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Original Research Article

Out of pocket expenditure on cancer patients at a tertiary care hospital of Lucknow

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ABSTRACT

Introduction: The increasing cost of cancer diagnosis and its management has led to a huge financial burden and noticed to be one of the major contributors to poverty. Out-of-pocket expenses (OOPE) significantly impact patients households work as well as experience to cancer treatment. Understanding its nature of burden will guide us in formulation of plans to avoid financial distress among the cancer patients.

Materials and Methods: A tertiary care hospital based cross-sectional observational and analytical study was conducted on 120 cancer patients attending surgical OPD at King Georges Medical University, Lucknow, from July 2020 to November 2021. Sociodemographic and economic variables, costs incurred under various headings and expenditure details of the subjects were obtained by pre-designed, pre-tested, semi-structured questionnaire. Direct medical and direct non-medical costs were calculated, and its total was used as the OOPE. Appropriate statistical tests were applied wherever applicable.

Result: Overall mean out-of-pocket expenditure by study participants was Rs 79925.5 (51776-121651). The expense on direct medical expenditure was Rs 45151(30051, 90051) and indirect non-medical expenditure was Rs 10000(5000,14000). We found significantly higher OOPE in subjects residing more than 100 km away from Lucknow (P = 0.017), with gall bladder cancer (P = 0.001), who were diagnosed with cancer while screening (P =0.034), who were diagnosed at Private clinic/hospital (P = < 0.001) and delayed treatment (P = 0.023).

Conclusion: Cancer patients experience significant OOPE following their diagnosis. Its impact on patient wellbeing with their treatment decisions need to be further studied.

1. Introduction

Generally, cancer burden is measured in terms of the health outcomes like morbidity and mortality. However, economic measures as well as burden are equally important for its outcome research.[1] These include the cost of screening, diagnosis, services or lost wages incurred as a result of the disease and its treatment.[2] The cost of cancer has gained considerable attention and importance at national as well as international level, given the rising healthcare costs and its financial consequences. High out-of-pocket expenditure (OOPE) and the indirect costs involved in cancer treatment often result in financial burden and toxicity.[3–5]

In India, every year, nearly seven hundreds thousands deaths are attributed to cancer.[6] Diagnostics as well as treatment determine the direct medical cost of any disease. The direct non-medical costs along with indirect and intangible costs associated with cancer is also huge. In majority of patients, cancer diagnosis leads not only to a health and psychological burden but a major financial burden as well. In India, each year, nearly half out of more than a million newly diagnosed cancer patients are suitable

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for curative aimed cancer directed therapy. If for financial reasons, these patients do not seek or are reluctant for treatment, they are actually being denied of the cancer care benefits. This inability to bear expenses for cancer diagnosis and treatment impose greater hindrance to the cancer fighting efforts of the nation.[7] Considering the increasing costs of cancer diagnostics and its therapeutic interventions, their formal assessment is imperative to structure value-based standard treatment guidelines.[8] Economic evaluations are used for informing healthcare funds allocations to ensure best value for money being spent. For facilitating such analyses in priority settings, strong information system will need to be structured and implemented in place.[9]

The purpose of our study was to determine out-of-pocket expenditure (OOPE) incurred by cancer patients at a tertiary care cancer centre at King Georges Medical University, Lucknow. In the present study, we noted socio-demographic as well as economic characteristics of patients seeking care at the centre along with descriptive analysis of the involved direct and medical and nonmedical costs incurred by these patients.

2. Materials and Methods

A tertiary care hospital based cross-sectional observational and analytical study was conducted on 120 cancer patients attending surgical OPD, at King Georges Medical University, Lucknow, for one year, from July 2020 to November 2021. Participants were directly interviewed at the site of first contact with no follow-up. No intervention was done.

2.1. Inclusion criteria

1. Patients of any age/sex diagnosed with cancer of any type.
2. Patient who had completed the primary treatment of cancer in KGMU, Lucknow.
3. Patient who gave consent to participate in the study.

2.2. Exclusion criteria

1. Patient who had undertaken primary cancer treatment from any other hospital and are coming to KGMU only for follow-up or any therapy.
2. Patient who did not give consent for the study.

Pre-designed, pre-tested, and semi-structured questionnaire was used to determine the socio demographic characteristics, economical details, cancer diagnosis details and out of pocket expenditure details related to the participants. All the questions with regard to charges incurred in the past on various aspects such as consultation, medicines, diagnostics, travel, and lodging were enquired retrospectively from the onset of symptoms to the registration of individual as a cancer patient in the cancer centre. OOPE was calculated based upon the collected data.

2.3. Statistical analysis

Data were analysed using SPSS software 23 and MS Excel 2017. The categorical variables were represented in the form of frequency tables. Median (IQR) was used as the measure of the central tendency for the continuous variables. Non-parametric tests of significance like the Man Whitney U test and Kruskal Wallis test were used for determining the difference between the median of two groups of the particular independent variables. Also, the chi-square test and Fischer exact test were used as a test of significance. Spearman's correlation was used to show an association between independent and dependent variables. Linear regression was applied to know the variability of dependant variables due to significantly correlated variables.

2.4. Ethical consideration

Institutional ethical clearance was obtained before starting data collection. Informed consent was obtained from the participants. Data collected from participants were maintained confidentially. Institutional ethical clearance reference number: 101^{st} ECM II B thesis/P81

The present study was done on cancer patients at Surgical oncology OPD, KGMU, Lucknow to study the economic burden on a cancer patient's household by estimating Out-of-pocket expenditure (OOPE).

3. Result

We observed participants 'majority (about 70%) of participants belong to the 31 to 60 years age group while only two were less than 14 years. The mean age of the total participants in the study was 45±13.6 years. There was equal distribution of participants on basis of gender i.e. 60 each. We noticed majority (about 85%) were married. About 54.2% of them were residing > 100 km away from the study area (Lucknow) and about $2/3^{rd}$ of participants resides in rural areas. Other Socio-demographic details have been tabulated (Table 1).

We observed 77.5% of the total had studied till intermediate while 22.5% of participants more than intermediate. Majority (37.5%) were either unemployed or were housewives while only 5% were with job. (Table 2)

About 18.3 percent of study participants had to spend extra on another family member who is suffering from some chronic illness other than the present cancer patient. Only 8.3 percent of study participants' family already taken loans for some other purpose. We observed the mean family income of study participants was Rs 16125 ± 19105.33 whereas the mean per capita income of study participants was Rs 2776.18.

Table 1: Out-of-pocket expenditure according to socio-demographic details of participants

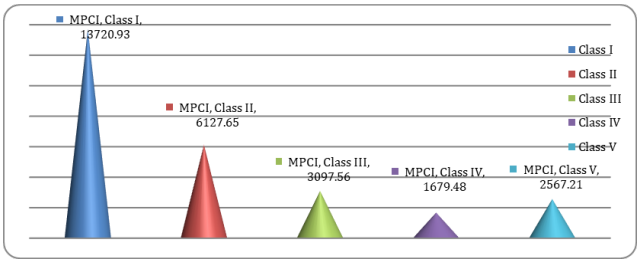
Socio-demographic profile		Frequency (n)	Percentage %	OOPE (Rs.) Mean ± SD	OOPE (Rs.) Median (IQR)	#P value
Age	0 to 14 years	2	1.7	16651	16651	0.086
	15 to 30 years	14	11.7	113422.28 ±115911.9	62601 (51851,87800)	
	31 to 45 years	48	40.0	106146 ±92751.35	71101 (52651,130126)	
	46 to 60 years	38	31.7	105823.68 ±68991.97	98101 (53151,121028.3)	
	61 to 80 years	18	15.0	116145.44 ±69975.17	95151 (53201,165151)	
Gender	Male	60	50.0	102988.67 ±82333.8	73751 (52826,122301)	0.273
	Female	60	50.0	110813.67 ±87671.13	87800 (48651,121551)	
Current marital status	Never married	8	6.7	112251 147608.2	41351 (21076,132526)	‘ 0.060
	Married	102	85.0	102630.62 ±78780.12	79051 (51626,119460)	
	Divorced/separated/ widow	10	8.3	146180.8 ±80559.3	121551 (95151,174700)	
Residential address	Less than 100 km from Lucknow	55	45.8	98939.07 ±81339.68	65051 (47325.5,122901	0.017
	More than 100 Km from Lucknow	65	54.2	113638.32 ±87640.08	98151 (53201,121651)	
Type of residence	Rural	80	66.7	103365.45 ±74222.6	91475.5 (55976,121551)	0.121
	Urban	40	33.3	113972.6 ±103412.6	59201 (47701,168351)	
Religion	Hindu	102	85.0	109880.98 ±81322.33	87800 (53163.5,121651)	0.125
	Muslim	18	15.0	90015.5 ±103268.8	55751 (26383,80800)	
Category	General	52	43.3	84107.92 ±64375.51	60551 (44851,98151)	.087
	OBC	39	32.5	118963.7 ±90204.4	99151 (66851,154851)	
	SC/ST	29	24.2	131549.75 ±100785.4	106501 (53151,174700)	
Type of family	Nuclear family	56	46.7	106764.6 ±94190.17	73701 (47701,113787.8)	0.143
	Joint family	64	53.3	107020.65 ±76357.87	91475.5 (55151,147751)	

#Mann Whitney/ Kruskal Wallis test

After applying modified BG Prasad classification[10] most of the study participants belonged to Classes V (44.2%) followed by class IV (23.3%) (Table 3). The highest monthly per capita income of participants' households was for a class I socio-economic class i.e. Rs 13720.93 whereas the lowest was for Class IV i.e., Rs 1679.48. On average, mean per capita income (MPCI) is Rs 2776.18 (Graph 1).

Majority (45.8%) were suffered from oral cancer. A majority (61.7%) of them were diagnosed at Medical Colleges. Most participants (81.7%) were diagnosed with cancer after being symptomatic for the disease. About 36.7% of the participants' treatment plan was surgery plus chemotherapy plus radiotherapy while 8.3%were planned for chemotherapy and radiotherapy.

Overall mean out-of-pocket expenditure by study participants was Rs 79925.5(51776-121651). Out of which expenditure done before coming to tertiary care hospital was Rs 9000(2700-35500), under this Rs 8000(2500-30000) was spent as a medical expense and Rs 1200(500-5000) as a non-medical expense. On average total expenses at a tertiary care hospital were Rs 54551(34138.25-110051). Other expenses shown in Table 5.



Graph 1: Distribution of Monthly per capita income (MPCI) of participant's household according to Socio-economic class (B G Prasad classification) (N=120)

Table 2: Out-of-pocket expenditure according to qualification and occupational details of participants

Socio-demographic profile		Frequency	Percentage	OOPE		#P value
				(Rs.) Mean ± SD	(Rs.) Median (IQR)	
Highest education qualification	Illiterate	8	6.7	69513 ±22429.29	67000.5 (51400.75, 85112.75)	0.074
	Literate but no formal education	19	15.8	128649.2 ±90911.27	111200 (55751, 154851)	
	Till Primary school	10	8.3	195411 ±128570.9	124251 (121551, 279451)	
	Till middle school	6	5.0	50117.67 ±26627.1	60051 (27501, 70251)	
	High school	18	15.0	129145.3 ±85691.93	101651 (51851, 174700)	
	Intermediate	32	26.7	100174.75 ±84881.94	74801 (52251, 113712.5)	
	Diploma	6	5.0	70651 ±35555.59	53151 (45276, 100401)	
	Graduate	6	5.0	62084.3 ±17298.4	53351 (49826, 76526)	
	Postgraduate and above	15	12.5	83084.3 ±52107.74	79051 (40551, 102151)	
Occupation of the patient	Professional/technical/ administrative/ managerial	6	5.0	75017.67 ±25830.27	84251 (53051, 94676)	0.325
	Sales and service	12	10.0	73481.17 ±29507.58	76425.5 (53351, 102151)	
	Skilled	6	5.0	34934.33 ±16913.09	36251 (20613.5, 48926)	
	Unskilled	16	13.3	121800.75 ±83420.59	92475.5 (64626, 134913.3)	
	Agriculture	26	21.7	129362.3 ±108473.9	80800 (68451, 124251)	
	Unemployed/ Housewife	45	37.5	112436.95 ±89050.94	95151 (41751, 154851)	
	Retired Pensioner	9	7.5	101639.88 ±55438.85	116151 (48651, 165151)	

#Mann Whitney/ Kruskal Wallis test

Table 3: Out-of-pocket expenditure of the different socio-economic group according to B G Prasad classification

Subclass	Frequency (n)	Percentage (%)	OOPE		#p-value
			(Rs.) Mean ± SD	(Rs.) Median (IQR)	
Class I	11	9.16	100496.5 ± 45494.4	84251 (73751,133651)	0.506
Class II	16	8.33	78258.38 ± 64231.06	51001 (32826,119982.8)	
Class III	12	10.0	149234.5 ± 111065.5	111151 (53151,236551)	
Class IV	28	23.33	119810.4 ± 95990.48	88601 (41751,154851)	
Class V	53	44.16	100472.5 ± 81604.57	75851 (53201,111200)	

#Kruskal Wallis test

The OOPE increases with an increase in age group, minimum OOPE being for 0 to 14 years age group and maximum OOPE for 46 to 60 years age group, although it was statistically non-significant. OOPE was more for participants who were divorced/separated/widow but was found statistically non-significant. For participants who resided in an area that is more than 100 km from tertiary care hospital, Lucknow, had to spend more OOPE than those who resided within 100 km from tertiary care hospital, and it was found to be statistically significant (p = 0.017). OOPE was more for SC/ST category than the General /OBC category although it's statistically non-significant. (Table 1) There is positive correlation between median OOPE and facility at which cancer was diagnosed that is if cancer is diagnosed in a private clinic/hospital more OOPE will be done by a cancer patient (Spearman coefficient = 0.407, P < 0.001).

OOPE was more for those who have a low level of education (illiterate to intermediate level) and less for those who are diploma/graduate/post-graduate, although it is statistically non-significant.(Table 2)

OOPE was more for participants who suffered from gall bladder cancer as compared to those who suffered from tongue cancer and it was found to be statistically significant (p = 0.001). Participants who were diagnosed with cancer while screening or by chance had to spend more OOPE than

Table 4: Out-of-pocket expenditure according to details of diagnosis of participants

Details of diagnosis		Frequency (n)	Percentage %	OOPE (Rs.) MEAN ± SD	OOPE (Rs.) Median (IQR)	#p-value
Site of cancer	Oral	49	40.8	107664.79 ±58269.05	98051 (68451,124251	0.001
	Breast	13	10.8	89424.07 ±69067.76	79051 (36251,147751)	
	Ovary	14	11.7	113701 ±111331.6	55751 (49788.5,155776)	
	Tongue	12	10.0	45992.67 ±18043.54	46601 (41751,51851)	
	Gall bladder	8	6.7	153613.25 ±119381.5	113851 (46000,176351)	
	Others	24	20.0	125725.83 ±113340.4	92975.5 (49876,142537.8)	
Facility at which cancer was diagnosed	Medical college/District hospital	76	62.3	76876.01 ±52175.09	60051 (42651,98051)	<0.001
	Pvt hospital/Clinic	44	37.7	154953.08 ±105435	111200 (68451,174700)	
When was cancer diagnosed	During screening/	22	18.3	125800.9 ±96787.62	98151 (72401,141201)	0.034
	Symptomatic for cancer	98	81.7	102658.36 ±81792.53	73751 (50551,121103.3)	
Time lost from first symptoms to making diagnosis	Within 1 month	55	45.8	109994.23 ±880602.18	87800 (49601,124251)	0.535
	2 to 5 months	48	40.0	92688.75 ±65660.88	71001 (51776,107413.3)	
	6 to 12 months	7	5.8	147986.42 ±115230.5	111200 (74576,211025.5)	
	More than 1 year	10	8.3	129351 ±116418.8	79051 (73751,84251)	
Delay in treatment after diagnosis	Yes	32	26.7	75760.25 ±77655.63	52376 (41076,84387.75)	0.023
	No delay	88	73.3	118225.13 ±84827.07	99901 (59051,154851)	
Treatment plan	Surgery + radiotherapy	16	13.3	93017.25 ±50223.5	78325.5 (65675,125826)	0.961
	Chemotherapy + radiotherapy	10	8.3	83250.8 ±28877.85	87800 (53201,102151)	
	Surgery + chemotherapy+ Radiotherapy)	44	36.7	102375.22 ±80857.1	88551 (41151,130126)	
	Only surgery	32	26.7	109893.43 ±81728.58	79001 (59051,113812.8)	
	Surgery + Chemotherapy	18	15.0	143512 ±130166.7	68451 (53151,187651)	

#Kruskal Wallis/Mann Whitney U test

Table 5: Details of out-of-pocket expenditure of participants

OOPE		**(Rs.) Mean ± SD**	**(Rs.) Median (IQR)**
Expenses before coming to tertiary care hospital**(a)**	**(a.1)** Medical expenses	22639.17 ±38326.9	8000(2500,30000)
	(a.2) non-medical expenses	4998.33 ±8761.22	1200(500,5000)
	(a) Total = **(a.1) + (a.2)**	27775.83 ±44686.55	9000(2700,35500)
Expenses after coming to tertiary care hospital **(b)= (b.1) + (b.2)**		84046.58 ±7627.3	54551(34138.25,110051)
Medical expenses **(b.1)**	Fees	189.91 ± 131.02	151(51,200)
	Medicines and equipment's	50066.67 ±49585.67	32500(19750,66250)
	Investigations	15316.67 ±10673.13	15000(10000,20000)
	(b.1) Total	65454.91 ±58752.7	45151(30051,90051)
Non- Medical expenses **(b.2)**	Transport	7499.16 ±12706.17	3600(2000,6000)
	Food and lodging	6852.5 ±6032.45	5000(3000,8500)
	(b.2) Total	14465 ±18143.9	10000(5000,14000)
Follow up expenditure **(c)** (Taking single follow up visit)	**(c.1)** Medical expenses	1600.41 ±3160.28	1000(700,2000)
	(c.2) non-medical expenses	1020 ±1108.9	700(400,1200)
	Mean expenditure per visit **(c) = (c.1) +(c.2)**	2630.4 ±3412.7	1800(1300,2525)
OOPE	Total **(a+b+c)**	1006901.17±84777.76	79925.5(51776,121651)

those who were diagnosed when they were symptomatic for cancer and it was statistically significant (p = 0.034). (Table 4)

Participants who were diagnosed at district hospital/medical college had to spend significantly less (p < 0.001) than those who were diagnosed at Private clinic/hospital and, those who had to suffer the delay in treatment due to some reason had to spend less than those who started treatment just after the diagnosis, and it was statistically significant (p=0.023). (Table 4) The OOPE for Class III socio-economic class was maximum followed by Class II socio-economic class (minimum), although it was statistically non-significant (p = 0.506.(Table 3)

4. Discussion

The ultimate concern for which the study was conducted was that people had to spend a heavy amount of money on cancer treatment and management which may lead to subsequent impoverishment, although some options and financial benefits are available for cancer patients its accessibility is still a problem.

The present study was performed in the tertiary care hospital of Lucknow district, recruiting 120 participants from surgical oncology OPD. The mean age of participants was 45±13.6 years with an equal number of males and females and most of the participants were married. According to Mathur et al. (2020)[11] there was a similar risk of cancer (1 in 9) among males and females. One-third of participants were from a rural area and about half of them lived in the districts which are located 100 km from Lucknow. Khan abas et al. (2020)[12] shows that majority of cancer patients were married and belonged to rural area.About half of them lived in a joint family, the majority belonging to the Hindu religion. Participants were mostly educated till intermediate and were agricultural workers/ unemployed or housewife with MPCI of Rs 2776.2 maximally belonging to class V socio-economic group. Khan abas et al. (2020)[12] also show that the majority (80%) of cancer patients belong to a low socio-economic class**.** Most of the participants were of oral cancer, diagnosed mostly at medical colleges, and were given chemotherapy, radiotherapy, and surgical intervention. Similarly, Mathur et al. (2020)[11] in study shows that one of the leading cancers in India is Oral cancer.

In this study, at first, we tried to estimate the Out-of-pocket Expenditure done by the cancer patients who visited and were treated at the tertiary care hospital of Lucknow. OOPE was estimated summing up the direct and indirect expenditure done at three steps- 1) Before coming to tertiary care hospital 2) at tertiary care hospital and 3) during one follow-up visit. Details of medical expenditure i.e., the fee paid, medicines/dyes/chemo drugs, equipment's/instruments purchased, procedure/ surgery costing, investigations cost etc. and details of non-medical expenditure like travel expenses, food and accommodation expenses were taken. The OOPE estimated in a study is Rs 79925.5 (51776, 121651) which is about double that estimated in the study Bindu et al (2011).[13]

The present study also included expenditure did before coming to tertiary care hospital and also expenditure did during follow up visit and also there have been increase in cost of products at a market or even in hospital since there is a gap of a decade in between the cited study. In an article what is the cost of cancer in India? Published in the magazine The WEEK stated that at the National level, the total cancer care cost at the public hospital was Rs 72,092 and while it is more in states like Uttar Pradesh.[14] Also Anushikha et al (2021)[15] shows that direct OOPE on inpatient cancer care was Rs 83396.07. The majority part of OOPE was done after coming to tertiary care hospitals. In the study, participants on average spent Rs 45151(30051, 90051) on direct medical expenses which is about 82.8 percent of total cancer treatment expenses in hospitals. This is comparable to the result of the study done by Rajpal et al. (2014)[16] which showed that the medical expenditure is estimated to be around 80-90 of total expenditure on cancer inpatient treatment. The OOPE done by participants before reaching to tertiary care hospital was done at different medical centers in search of making correct diagnosis and treatment and other expenses related to it, on average it was estimated Rs 9000(2700,35500), while in a study Bindu et al (2011)[13] mean cost of expenses before coming to hospital was Rs 14031, it was estimated slightly more than the study done, due to positive change in health-seekingbehaviour of participants, directly reaching to medical centers where the diagnosis is made early and people reach desired tertiary care hospital early. And also, there has been an increase in the number of health centers and doctors, increasing their availability and accessibility. The expense made during follow-up visits after completing primary cancer treatment was also a contribution to OOPE although in the present study it was estimated mere Rs 1800 per visit the total expense may vary according to the frequency of follow-up visits. Per visit on average a participant spends Rs 1000 on medical and Rs 700 on non-medical, although data on the follow-up visit of cancer is not sufficiently available.

In the present study, the mean age of participants was 45 ±13.6 years, estimation of OOPE shows that female patients had to spend more than male patients which are in accordance with Rajpal et al (2014)[16] study which also mentions that total expenditure on cancer treatment in males is Rs 27427 and in females is Rs 30835 which is higher than that in male. OOPE for the participants whose home town district is more than 100 km from the tertiary care hospital, Lucknow was more than those participants who resided within 100 km from tertiary care hospital which is supported by the study Emily et al (2019) which says that indigenous people with cancer have half the OOPE than non-indigenous people in Australia.[17] Travel expenses and accommodation/food charges increase if the patient's residence is far away from the treatment center. Participants residing in urban areas have to do less OOPE than participants residing in rural areas as the household income of urban areas is higher and good medical facilities are available in urban areas and more health awareness. Total OOPE was estimated to be more in gall bladder cancer and oral cancer, this may be due to more interventions needed in its management, and it's difficult to diagnose in the early stages. As the charges are higher in private clinics or hospitals, all those who were diagnosed in the Private sector spend more OOPE than those who were diagnosed at public health centers.

One of the limitation of present study was small sample size and the result cannot be generalised as the sample was not the true representation of all population. Also, response of the participants could not be verified by records.

5. Conclusion

We concluded that cancer patients face the burden of out of pocket expenditure at every stage, beginning from the initial visit to a health care facility till the final diagnosis and treatment. Wenoticed The estimated OOPE is Rs 79925.5 (51776,121651) in comparison with MPCI of Rs. 2776.20. We documented significantly higher OOPE in gall bladder cancer treatment, treatment at private hospital / clinic, if diagnosed at screening time and if started treatment without delay. We recommend for strategic policy action to invest on reducing the economical burden of direct non-medical expenses and further study with large sample size.

6. Source of Funding

None.

7. Conflict of Interest

None.

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