.

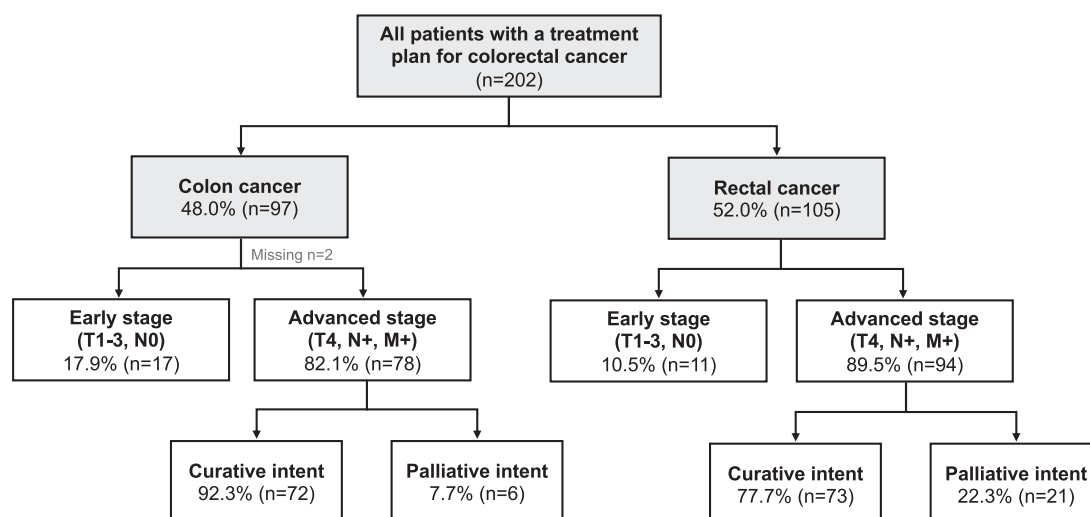


Figure 2. Flowchart displaying treatment intent and cancer stage for colon and rectal cancer patients included in the analysis.

Missing data for cancer stage $n = 1$.

deviation 14.8). Regarding patient education status, 38.6% (78/202) of the patients held a graduate degree, 36.1% (73/202) attended secondary school and 25.2% (51/202) attended primary school or had no school education. Half of the patients were employed (101/202), 18.3% were retired (37/202) and 31.7% (64/202) were unemployed, of which the vast majority were housewives (84.4% [54/64]). The median household size was 5 people (IQR 4-6 people), the median distance from patients' home to hospital was 200 km (IQR 51.5-1622.5 km) and the median household income per year was 228,000 Indian rupees (IQR 120,000-501,000).

Colorectal cancer presentation and treatment

The majority of the patients had advanced disease at presentation to tertiary care (85.1% [172/202]), of which 84.3% (145/172) had a treatment plan with curative intent and 15.7% (27/172) with palliative intent. Palliative treatment intent was more frequent in rectal cancers (see Figure 2). Local clinical teams decided the treatment plan for each patient according to usual practices, consisting of one or more treatment modalities and including chemotherapy in 79.2% (160/202) of the patients, resection surgery in 68.3% (138/202), radiotherapy in 30.7% (62/202), formation of a diverting stoma in 25.7% (52/202) and targeted therapy in 2.5% (5/202).

Cost of colorectal cancer treatment

The median total cost of colorectal cancer treatment was 407,508 INR. (IQR 303,724-549,366) and the largest proportion of these were medical costs (median

339,027 INR [IQR 219,005-504,477]). Medical costs paid out-of-pocket (median 238,946 INR [IQR 119,935-381,291]) were higher than the medical expenses covered by third parties (median 22,109 INR [IQR 73-145,841]). See Figure 3 for a full breakdown of median total costs and OOPP. From the total costs at the index hospital, surgery and anaesthesia fees (median 85,944 [IQR 36,010-130,165]) were higher than radiotherapy (median cost 55,525 [IQR 8000-95,900]) and chemotherapy (median 14,780 [IQR 0-63-732]). Charged fees for other items at the index hospital are shown in Supplementary Table 3.

The median OOPP made by patients for colorectal cancer care was 330,277 INR (IQR 191,849-466,346). This included the OOPP for medical expenses but also non-medical expenses such as travelling, accommodation and food (median 54,197 INR (IQR 27,000-90,676)) and indirect expenses in the form of income loss (median 0 INR (IQR 0-7650)). On average, 73.4% of the total OOPP made by patients were direct medical expenses, 22.4% were non-medical expenses and 4.1% was income loss. From all patients, 43.1% (87/202) applied for government funding schemes, 13.9% (28/202) had private or employer-provided insurance and 20.8% (42/202) benefited from discounts/concessions provided by the hospital. The most common funding schemes that patients applied for were Ayushman Bharat ($n = 41$) and Swasthya Sathi ($n = 19$), with the remaining patients applying for other (less frequent) central or state government schemes. Distress financing strategies included donations from friends or relatives in 12.8% (26/202) of the patients, money loans in 10.9% (22/202) and property selling in 1.9% (4/202).

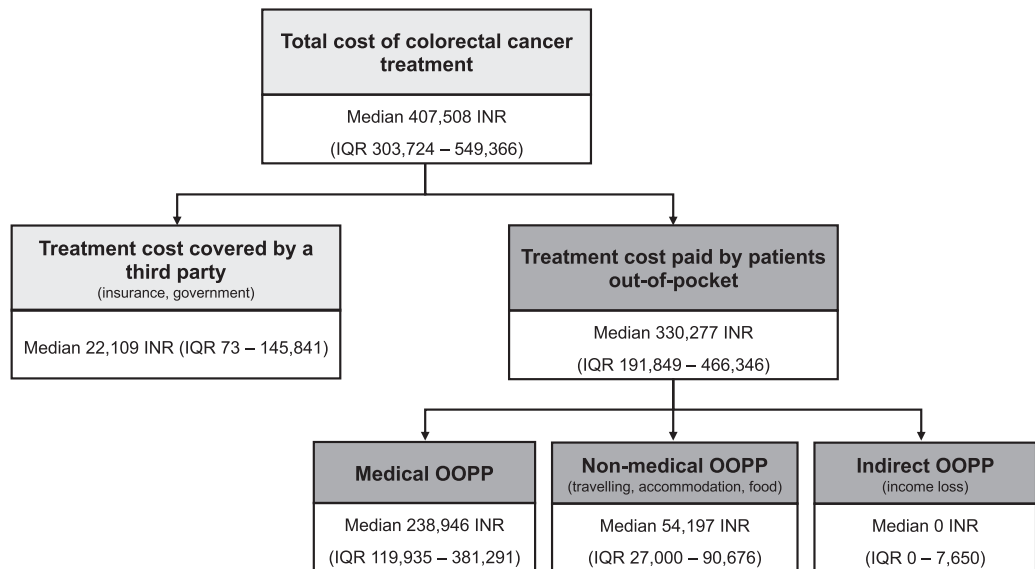


Figure 3. Total costs and out-of-pocket payments (OOPP) for colorectal cancer treatment.

Missing data for the cost of colorectal cancer treatment $n = 1$.

Catastrophic expenditure

The overall rate of catastrophic expenditure was 90.1% (95% CI 85.1%-93.8%, [182/202]). The median OOPP made by patients who suffered catastrophic expenditure was 354,528 INR (IQR 234,077-473,064), being lower in those without catastrophic expenditure 148,489 INR (IQR 37,997-201,030), $p < 0.001$. Patients who didn't suffer from catastrophic expenditure had no income losses and had a higher proportion of OOPP for non-medical expenses (29.1%) (illustrated in Figure 4, full breakdown of OOPP in Supplementary Table 4).

In the unadjusted analysis, catastrophic expenditure was associated with employment status, distance from the patient's home to hospital and insurance coverage. The catastrophic expenditure rates were higher in employed (94.1%) and unemployed patients (93.7%), compared to patients who were retired (75.7%, $p = 0.003$). Patients who lived farther from the hospital had higher catastrophic expenditure rates (81.5% in patients living up to 100km, 93.8% if living within 100-500 km and 95.8% if living more than 500 km from the hospital, $p = 0.01$). Patients with insurance coverage had lower rates of catastrophic expenditure (75.0% vs 93.1%, $p = 0.007$). The full unadjusted results are shown in Table 1.

After adjustment, catastrophic expenditure was independently associated with male sex (OR 13.16, 95%CI 2.05-105.09, $p = 0.009$), primary or no education (OR 40.88 95%CI 2.88-1870.7, $p = 0.021$), treatment in private hospitals (OR 6.74, 95%CI 1.32-41.75, $p = 0.027$), rectal cancer (OR 5.31, 95%CI 1.08-31.27, $p = 0.049$) advanced cancer stage (OR 5.94, 95%CI 1.11-34.95, $p = 0.038$), and receiving surgical resection (OR 11, 95%CI 1.27-119.37, $p = 0.036$). Patients who were retired

(0.12, 95%CI 0.01-0.87, $p = 0.047$) and who had medical insurance (OR 0.10, 94%CI 0.01-0.56, $p = 0.012$) were less likely to have catastrophic expenditure (full model in Supplementary Table 5 and model with Firth's correction in Supplementary Table 6, showing similar direction of findings).

Treatment attrition

Of all patients, 9.4% (95% CI 5.8%-14.3%, [19/202]) had treatment attrition, the majority due to declining treatment ($n = 10$) or opting for alternative medicine ($n = 4$), with the remaining mentioning inability to pay ($n = 3$), inability to travel ($n = 1$) or other reasons ($n = 1$) (see Supplementary Table 7 for further details). Patients with treatment attrition made lower OOPP than those who completed treatment (median 205,926 INR vs 349,398 INR, $p = 0.008$, Figure 4 and Supplementary Table 4) but had a similar risk of catastrophic expenditure (84.2% vs 91.2%, $p = 0.562$, Supplementary Figure 1), including after adjustment (OR 0.23, 95%CI 0.03-2.28, $p = 0.186$, full model in Supplementary Table 5).

Treatment attrition was more common in patients with lower education levels (17.6% for primary or non-educated patients versus 6.6% for secondary or higher education, $p = 0.04$). The rates attrition varied with distance from the patient's home to the hospital, being 10.6% in patients living within 100km, 15.6% in patients living within 100-500 km and 2.8% in patient living beyond 500 km from the hospital. Patients being treated in public hospitals were more likely to have treatment attrition than in private hospitals (18.5% vs 5.1%, $p = 0.005$) (see Table 1 for full characteristics of patients with and without treatment attrition).

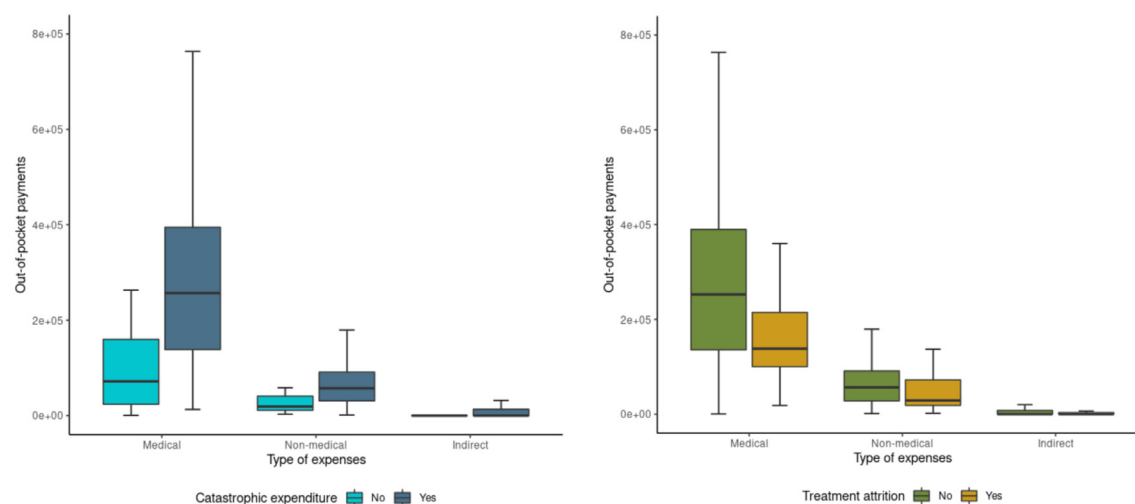


Figure 4. Out-of-pocket payments in patients with and without catastrophic expenditure and treatment attrition.

Charts display OOPP for medical, non-medical and indirect expenses by catastrophic expenditure and treatment attrition. Absolute figures for all types of OOPP are given in Supplementary Table 4. Missing data for the cost of cancer treatment $n = 1$.

Discussion

This study demonstrated that most of the costs of colorectal cancer treatment were supported by patients through out-of-pocket payments, with 90% of households subject to catastrophic expenditure within six months of a new treatment plan. Surgical and anaesthesia fees were among the most expensive items of treatment and tumour resection was independently associated with catastrophic expenditure. Surgery for colorectal cancer was previously identified as a risk factor for catastrophic expenditure in Malaysia but not in India, and this can have direct policy implications.²⁵ Treatment attrition rates in tertiary care were low, raising the hypothesis that attrition is a bigger problem at other levels of the healthcare system (e.g. district and community facilities). Patients with treatment attrition made fewer OOPs, which might be a cause or a consequence of attrition but suggests that financial barriers might impact treatment completion.

The 90% catastrophic expenditure rate found in this study is high, compared to previous studies. A systematic review showed a pooled catastrophic expenditure rate for cancer of 67.9% in countries with low HDI and an international study in Southeast Asia (not including India) showed that 48% of the patients experienced financial catastrophe at one year after a cancer diagnosis.^{7,28} Among Indian households, cancer was proven to be the disease causing highest catastrophic expenditure rates but no data exists on colorectal cancer.³¹ The high rates of financial catastrophe found in this study can reflect a meticulous methodology to include all sources of cost but also suggest that treatment for colorectal cancer is particularly expensive,

requiring focused funding. However, high costs at the participating hospitals, a degree of underreporting of household income and incomplete reimbursement at the time of follow-up need to be acknowledged.³²

Patients with rectal cancer, advanced disease and being treated in private hospital were at increased risk of catastrophic expenditure, possibly reflecting their eligibility for expensive surgery or multimodal treatment. Following surgery, radiotherapy was the main contributor to colorectal cancer costs, reinforcing previous recommendations for cost-effectiveness research on radiotherapy strategies in India.³³ Patients in India often purchase chemotherapy drugs from external suppliers, to be administered at the hospital, explaining the apparent low cost of chemotherapy collected from hospital bills in this study.³⁴ Cancer care in India is often funded through budgets that are common to other non-communicable diseases and fail to account for the complexity and high cost of cancer treatments.²³ This study emphasizes the need for tailored cancer care funding, highlighting that patients with advanced disease and who require surgery require additional funding. Having medical insurance seemed to protect patients from catastrophic spending, reinforcing that pre-paid mechanisms are a better strategy of financial protection and that costs covered government schemes need to be expanded.

There are some important secondary findings of this study. Travelling and accommodation expenses contributed to 20% of the overall OOPP, meaning that providing cheap or free transport and lodging could reduce the financial burden of colorectal cancer.³⁵ Although indirect costs had a low impact on total OOPP, the median income loss was zero in patients without

		Catastrophic Expenditure			Treatment attrition		
		No	Yes	p-value	No	Yes	p-value
Age	18–40 years	3 (5.8)	49 (94.2)	0.066	49 (94.2)	3 (5.8)	0.177
	41–60 years	5 (6.2)	76 (93.8)		76 (92.7)	6 (7.3)	
	>60 years	11 (16.2)	57 (83.8)		58 (85.3)	10 (14.7)	
Sex	Female	8 (11.3)	63 (88.7)	0.691	62 (86.1)	10 (13.9)	0.17
	Male	11 (8.5)	119 (91.5)		121 (93.1)	9 (6.9)	
Patient education	Secondary/Graduate	18 (11.9)	133 (88.1)	0.072	141 (93.4)	10 (6.6)	0.04
	Primary/none	1 (2.0)	49 (98.0)		42 (82.4)	9 (17.6)	
Employment	Employed	6 (5.9)	95 (94.1)	0.003	94 (93.1)	7 (6.9)	0.465
	Unemployed	4 (6.3)	59 (93.7)		56 (87.5)	8 (12.5)	
	Retired	9 (24.3)	28 (75.7)		33 (89.2)	4 (10.8)	
Household size	<4 people	8 (8.0)	92 (92.0)	0.646	91 (91.0)	9 (9.0)	1
	>= 4 people	11 (10.9)	90 (89.1)		92 (90.2)	10 (9.8)	
Cancer location	Colon	11 (11.5)	85 (88.5)	0.491	91 (93.8)	6 (6.2)	0.206
	Rectum	8 (7.6)	97 (92.4)		92 (87.6)	13 (12.4)	
Cancer stage	Local	5 (17.9)	23 (82.1)	0.201	27 (96.4)	1 (3.6)	0.42
	Advanced	14 (8.1)	158 (91.9)		154 (89.5)	18 (10.5)	
Treatment intent	Curative	17 (9.8)	157 (90.2)	0.971	159 (90.9)	16 (9.1)	1
	Palliative	2 (7.4)	25 (92.6)		24 (88.9)	3 (11.1)	
Distance to hospital	0–100 km	12 (18.5)	53 (81.5)	0.01	59 (89.4)	7 (10.6)	0.035
	100–500 km	4 (6.2)	60 (93.8)		54 (84.4)	10 (15.6)	
	>500 km	3 (4.2)	69 (95.8)		70 (97.2)	2 (2.8)	
Hospital type	Government	10 (15.4)	55 (84.6)	0.084	53 (81.5)	12 (18.5)	0.005
	Charity / Private	9 (6.6)	127 (93.4)		130 (94.9)	7 (5.1)	
Funding scheme	No	11 (9.6)	103 (90.4)	1	106 (92.2)	9 (7.8)	0.522
	Yes	8 (9.2)	79 (90.8)		77 (88.5)	10 (11.5)	
Insurance	No	12 (6.9)	161 (93.1)	0.007	155 (89.1)	19 (10.9)	0.137
	Yes	7 (25.0)	21 (75.0)		28 (100.0)	0 (0.0)	

Table 1: Descriptive table of patient characteristics by catastrophic expenditure and treatment attrition. Missing data for cancer stage $n = 1$ and for catastrophic expenditure $n = 1$.

catastrophic expenditure, highlighting the importance of job protection policies to improve financial protection.

The demographic features associated with catastrophic expenditure need careful interpretation, as there might be a wider group of vulnerable patients who didn't reach tertiary care. Men were found to have higher odds of catastrophic expenditure, which might reflect a higher ability to access funds for cancer care, a higher baseline income or easier access to healthcare in general.^{17,36} Lower education has been vastly identified as a risk factor for catastrophic health expenditure, reinforcing the need for investment in education and health literacy to improve health outcomes.¹³ Although some of these households could have fallen into poverty due to cancer care expenditure, data on pre and post-treatment household expenditure was not collected and it is not possible to calculate impoverishing expenditure rates. Treatment attrition rates were lower in patients who lived very far from the hospital, suggesting that these might have the resources and the motivation to complete their treatment.

This study had limitations, mainly related to the small sample and potential selection biases. Formal sample size calculations are not always performed for cohort studies and we have used a pragmatic approach, guided by methodology and feasibility. The high proportion of patients with rectal cancer and curative treatment plans reflects that most hospitals were referral centres with expertise in colorectal cancer, potentially underrepresenting palliative cases and socio-economically challenged patients who could not access tertiary care. Although this is a unique study with detailed data on costs of colorectal cancer, it is possible that some patients may have overreported expenses or underreported income. Finally, because the direct costs of cancer treatment were collected from hospital bills (complemented by patient reported expenses), public schemes' contributions that are not reflected in hospital bills might have been missed. Delayed reimbursements of these schemes can also contribute to a degree of overestimation of out-of-pocket payments but is unlikely to change the direction of findings, whereby catastrophic expenditure rates are concerningly high.

As colorectal cancer incidence increases in India, better financial protection is needed, especially for patients who require surgery. Strategies for screening and early diagnosis should be planned, as patients with advanced cancers are more likely to require expensive treatment. Non-medical expenses should not be neglected in future policies for funding cancer, as these account for a quarter of the OOPP made by patients in the present study. Although this paper reports cancer care expenses mainly from a patient perspective, societal costs can be even higher if we consider whole system expenses that are not reflected on patients' bills and costs incurred by patients' companions that were not reported here. Larger investment from the central government of India is needed to improve health outcomes and secure financial stability of cancer patients.

Provided that this study focused on tertiary care hospitals and the sample is small, it is difficult to generalise the findings to the whole India population with colorectal cancer. Although the proportion of private and public hospitals is similar to the whole India healthcare system (63% private and 37% public),³⁷ more research is needed to identify cancer outcomes and cancer care coverage at previous stages of care (district hospitals, community practices and communities with difficult access to healthcare facilities). This study generated early information through feasible methodology, hopefully informing future and larger studies on this topic that can assess the consequences of the cost of cancer treatment in a wider population.

Further research is needed to achieve a better understanding of the factors influencing adherence to treatment, given that most patients with treatment attrition declined treatment and or opted for alternative medicine whose outcomes are uncertain but costs are high.³⁸ This could allow the development of evidence-based interventions to improve patient retention and cancer outcomes.

Although our sample was small, we believe it generated early and feasible information to inform the sampling of future studies on catastrophic expenditure that should include a larger sample of patients and hospitals.

Contributors

The authors in the writing group contributed to study design, data collection, analysis and interpretation, writing and reviewing of the manuscript. The statistical analysis group contributed mainly to data cleaning, analysis and interpretation. The collaborators contributed to data collection.

Data sharing statement

Deidentified data is available upon request and will be provided once the study group approves access, based on a structured proposal for data sharing.

Declaration of interests

None.

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Supplementary materials

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