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Out-Of-Pocket Expenditure by Patients in Pre-treatment Evaluation of Gynaecologic Cancer

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Abstract

Objective: Out-Of-Pocket Expenditure (OOPE) is a substantial economic burden to gynaecologic cancer patients and their families. The purpose of this study was to calculate the Out-Of-Pocket Expenditure and incidence of Catastrophic Health Expenditure (If OOPE exceeds 40% of non-food expenditure of family) during the gynaecologic cancer diagnosis.

Methods: 89 patients of various gynaecological cancers were enrolled from the Out-Patient Department and data was collected regarding cost incurred by patients and caregivers under heading of direct medical, direct non-medical, and indirect cost.

Results: The average OOPE for diagnostic evaluation of a patient receiving care for gynecological cancers in this institute was found to be INR 27587.16 with a standard deviation (SD) of INR 27334.4. The average direct medical cost, direct non-medical cost, and indirect costs were INR 8106.8 (SD 8368.2), INR 3113.4 (SD 3346.99), and INR 16366.8 (SD 21507.14) respectively. The patients with ovarian cancers (INR 37356.80) spent the highest OOPE which was statistically significant (p <0.05). The direct non-medical and indirect costs, were highest for ovarian cancer patients at INR 4115.29 (3921.62) and INR 22774.29 (25768.9) respectively. It was observed that 30.33% of the individuals were found to have catastrophic health expenditures.

Conclusion: The high cost paid by patients in terms of OOPE in gynaecologic cancers diagnosis has a direct impact on delayed cancer diagnosis and related morbidity.

Key words: Gynaecologic cancers, Out-Of-Pocket Expenditure, direct medical cost, direct non-medical cost, indirect cost, catastrophic health expenditure.

Introduction

The incidence of cancer is rising worldwide and is expected to increase further in the coming decades^{1,2}. According to the Global Cancer Observatory (GLOBOCAN) 2020, the total incident cancer cases were 19.3 million worldwide. India comes in third place after China and the United States of America². The diagnosis and treatment of cancer are not only associated with physical and emotional burdens but also with a huge financial burden on the affected households. In developed countries, the state shares a large part of the financial burden of cancer treatment because of comprehensive health insurance policies. The greatest sources of economic burden among cancer patients include health services expenditures and lost income of patient and caretaker^{3,4}. The situation is worse in developing countries like India with little assistance from the government. Only 25% of the Indian population is covered by some kind of health insurance scheme.

Like any other cancer, gynaecologic cancers are associated with a high economic burden of diagnosis and treatment on both families and society. The cost incurred by patients and families not only includes the cost of diagnostic investigations, medicines, and consultation charges but also the money spent on travel, food, accommodation, and daily wage losses. Out-of-pocket expenditure (OOPE) is defined as the total amount of money spent by the patient or family during diagnosis/treatment, which includes direct medical and non-medical costs as well as indirect costs. Direct medical expenditure includes costs of investigations, medicines, consultation charges, etc. Direct non-medical expenditures include costs on travel, food, and accommodation expenses⁵. Indirect cost is defined as loss of income due to absence from work of a patient/caretaker while being investigated/treated. Catastrophic health expenditure (CHE) is said to be present if the health expenditure of the family for the present cancer (total OOPE) is more than or equal to 40% of the annual Capacity To Pay (CTP). CTP can be defined as the total non-food expense of the family (household expenses-food expenses per month). The monthly CTP is multiplied by 12 to get the annual CTP⁶.

According to the National Sample Survey Organisation (2015), around 60% of the healthcare expenditure is paid

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out-of-pocket by patients in India⁷. This causes an extra strain on household finances. Even before reporting to tertiary care hospitals, patients spend money going to small or private health facilities. To our knowledge, there have been very limited studies conducted in India which estimated the OOPE borne by cancer patients⁸⁻¹¹. Therefore, we conducted this study to estimate the OOPE from the onset of symptoms till the diagnosis for various types of gynaecological cancers at a tertiary care hospital in Delhi. The various gynaecologic cancers were cervical, ovarian, uterine, vulval, and vaginal cancers. The primary objective was to calculate the OOPE (direct and indirect) by patients in the pre-treatment evaluation of gynaecologic cancer and the secondary objective was to calculate the CHE rate in the pre-treatment evaluation of gynaecologic cancers. The CHE rate is the proportion of patients who experience catastrophic expenditure out of total patients included in the study.

Methodology

This cross-sectional study was conducted at a tertiary care government hospital in Delhi from July 2023 to Oct 2024. We receive referrals from other smaller government hospitals and private clinicians from Delhi and other states. This was a pilot study, approved by the ethics committee of the hospital (GTBHEC 2024/P-201), and the study was registered under ClinicalTrials.gov (Reg. No.-CTRI/2024/07/070008). The patients who had been diagnosed/suspected gynaecological cancers referred from smaller health sectors, both government and private, were included in the study. The exclusion criteria were any other non-gynaecologic cancers. Patients were enrolled from the Out-Patient Department and data was analysed for 89 participants. Written consent was taken from all participants. Pre-designed performa was used to collect data from patients and/or family members. In the study, a bottom-up micro-costing method was used to estimate the OOPE (direct and indirect costs) associated with diagnosing gynaecologic cancer. Micro-costing or bottom-up costing is defined as a method of cost calculation in which each component of resource use (e.g., laboratory tests, drugs, travel, food expenses) is estimated and a unit cost is derived for each. This is used for precise calculation of the economic costs of health interventions. Here, the cost was calculated for each element of an intervention.

The data was collected by the principal investigator along with the co-investigator. The details were collected regarding demographics. The details of the money spent under various headings, e.g., laboratory investigations, imaging, drugs, blood transfusion and medical materials, transportation to the hospital, food expenses during hospital visits, and accommodation expenses for both the patients and the caretaker were collected based on the recall of patient and relatives. Details of the patient's total family income from all sources were collected. The total family expenditure pattern was obtained from the patient or the caregiver to calculate the capacity to pay. The CHE rate, i.e., the proportion of patients who experienced catastrophic expenditure out of the total patients included in the study, was also calculated. All costs are reported in Indian National Rupees (INR). We only took the details of the cost incurred during the diagnostic workup of gynecologic cancers, i.e., from the onset of first symptoms till the final diagnosis of cancers. The histopathological reports of gynaecological cancers were also collected and recorded to confirm the final diagnosis. Complete confidentiality of the information collected was ensured.

Statistical and sensitivity analysis

Data were managed by MS Excel and then statistically analysed using SPSS statistical software, version 22 (SPSS Inc., Chicago, IL). Descriptive statistics were used to describe basic characteristics. Age as a quantitative variable was presented as the mean, while qualitative variables including residence, education status, occupation, level of income per month, and payment scheme were presented as frequency and percentage. All costs were reported as INR in terms of mean and Standard Deviation (SD).

Results

A total of 89 cases of gynaecological cancers were recruited. The basic demographic characteristics are shown in Table I. The mean age of study participants was 49 years. Around 74.15% of participants were from urban backgrounds. Almost half (59.55%) of the participants received no formal education.

The disease characteristics of all participants are shown in Table II. Cancer patients comprised of ovarian (35), cervix (33), endometrial (19), choriocarcinoma (1), and vulval (1) cancer. The majority of patients (72.9%) presented in stage II and onward. Usually the cancer patients first approach nearby private practitioners or smaller government hospitals before being referred to tertiary care hospitals. Therefore, patients have to spend money and time before the final diagnosis and initiation of treatment. The mean duration from onset of symptoms till reporting to this tertiary care hospital was 10.56 months across all cancers. This could be a causative factor for presentation of cancers in the advanced stage. It was observed that almost 60% of participants showed up in other smaller government hospitals before coming to our hospital and the rest were showing in private clinics, quacks, or ayurvedic doctors.

Table I: Socio-Demographic Characteristics of theStudy Group.

Characteristics	N (%)			
Mean Age (years)	49			
Marital status	Unmarried	4 (4.49)		
	Married	74 (83.14)		
	Widow/ Divorced	11 (12.3)		
Religion	Hindu	63 (70.7)		
	Muslim	25 (28.0)		
	Other	1 (1.1)		
Education	Illiterate	53 (59.55)		
	Senior Secondary	30 (33.7)		
	Graduate	6 (6.7)		
Occupation	Unskilled	65 (73)		
	Semiskilled/Skilled	24 (26.96)		
Type of family	Nuclear	50 (56.17)		
	Joint	39 (43.82)		
Locality	Urban	66 (74.15)		
	Rural	23 (25.84)		

Table II: Disease characteristics of cancer patients.

Stage	Ovarian	Cervix	Endometrial	Others
I (25.84%)	5	8	10	1 (Choriocarcinoma)
II (35.95%)	8	16	7	1 (vulval)
III (33.7%)	20	9	1	
IV (3.3%)	2	-	1	
Mean duration from onset of symptoms till hospital visit (months)	11.8	9.7	11.38	8.5
Type of Previous consulta	tion			
Private (41.57%)	16	12	8	1
Government (59.55%)	19	22	11	1

Table III shows socio-economic characteristics of the study participants. Among the 89 participants, 77.52% had above the poverty line ration card. The awareness regarding various government health schemes was very limited and only 34.83% of participants were aware of the Ayushman Bharat Scheme. Only one of the participant reported utilisation of any health insurance scheme.

Out-Of-Pocket Expenditure

The average OOPE for diagnostic evaluation of a gynaecological cancers patients borne by was found to be INR 27587.16 with a SD of INR 27334.4 as mentioned

in Table IV. The average direct medical, direct non-medical, and indirect costs were INR 8106.8 (SD 8368.2), INR 3113.4 (SD 3346.99), and INR 16366.8(SD 21507.14) respectively. The patients with ovarian cancers (INR 37356.80) spent the highest OOPE which was statistically significant (p < 0.05). The average money spent by other type of cancers (choriocarcinoma and vulval cancer) patients on direct medical costs was INR 14150.0 (20011.12) followed by ovarian cancer patients as INR 10467.23 (7850.17). Although the other group comprised only two patients. The Direct non-medical and indirect costs were highest for ovarian cancer patients at INR 4115.29 (3921.62) and INR 22774.29 (25768.9) respectively as shown in Table IV. The difference in direct non-medical and indirect costs among the various sites of cancer was found to be statistically significant (p value < 0.005).

Table III: Socio-economic characteristics of the participants.

Characteristics	n (%)		
Type of Ration Card	Above Poverty Line	69 (77.52)	
	Below Poverty Line	3 (3.37)	
	No Ration Card	17 (19.10)	
Awareness of Ayushman Bharat Scheme	Yes	31 (34.83)	
	No	58 (65.16)	
Recipient of any Health Benefit	Yes	0	
	No	89 (100)	
Recipient of any Health Insurance	Yes	1 (1.12)	
	No	88 (98.87)	

Table IV: Out of Pocket Expenditure (OOPE) of different cancer types.

Type of cancer	Ovarian	Cervical	Endometrial	Others (GTN, Vulval)	p-value
Direct Medical	10467.23	5431.21	7770.00	14150.0	0.005
Mean (SD)	(7850.17)	(8325.32)	(7235.38)	(20011.12)	
Direct Non-Medical	4115.29	2129.09	3118.42	1775.0	0.003
Mean (SD)	(3921.62)	(2745.0)	(2887.33)	(1025.31)	
Indirect	22774.29	9725.76	17084.2	7000	0.001
Mean (SD)	(25768.9)	(14362.91)	(21664.36)	(707.11)	
Total OOPE	37356.80	17286.06	27972.63	22925.0	<0.05
Mean (SD)	(30457.36)	(20249.09)	(27676.83)	(20329.32)	

*OOPE – Out of Pocket Expenditure, GTN – Gestational Trophoblastic Neoplasia

*Direct (medical) cost includes costs of investigations, medicines, consultation charges, etc.

*Direct (non-medical) cost include costs on travel, food, and accommodation expenses.

*Indirect cost is defined as loss of income due to the absence from work of a patient/caretaker while being investigated/treated.

*All costs are in INR.

	Direct (Medical) Mean (SD)	p-value	Direct (Non-medical) Mean (SD)	p-value	Indirect Mean (SD)	p-value	Total OOPE Mean (SD)	p-value
Age (years)								
<30	11829.29 (8884.11)	0.41	3288.57 (1812.81)	0.72	9142.86 (5421.51)	0.41	24260.71 (11961.12)	0.42
31 - 60	8645.33 (8340.55)		3608.00 (3885.76)		17593.33 (16556.92)		29846.67 (23634.53)	
>60	7840.56 (6810.03)		3827.22 (5476.91)		21386.11 (29378.63)		33053.89 (36796.43)	
Occupation								
Unskilled	7209.74 (7767.76)	0.11	3068.85 (3705.42)	0.09	14776.92 (19812.5)	0.104	25055.51 (25482.22)	0.08
Skilled	10536.67 (9570.68)		3234.17 (2152.88)		20672.92 (25515.85)		34443.75 (31379.91)	
Locality								
Rural	9238.26 (9075.26)	0.36	3710.00 (3499.59)	0.25	15263.04 (14331.05)	0.41	28211.30 (20203.72)	0.31
Urban	7712.62 (8143.69)		2905.53 (3294.13)		16751.52 (23582.56)		27369.67 (29550.14)	
Education								
Illiterate	7763.36 (8934.21)	0.03	2793.49 (3008.09)	0.01	15576.42 (24493.76)	0.08	26133.26 (30595.37)	0.07
Senior secondary	7321.83 (7099.81)		2807.33 (2063.37)		18203.33 (17357.56)		28332.50 (22548.17)	
Graduate	15066.67 (6849.42)		7470.00 (7344.38)		14166.67 (11021.19)		36703.33 (18458.01)	
Socio-economic status								
Lower	9300	0.58	2200	0.03	24100	0.56	35600.00 (NR)	0.53
Lower-middle	7854.40 (8748.22)		2923.58 (2847.91)		15691.51 (21741.6)		26469.49 (28083.07)	
Upper-lower	7551.50 (8389.61)		2346.25 (2396.09)		17605.0 (26097.9)		27502.75 (29750.28)	
Upper-middle	9323.08 (7996.78)		3386.15 (2374.95)		16061.54 (14695.66)		28770.77 (21900.33)	
Upper	11850.0 (4454.77)		14500.0 (10606.61)		20000 (21213.21)		46350.0 (36274.57)	
Ration card								
Above poverty line (70)	7831.83 (8157.37)	0.28	3204.64 (3620.91)	0.57	16997.86 (22705.29)	0.52	28034.33 (29469.19)	0.37
Below poverty line (2)	20250.00 (15485.63)		4150.00 (2757.71)		15050.0 (12798.63)		39450.00 (5444.72)	
No card (17)	7810.88 (8021.31)		2615.88 (494.86)		13923.53 (17386.82)		24350.29 (18244.67)	
Health insurance utilis	ation							
Yes (1)	8700.0	_	7000	—	5000	_	207000.0 (NR)	NR
No (88)	8100.15 (8415.94)		3069.26 (3339.99)		16496.02 (21595.65)		27665.43 (27481.03)	
Awareness about Ayus	hman Bharat Scheme							
Yes	10857.03 (8691.01)	0.01	4445.16 (4302.88)	0.01	21801.61 (24192.21)	0.003	37103.81 (29534.64)	0.002
No	6636.98 (7876.92)		2401.64 (2463.78)		13462.07 (19530.51)		22500.69 (24876.53)	

Table V: Direct (medical and non-medical) and indirect costs incurred by gynecological cancers (n = 89).

Table V shows the section-wise direct (medical and nonmedical) and indirect costs experienced by patients. Direct medical, direct non-medical, and total OOPE costs for each of the independent variable categories is given as mean with standard deviation (SD). Direct medical cost was higher in the <30 years age group (INR 11829.2) whereas direct non-medical cost and indirect cost were higher in the >60 year age group with INR 3827.2 and INR 21386.1 respectively. The OOP expenditure for the age group >60 years was highest at INR 33053.89 than younger age groups, although it was not statistically significant. As per the different occupational categories, there was no statistically significant difference in the total OOPE. Based on residence, we found no statistically significant difference in OOPE between urban and rural patients (INR 28211.30 vs INR 27369.67, p value 0.046).

As per the literacy status of the study group, graduates

spent the highest average OOPE of INR 36703.33, direct medical of INR 15066.67, and non-medical costs of INR and 7470.00 (p value 0.07, 0.03 and 0.01 respectively).

The OOP expenditure by upper class as per Modified Kuppuswamy Classification was higher. This could be due to the high direct non-medical cost spent by upper class patients (INR 14500.0). The upper-class patients had the highest average OOPE of INR 46350.0, although not statistically significant. The OOPE was slightly more in the patients having below poverty line ration card (INR 39450.00), although not statistically significant. In the present study, only one patient utilised health insurance, while rest 88 patients did not utilise health insurance, hence comparison was not done.

Patients who were aware about the Ayushman Bharat Scheme spent highest direct medical, non-medical (INR 10857.03, INR 4445.16) and indirect medical cost (INR 21801.61) when compared to those who unaware about this scheme (p value <0.005).

Catastrophic health expenditure calculation

The details of household expenditure patterns of families and the OOPE were analysed to explore the proportion of households suffering catastrophic health expenditure due to gynaecological cancer evaluation and diagnosis. The findings revealed that 30.33% of the patients' families had experienced catastrophic health expenditures (OOPE payments are greater than 40% of non-food expense of the family per year). According to type of gynaecological cancer, it was observed that 50% of other types of cancers (vulval and choriocarcinoma) and 45% of ovarian cancer patients had suffered CHE as mentioned in Table VI.

Table VI: Proportion of study population with Catastrophic health expenditure (CHE) present due to gynaecologic cancers (n = 89).

Variable	CHE Present n (%)
PverallI	27(30.33%)
Site of cancer	
Ovarian	16 (45%)
Cervix	7 (21.2%)
Endometrial	3 (15.7%)
Other	1 (50%)

Discussion

The mean age of patients was ~ 49 years; the age distribution of the study participants of the present study was more towards the younger population as compared to previous studies conducted among head and neck cancer (HNC) patients in north india¹². The same was seen in a study of 957 ovarian neoplasms, where malignant tumours presented between 41 and 50 years of age¹³.

Most of the study population (74.15%) belonged to urban areas and from the lower middle class. The utilisation of health insurance was almost negligible (only one patient among 89), which is much less than reported in the study of Chauhan *et al*¹². In the present study, awareness regarding Ayushman Bharat Scheme was also checked. Only 34.8% of patients were aware of Ayushman Bharat Scheme.

The results of the present study show that direct medical and direct non-medical costs for diagnostic workup of gynaecological cancers at a public facility in north India is INR 8106.8 and INR 3113.4, respectively. The indirect cost was highest at INR 16366.8. The addition of all, i.e., OOPE was INR 27587.16 which was less than the OOPE reported for various solid cancers treatment by KM Pradeep et al¹⁴ from South India (INR 35,8169). The reported OOPE was INR 36,812 for Head and Neck Cancers from New Delhi in 2006. while a center from Chandigarh reported OOPE of INR 37,845 for Head and Neck Cancers (Chauhan et al 2017)¹². The lower OOPE in the present study can be explained by the fact that we calculated the OOPE spent by patients from the onset of symptoms till the diagnosis was made, while other studies looked at the entire treatment of the cancers. To the best of our knowledge, no such study is reported in literature.

The present study focuses on the expenses of diagnostic evaluation during outpatient and in-patient care received by gynaecological cancer patients including the indirect cost. The indirect cost has not been studied in previous studies. The major part of the OOPE (59.32%) was in the indirect domain followed by direct medical cost (29.38%). This can be explained by the fact that although the diagnostic modalities are free of cost, the patients or the caregivers need to leave their daily jobs during their hospital visits. This loss of income due to the absentism from work of a patient/caretaker is directly proportional to the number of hospital visits and time spent in OPD and hospital. Sometimes the patients have to take loans or sell their land or jewelry also. This is observed by the significantly highest direct (medical and non-medical) and indirect costs among individuals who showed earlier to private practitioners before reporting to this hospital. Before reporting to tertiary care hospitals, patients spent money in small or private health facilities for the evaluation of symptoms. Older people (>60 yrs) were spending more money when compared to the younger people, although this was not statistically significant. This could again be attributed to the extra expense of traveling to the health facility. The richer households belonging to the upper socio-economic class were spending more on the management of cancer, which

was also observed in other studies by Chauhan *et al*¹² and Rajpal *et al*⁸. The OOPE was not significantly different between urban and rural patients, whereas other studies reported that individuals from urban settings were spending more than those from rural areas. Patients with ovarian malignancy spent more than any other type of cancer.

Catastrophic health expenditure

The 40% cut-off on the CTP was used to calculate the incidence of CHE in the present study. The calculated value of CTP was 30.33%, which was not higher, when compared to other studies¹². Infact, lower CHE in the present study could be again explained by fact that our study took the account of OOPE in the diagnostic part of gynaecologic cancers. The incidence of CHE was found to be almost the same in all sites of cancer (50% for vulval cancer, and 45% of ovarian cancer).

The overall OOPE was contributed mainly by the indirect costs. In a tertiary care hospital setting, unnecessary OPD visits by both patients and caretakers can be avoided by utilizing telemedicine. Further research should focus on developing protocols for follow-up visits, along with establishing specialised cancer clinics in tertiary care hospitals.

Strengths and Limitations

Strengths

There are few studies in literature, regarding the cost analysis of gynaecological cancers. Moreover, the present study is the only study to look into cost by the gynaecological cancer type. The indirect costs under various headings (loss of income due to the absence from work of a patient/caretaker while been investigated/treated) was collected, which has not been done in most of previous studies. This would reflect the expenditure pattern and in calculating the OOPE. An important finding was that cancer patients paid substantial out-of-pocket costs under the category of indirect cost. Patients with higher socio-economic class and higher education (graduates) had the highest direct medical and direct non-medical expenditure. More then half of patients (65.16%) were aware about government scheme like Ayshman Bharat Scheme; however, almost all patients (98.87%) were not covered by any health insurance scheme.

Limitations

We collected information related to economic burden, based on the recall method. It was the patient's perspective for capturing the cost incurred during diagnoses of gynaecological cancers. The calculation of OOPE was dependent on self-reported costs by the patients, but lacked verification (e.g., bills or receipts). Information was not collected about coping strategies used by patients and families to overcome catstrophic health expenditure. It was a cross-sectional study to quantify OOPE among selected cancer patients attending the OPD of a tertiary care center. Therefore, the results of the study may not be representative of all cancers in the general population. The sample size was small, so further studies with large sample size may give more insight into the health related economic burden on patients.

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