ORIGINAL RESEARCH ARTICLE

Out of Pocket Expenditure among Cancer Patients Availing Treatment at A Tertiary Care Centre in Hyderabad, India

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A B S T R A C T

Background: The expenses that the patient or the family pays directly to the health care provider, without a third-party (insurer or State) is known as 'Out of Pocket Expenditure' (OOPE). These expenses could be medical and non-medical. About 150 million people face financial catastrophe every year due to health care payments and cancer is one of the leading causes of high OOPE.

Objectives: This study was conducted to estimate the OOPE among cancer patients and to determine the OOPE in relation to type of cancer and treatment modality.

Methodology: A cross sectional study was conducted at a tertiary care centre in Hyderabad during August and September,2022 with a total study population of 400 cancer patients. After consenting the participants, data was collected via face-to-face interview using a semi structured questionnaire.

Results: The mean OOPE per patient was found to be \$1032.65 (₹84,643.20). This includes the medical and non-medical costs. Leukaemia was found to have the highest OOPE amongst all cancers followed by colon cancer. Similarly, radiotherapy + surgery was found to have the highest OOPE followed by chemotherapy + radiotherapy + surgery.

Conclusion And Interpretation- This study is unique in its way that no other study has considered OOPE for different cancers in single research. We would like to highlight the quantification of OOPE among various types of cancers and its variation based on treatment modality used. It is necessary that future government initiatives consider the importance of mitigating the OOPE along with provision of cancer care.

Keywords: Cancer, Medical Expenses, Non-Medical Expenses, Out of Pocket Expenditure, Treatment modality

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INTRODUCTION

Non-Communicable Diseases (NCD) are responsible for around half the deaths in the developing countries, majorly affecting the working age group (15-65 years) leading to dire socioeconomic consequences.¹ Among NCDs, cancer related deaths are increasing very rapidly and almost 9.3 million cancer related deaths were recorded in the year 2018, which is further expected to rise to 16.3 million by the year of 2040.² A recent study conducted in India has revealed that collectively NCDs have higher economic and catastrophic burden of which, cancers have a higher catastrophic burden and resultant impoverishment in India.³ Cancer care expenses includes expenditure for investigations, treatment, traveling, loss of productivity due to cancer disability, potential life years lost due to premature cancer deaths and other miscellaneous expenditures (like food, accommodation, bribe, etc).4

Among various diseases, cancer has highest Out of Pocket Expenditure (OOPE) due to its chronicity and expensive treatment.⁵ OOPE is defined as any payment paid to the health care provider without a third-party involvement. It includes both medical and non-medical expenses.6 Medical costs include costs for treatment, investigations, and hospitalization while non-medical costs include expenses for food, accommodation and travelling to the treatment facility. All over world, around 150 million people have catastrophic out of pocket expenditure due to their health care expenses, with majority (90%) residing in low-income countries.¹ It results in a significant financial and psychological strain on the lives of the cancer patients and their families. Due to weak health financing system in developing countries, majority of the cancer patients resort to coping methods such as mortgage, borrowing and selling assets to overcome the high OOPE.¹ This further emphasizes the need for studying the economic burden of cancer in order to determine the extent to which mitigation of such a burden is required.⁵

A recent study in Kerala, India has reported that direct cost for cancer care contributed 75% towards the cost of treatment and the remaining was found to be an indirect cost. Treatment-related costs include costs of consultation, stay, investigations, medications, and procedure cost where applicable. Nonmedical costs include food, loss of income, and travel to treatment centres.⁴

A recent study at Sewagram, India has shown that cancer patients and their caregivers go through tremendous psychological stress from the time of diagnosis till the end of life. OOPE and the financial catastrophe caused because of the treatment adds onto it. Non-medical costs including transportation, accommodation, and cost of childcare add on to this burden, more so for the lower socioeconomic status (SES).⁷ People belonging to younger age group, residing in rural areas and those with lower income have the greatest impact due to health care expenses.8

The burden of cancer is increasing at an alarming rate and cost of treatment is exorbitantly high especially for people of middle and low SES. Majority of the cancer patients face catastrophic out of pocket expenditure during treatment. Most of the studies in India focus on out-of-pocket expenditure of noncommunicable diseases as a whole or as a one single type of cancer. As cancer incidence is rising, this study was carried out to assess OOPE in all cancer patients and to quantify the expenditure based on the type of cancer and the treatment modality used.

Methodology

A cross sectional study was conducted at a tertiary cancer care centre in Hyderabad for a period of 2 months (August and September 2022). This tertiary cancer care centre is a nodal government cancer hospital in Telangana with a bed strength of 450. Cancer patients who were admitted to the hospital comprised the study population. A sample size was calculated using the formula $Z^{2*}p^*q/l^2$ where the value of p was taken as 62.7%9 at 95% confidence interval with an allowable error of 5%. 10% was added to the sample size to make up for non-responders. A sample size of 396 was calculated which was rounded of to 400. All inpatient cases of age 18 years and above diagnosed with any type of cancer were included in the study. The patients with a minimum duration of 3 months post diagnosis were considered for this study. An informed consent was obtained from the participants if they were willing to be a part of the study. Participants who were unable to recollect the expenditures and terminally ill patients were excluded. With the help of a semi structured questionnaire which was previously validated in a pilot study, face to face interview was conducted with the participants and their caregivers and information was collected. Data was collected regarding their demographic details, type of cancer, time since diagnosis, all the medical and non-medical expenditures which incurred from the time of diagnosis till the point of interview were collected. All the expenses incurred during diagnosis, during course of entire treatment till date, investigations, hospitalisations, travel and other miscellaneous expenditures were recorded. Maximum care was taken to ensure that exact amounts were recorded, and expenditure bills were physically verified wherever present. Collected data was entered in Microsoft Excel and analysis was done using EPI info 7. Descriptive statistics like frequencies, mean, median and range were calculated. This study was conducted after taking approval from institutional ethics committee (Ref. No. IEC/OMC/ 2022/M.No.(3)/Acad - 26). All monetary values, initially collected in Indian Rupees (₹), have been represented in US Dollars (\$), with US Dollar value calculated with conversion rates on that of the last date of data collection i.e., 30th September 2022 utilized

that being at 1 USD (\$) = 81.80 INR (₹) (or) 1 INR (₹) = 0.0122 USD (\$).

RESULTS

Results from table 1 showed that most affected people are within the age group of 36 to 45 years and majority of the patients were between 36 to 55 years. The average age of study population is 46 years with an almost equal distribution between male and female population. Almost 60% of the cancer patients came from rural areas. Majority of the patients were married (83%) and almost 78% of the patients belonged to Hindu religion. Larger part of the patients are illiterates (31.8%). Greater part of the patients under study are semiskilled (30.8%) and unskilled workers (30.5%). According to Modified B.G. Prasad Socioeconomic Classification¹⁰, patients most commonly belong to lower middle class. Majority of the study subjects belong to the lower middle, middle and upper middle classes.

100% of the participants experienced some form of OOPE, with minimum total OOPE of \$4.88 (₹400) to a maximum total OOPE of \$12,956.4 (₹10,62,000). Not every patient has experienced an Out-of-pocket expenditure under each category. 99.75% of participants had OOPE with regards to travelling expenses. 81.75% of participants had OOPE with regards to investigation expenses and 39.5% have OOPE with regards treatment related expenditures. Only 50.5% had any miscellaneous expenses.

Table 2 shows that the average total OOPE was \$1032.65 (₹84,643.2) with a median of \$634.4 (₹51,893.9). Most of the participants reported to have high expenditure for travelling which accounted to a median value of \$156.16 (₹12773.9) and a mean value of \$368.35 (₹30,192.90) as they are coming from far off places for treatment to the tertiary care centre in Hyderabad. The participants also had high expenditure for investigations (\$271.83) (₹22,280.89) as basic investigations are available free of cost in the government health facilities while more sophisticated tests and scans like PET scan, nuclear imaging, biochemical markers, and Genetic testing are usually not available. The average OOPE for treatment was \$333.7 (₹27,352.18) while the median OOPE was \$0 which could be due to that the patients were admitted to a government hospital where treatment was free thus contributing to an overall a low median OOPE, whereas the patients that incurred OOPE (39.5% of the participants) for treatment could have been incurred due to utilisation of services in private setups before admission into the study hospital and purchase of medical consumables outside the hospital. Miscellaneous costs include expenses for food, accommodation, and bribe.

Table 1: Sociodemographic characteristics	s in	the
study population		

Socio demographic Variables	Frequency (%)
Age	
<25 years	24 (6)
26 to 35 years	47 (11.75)
36 to 45 years	116 (29)
46 to 55 years	112 (28)
56 to 65 years	63 (15.75)
>65 years	38 (9.5)
Sex	
Male	206 (51.5)
Female	194 (48.5)
Marital status	
Married	332 (83)
Unmarried	21 (5.3)
Widowed	43 (10.8)
Divorced	4 (1)
Address	
Urban	162 (40.5)
Rural	238 (59.5)
Religion	
Hindu	311 (77.8)
Muslim	75 (18.8)
Christian	14 (3.5)
Education	
Illiterate	127 (31.8)
Primary	79 (19.8)
Middle	64 (16)
Secondary	75 (18.8)
Intermediate or diploma	38 (9.5)
Graduate or PG	16 (4)
Professional	1 (0.3)
Occupation	
Professional	4 (1)
Semi Professional	4 (1)
Clerical or Shop Owner	12 (3)
Skilled worker	61 (15.3)
Semi-skilled	123 (30.8)
Unskilled	122 (30.5)
Unemployed	74 (18.5)
Socioeconomic Status*	
Lower Class	65 (16.25)
Lower Middle Class	106 (26.5)
Middle Class	87 (21.75)
Upper Middle Class	101 (25.25)
Upper Class	41 (10.25)

*According to B.G. Prasad's SE Classification¹⁰

Table 2- Out of Pocket Expenditure and its components in study population

Expenditure head	Amount (in USD\$)		
	Mean ± SD	Median (IQR)	
Total OOPE	1032.65 ± 1382.1	634.4 (260.5-1263.9)	
Travelling expenses	368.35 ± 645.3	156.16 (65.9-366)	
Expenditure on investigations	271.83 ± 335.7	172.63 (25-366)	
Treatment expenditures	333.7+/-1040.7	0 (0-122)	
Miscellaneous expenditures*	58.77 ± 140	0.49 (0-49.4)	

SD - Standard Deviation; IQR - Inter Quartile Range (Q1-Q3); *Include Food, Accommodation, etc



Figure 1: Different components of OOPE in the study population

An average of \$100.35 (₹8,225.7) was spent on food related expenses by the patients (n= 182), while an average amount of \$157.26 (₹12,890) (n= 33) was spent by people for accommodation near the hospital during their course of treatment. Some participants also mentioned that they had to resort to paying bribes for getting their services done (n=16) which had a mean of $(5.54 \ (5.536.25))$.

Figure 1 shows the breakup of total OOPE into different categories. The highest proportion of OOPE was for travelling expenditures followed by treatment expenditures.

Results from table 3 show that most common cancers in the current study were oral cancer (19.3%), breast cancer (12.8%), colon cancer (9.5%) and lung cancer. Cancers which had the highest mean OOPE were leukaemia (\$1661.12) (₹1,36,157.14), colon cancer (\$1480.31) (₹1,21,336.57) and bone tumour (\$1466.22) (₹1,20,181.87) (cancers with more than 5 patients were considered). Whereas when looked up in the perspective of median OOPE of patient with respect to their cancer a similar pattern has been observed. Minimum total OOPE of a cancer patient was \$4.88 (₹400) while maximum total OOPE of a cancer patient was \$12965.4 (₹10,62,000). Results from Table 4 show that highest OOPE was seen in cancers related haematological system to (\$1661.12) (₹1,36,157.14) followed by the musculoskeletal system (\$1397.05) (₹1,14,512.38) and gastrointestinal system (\$1317.37) (₹1,07,980.8) (systems with more than 5 patients were considered).

Table 3: Distribution of study population	according to	various types	s of cancers and	d their respective
OOPE incurred (in USD)				

Cancer	Cases (%*)	OOPE (Mean ± SD)	OOPE (Median (IQR))
Breast Cancer	51 (12.8)	1216.2 ± 2160.8	561.2 (212.3-1259.0)
Endometrial Cancer	26 (6.5)	838.7 ± 752.1	737.5 (156.2-1274.9)
Cervical Cancer	22 (5.5)	1149.1 ± 1278.8	649.7 (334.3-1295.6)
Ovarian Cancer	18 (4.5)	535.1 ± 493.9	456.9 (158.6-585.6)
Prostate Cancer	7 (1.8)	1124.4 ± 1425.6	414.8 (244.0-2468.1)
Oral Cancer	77 (19.3)	753.1 ± 900.2	466 (212.3-894.5)
Laryngeal Cancer	25 (6.3)	821.5 ± 719	732 (208.6-1256.6)
Colon Cancer	38 (9.5)	1480.3 ± 2127.2	834.6 (335.5-1464)
Gastric Cancer	17 (4.3)	1025.3 ± 1651.6	457.5 (181.8-1268.8)
Oesophageal Cancers	7 (1.8)	1373 ± 1325.7	617.3 (334.3-2098.4)
Lung Cancer	30 (7.5)	996.6 ± 1072.7	688.4 (390.4-1303.8)
Bone Tumours	16 (4)	1466.2 ± 1208	892.4 (663.1-2361.4)
Squamous Cell Carcinoma	5 (1.3)	1175.7 ± 754.8	902.8 (878.4-1898.3)
Leukaemia	14 (3.5)	1661.1 ± 1800.2	1080.4 (99.6-2313.1)
Thyroid Cancer	9 (2.3)	1034.7 ± 1154.3	878.4 (250.1-1390.8)
Brain Tumour	5 (1.3)	1034.1 ± 1083.3	805.2 (402.6-1037.0)
Others	33 (8.3)	838.1 ± 795.4	707.6 (289.8-1259.7)

SD: Standard Deviation, IQR: Inter Quartile Range Q1 - Q3 (Inter Quartile Range = 25^{th} Quartile – 75^{th} Quartile) All the above monetary values are in US Dollars \$) (*n = 400 = 100%)

Tab	le 4: Distril	oution acco	ording to v	arious types of	f systems and	thei	r respective	OOPE incurred
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Cancer System	Cases (%*)	OOPE (Mean ± SD)	OOPE (Median (IQR))
Reproductive System Cancers	131 (32.8)	1007.1 ± 1542.9	561.2 (219.6-1244.4)
Head and Neck Cancers	114 (28.5)	769.1 ± 841.4	483.1 (208.6-1024.8)
Gastrointestinal Cancers	71 (17.8)	1317.4 ± 1827.3	712.5 (327.0-1512.8)
Respiratory Cancers	30 (7.5)	996.6 ± 1072.7	688.4 (390.4-1303.8)
Musculoskeletal System Cancers	21 (5.3)	1397.1 ± 1106.6	900.4 (677.1-1988.6)
Haematological Cancers	14 (3.5)	1661.1 ± 1800.2	1080.4 (99.6-2313.1)
Endocrine System Cancers	11 (2.8)	966.3 ± 1046.0	816.9 (250.1-1390.8)
Central Nervous System Cancers	5 (1.3)	1034.1 ± 1083.3	805.2 (402.6-1037.0)
Excretory System Cancers	3 (0.8)	543.1 ± 457.3	796.7 (15.1-817.4)

SD: Standard Deviation, IQR: Inter Quartile Range Q1 - Q3 (All the above monetary values are in US Dollars \$) (*n = 400 = 100%) (Inter Quartile Range = 25th Quartile – 75th Quartile)

Table 4: Distribution of OOPE with respect to treatment modality used

Treatment modality		Total OOPE	Investigation	Travelling	Treatment	Miscellaneous	
			Expenditures	Expenditures	Expenditures	Expenditures	
Chemo	Mean ± SD	988.7±1435.3	277.9±300.4	221.9±432.7	456.5±1100.8	32.4±104	
	Median(IQR)	545.3(202.5-1220.9)	183(55.8-378.2)	93.9(50-219.6)	0(0-445.3)	0(0-27.5)	
Radio	Mean ± SD	852.5±883.4	345.7±323.8	154.1±167.7	282±657.1	70.8±144.9	
	Median(IQR)	598.4(240.0-1088.9)	274.5(17.1-610)	83.6(34.8-250.1)	0(0-244)	5.4(0-103.7)	
Surgery	Mean ± SD	742.8±1093.1	226.7±287.2	255.2±456.6	226.6±707.5	34.3±110.6	
	Median(IQR)	335.5(158.6-888.2)	97.6(24.4-366)	146.4(63.0-256.2)	0(0-36.6)	0(0-19.5)	
Chemo + Radio	Mean ± SD	1092.7±1497.9	245.6±325	439.7±641.8	321.5±1249.6	85.9±140.6	
	Median(IQR)	717.36(327.6-1281.7)	122(24.4-366)	227.8(91.5-512.4)	0(0-91.5)	11.6(0-97.6)	
Chemo + Surgery	Mean ± SD	1171.9±1177.8	316.6±458	569.2±823.5	210.3±539.8	75.8±231.2	
	Median(IQR)	900.4(302.6-1496.9)	122(42.7-427)	244(73.2-915)	0(0-61)	0(0-29.3)	
Radio + Surgery	Mean ± SD	1845.9±2665.5	155.9±259.5	669±755.2	970.6±2617.2	50.4±55.8	
	Median(IQR)	647.9(419.7-1830)	24.4(0-154)	273.28(156.2-1478.6)	0(0-122)	20.9(0-109.8)	
Chemo + Radio	Mean ± SD	1389.6±1503.1	320.2±317.4	810±1295.5	172.3±508.9	87.2±163.3	
+ Surgery	Median(IQR)	896.7(530.7-1634.8)	244(61-366)	372.1(139.1-819.8)	0(0-30.5)	14.6(0-109.8)	
Palliative	Mean ± SD	1113.9±138	434.9±247.6	354.4±361.5	305±258.8	19.5±6.9	
	Median(IQR)	1113.9(1016.3-1211.5)	434.9(259.9-610)	354.4(98.8-610)	305(122-488)	19.5(14.6-24.4)	
Other Medicines	Mean ± SD	894.1±1156.8	316.5±513.3	200.6±261.7	352.2±809.8	24.8±33.5	
	Median(IQR)	340.4(117.8-1430.8)	102.5(0-520.9)	109.8(36.6-254.7)	28.4(0-274.5)	10.4(0-58.0)	

Chemo: Chemotherapy; Radio: Radiotherapy

SD: Standard Deviation, IQR: Inter Quartile Range Q1 - Q3 (All the above monetary values are in US Dollars \$)

Table 4 shows that, out of the various treatment modalities for the cancer patients in the study population, it was found that the total mean OOPE was highest for patients undergoing Radiotherapy + Surgery (\$1845.87) (₹1,51,301.11) followed by those on Chemotherapy + Radiotherapy + Surgery. Mean expenditure for investigations was found to be highest for patients on Palliative care (\$434.93) (₹35,650) followed by those on Radiotherapy. Whereas average expenditure for travelling was found to be highest for patients on a combination of Chemotherapy + Radiotherapy + Surgery (\$810.01) (₹66,394.4) followed by those on Radiotherapy + Surgery. Mean expenditure for treatment was found to be highest for Radiotherapy + Surgery (\$970.58) (₹79,555.56) group and mean expenditure for miscellaneous was found to be highest for patients on combination of Chemotherapy + Radiotherapy + Surgery (\$87.17) (₹7,144.8) followed by those on Chemotherapy + Radiotherapy (\$85.88) (₹7,039.47). The median value and 25th quartile for the column out of pocket expenditure with regards to treatment expenditure is zero as almost 60% of the subjects did not have any expenditure incurred under this category.

DISCUSSION

With newer modalities of investigation and treatment coming up for cancer care, the burden of cancer treatment on the patient has also increased tremendously. The National Health Policy 2017, stresses on the need to cut down on Out-of-Pocket Expenditure for cancer care for overall financial wellbeing of the patient. Hence it is imperative to quantify the expenditures which the patient incurs from the point of diagnosis of cancer to their eventual outcome.

In the present study, the mean OOPE for the 400 patients was \$1,032.65(₹84,643.20) per patient. The mean amount for the patients was significantly higher for travelling expenditures (\$368.34) (₹30,192.20), followed by treatment expenditures (\$333.7) (₹27,352.17) then expenditures on investigations (\$271.83) (₹22,280.89). Among the various types of cancers in the study population, highest OOPE was incurred in leukaemia (\$1661.12) (₹1,36,157.14) followed by colon cancer (\$1,480.31) (₹1,21,336.57) and then bone tumours (\$1,466.22) (₹1,20,181.87).

In a study conducted by Vijay Kumar Barwal et.al., mean OOPE was found to be ₹36,812 (\$449.11)¹¹, whereas in the present study the mean OOPE was found to be ₹84,643.20 (\$1,032.65). This difference could have been due to the fact that only lung cancer patients were included, and the sample size was limited in their study.

According to the study conducted by T.A. Dinesh et.al., most common cancer in the study population was found to be breast cancer (49%) followed by intestinal cancer (11%) followed by Leukaemia (7%).⁴ In this study, the most common cancers were found to be oral cancer (19.3%) followed by breast cancer (12.8%) followed by colon cancer (9.5%).

According to the study conducted by Kesavan Sreekantan Nair et.al., nearly 60% of the patients belong to rural areas and rest 40% belong to urban areas.¹² In this study a similar finding has been observed with 59.5% of the patients belong to rural areas and 40.5% belong to urban areas. In this study, the mean OOPE for hospitalisation per patient was found to be ₹27,352.17 (\$333.7), whereas in a study conducted by Anshul Kastor et.al., mean OOPE on hospitalisation for cancer was ₹57,232 (\$698.23).¹ This lower OOPE for hospitalisation observed in our study population could be attributed to the fact that majority of the patients are utilising government

health schemes like Aarogyasri and free treatment at the government tertiary care centre.

According to the study conducted by Mohemmed N. Khan et.al., mean OOPE was found to be highest for chemo radiation.¹³ Whereas in this study, it was found that radiotherapy + surgery had the highest OOPE. This difference could be due to the fact that only head and neck cancer patients were considered in their study whereas in the present study all types of cancer patients were considered.

According to the study conducted Bidhu Kalyan Mohanti et.al., mean OOPE for patients undergoing radiotherapy treatment for cancer had an OOPE of ₹36,812 (\$449.1).¹⁴ Whereas in this study, the mean OOPE for patients undergoing radiotherapy was ₹69,734.5 (\$852.5). This higher OOPE in the present study could be due to cancer investigations and treatment of the patients at private sectors before being shifted to the government setup for treatment.

The OOPE was due to high travel expenses for patients who had to travel from different districts of the state and neighbouring states to the capital city of Hyderabad. These costs could be overcome by providing patients with free passes for travel and provision of free ambulance transport. Based on our results, we assume that these changes could significantly decrease the costs. Decentralisation of cancer care and availability of services in district hospitals can lead to a significant reduction in travelling costs.

Despite basic investigations being provided free of cost under various government schemes many patients had a high expenditure for investigations due to less availability of certain diagnostic modalities like PET scan, genetic and molecular diagnostic modalities. These costs could be decreased by increasing the facilities for investigations.

LIMITATIONS

Despite the best possible efforts, some amount of recall bias cannot be ruled out which might have led to slight under and overestimating of financial expenditures incurred. We have tried to minimise this by verifying with the bills produced by the patients wherever possible.

Since cancer treatment is long term, the expenditure incurred up to the point of interview was recorded. During the course of further treatment, the patient might spend a considerable amount of money.

CONCLUSION

This study is unique in its way that no other study has considered OOPE for all cancers in single research and we have tried to quantify the amounts spent on various OOPEs and OOPE in relation with type of cancer and treatment modality used. Through this study we would like to highlight the burden of high OOPE among various cancers. It is necessary that government initiatives take into consideration the importance of mitigating the OOPE expenditures along with provision of essential cancer care. Provision of universal health coverage with affordable and accessible cancer care services is the need of the hour and this can be achieved only by eliminating OOPE related to health care.

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