

Original Research Article

Coping up mechanism and financial aid scheme for cancer treatment at a tertiary care hospital in Lucknow

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Received: 27 February 2023

Accepted: 13 April 2023

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ABSTRACT

Background: Cancer treatment has one of most expensive disease treatment due to its chronicity and expertise. In a region where per capita income of persons/ annual income of household is low, they have to depend on some coping up mechanism or financial aid schemes for successful completion of treatment. But awareness and proportion of utilization of the financial benefit for cancer patient is doubtful. The present study aims to study coping up mechanism and financial benefits availed by cancer patients at a tertiary care hospital in Lucknow.

Methods: The study was done in a tertiary care hospital in Lucknow. 120 cancer patients who had undergone treatment and come for follow-up were taken from surgical oncology OPD. Data was collected using an interview-based pre-tested, self-administered questionnaire and analyzed using MS excel 2017 and SPSS v 23.

Results: About 64 % of participants borrowed money from social net, 3% took loans, 10% mortgage assets, and 20% sold their assets to cope up with high expenditure on cancer treatment. Financial benefit of schemes was availed by about 1/3rd of participants and 20% availed concessions in rail/road travel fare and 16% availed concessions in income tax.

Conclusions: Large number of people had to use some of the coping up mechanism for treatment of cancer this further pushes them into viscous cycle of poverty And at same time they are unable to avail benefits of financial aid schemes by government and others for cancer patients. Thus, an increase in utilization and coverage of government financial aids or insurance is needed.

Keywords: Coping up mechanism, Distress financing, Financial aid schemes

INTRODUCTION

The incidence of catastrophic expenditure related to health-care costs is increasing and is now being considered as one of the major contributors to poverty.¹ The need to pay out-of-pocket can also affect the households for its non-availability to seek care when they need it. As per the report of National Sample Survey Organization estimate, nearly 30% of rural and 20% of urban households cited lack of financial resources as the reason for non utilization of medical care as a reason of

not seeking health care for a recent self-reported morbidity.^{2,3}

Cancer is one of the important diseases which lead to catastrophic health expenditure. In majority of patients, it leads to a major financial burden also along with a health and psychological. in India, nearly half of the newly diagnosed cancer patients per year are suitable for curative-aimed cancer-directed therapy. For financial reasons, many patients do not seek or are reluctant for treatment.⁴

Literature also have reported that the households with a cancer patient experienced significantly higher out of pocket health expenditure per capita in comparison to households with noncancer patient. In India, the likelihood of experiencing catastrophic health expenditure in cancer case was 160% more than for any other disease. In case of rural households affected with the cancer, they adopt various coping up mechanisms like borrowing of money, financial gifts from relatives/friends, and selling of assets etc. and these incidence are higher as compared to urban households for coping the related expenditure. Lower income group is reported to face distress financing even seeking treatment in public sector.^{5,6}

The government of India has come up with many schemes for cancer patients with funds, a part of which is allotted for treatments of diseases including cancer. Despite the schemes available, due to unawareness, patients are compelled to spend from their pockets as the total expenditure for treatment is huge.

Sometime, even after availing the schemes benefits, they have to expand from the pocket as expenditure exceeds the help from the schemes. India spends approximately 4% of its total GDP for healthcare. Households with a cancer patient have to spend 36-44% more than households with similar demographics. The cost of cancer treatment has been rising up because of increased need of sophisticated infrastructure, investigations requiring high technology, late presentations and costly drugs.⁷

Thus, awareness and proportion of utilization of the financial benefit for cancer patient is doubtful. The present study aims to study coping up mechanism and financial benefits availed by cancer patients at a tertiary care hospital in Lucknow, India.

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.

Inclusion criteria includes patients of any age/sex diagnosed with cancer of any type, patient who had completed the primary treatment of cancer in KGMU, Lucknow, patient who gave consent to participate in the study.

Exclusion criteria include patient who had undertaken primary cancer treatment from any other hospital and are coming to KGMU only for follow-up or any therapy, 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 (OOPE) 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 and thus benefits of various relief schemes to participants and coping mechanism from OOPE by the participants.

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.

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: 101st ECM II B thesis/P81.

The present study was done on cancer patients at Surgical oncology OPD, KGMU, Lucknow to study the Utilization of Coping up mechanism and financial aid scheme for cancer treatment at a tertiary care hospital in Lucknow.

RESULTS

The present study was performed in the tertiary care hospital of Lucknow district, recruiting 120 participants from surgical oncology OPD aiming to study coping up mechanism and financial benefits availed by the cancer patients.

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. About 54.2% of them were residing > 100 km away from the study area (Lucknow) and about 2/3rd of participants reside in rural areas. Majority were unemployed or housewives.

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.

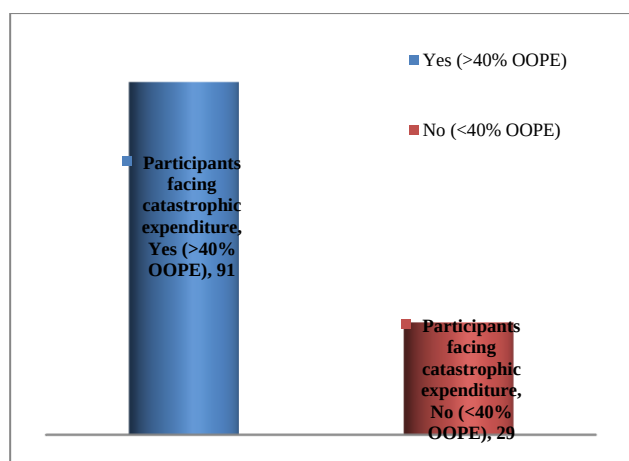


Figure 1: Participants facing catastrophic expenditure (N=120).

We observed that overall mean Out-of-pocket Expenditure by study participants was Rs 79925.5 (51776-121651). The Majority of participants (76 percent) had to spend more than 40 percent of household annual income (Catastrophic expenditure) on the management of cancer of their patient (Figure 1). The majority of participants (64.2 percent) had to borrow money from social nets like friends, relatives and the least (3.3 percent) had to take loans to cope up with OOPE. About 3/4th of people whose OOPE was catastrophic had to borrow money from their social net whereas only 1/4th of them had to borrow money whose OOPE was non-catastrophic, it was statistically significant. Almost none of those whose OOPE was non-catastrophic had to use a coping up mechanism. While about 1/4th of participants had to delay in paying bills and 90 percent of them were those experiencing catastrophic expenditure, it was statistically significant (Table 1).

Table 1: Association of coping up mechanism and benefits of financial aid schemes with catastrophic expenditure of participants.

Effect due to OOPE			OOPE			#P value
			Catastrophic (n=91)	Non-catastrophic (n=29)	Total (n=120)	
Coping Up mechanisms	Borrow money from social nets for expenditure due to cancer treatment	Yes	70 (76.9)	7 (24.1)	77 (64.2)	<0.001
		No	21 (23.1)	22 (75.9)	43 (35.8)	
	Taken any loan due to cancer treatment	Yes	4 (4.4)	0 (0.0)	4 (3.3)	0.571
		No	87 (95.6)	29 (100.0)	116 (96.7)	
	Mortgage any asset	Yes	12 (13.2)	0 (0.0)	12 (10.0)	0.038
		No	79 (86.8)	29 (100.0)	108 (90.0)	
	Sold any asset	Yes	20 (22.0)	2 (6.9)	22 (18.33)	0.097
		No	71 (78.0)	27 (93.1)	98 (81.7)	
Financial Aid schemes	Any delay in paying bills/EMI/ etc.	Yes	36 (39.6)	3 (10.3)	39 (32.5)	0.003
		No	55 (60.4)	26 (89.7)	81 (67.5)	
	Financial Aid	Availed	31 (34.1)	9 (31.0)	40 (33.3)	0.824
		Not availed	60 (65.9)	20 (69.0)	80 (66.7)	
	Concession on rail/airway travel	Yes	16 (17.6)	8 (27.6)	24 (20.0)	0.288
		No	75 (82.4)	21 (82.4)	96 (80.0)	
	Concession in income tax	Yes	5 (5.5)	14 (48.3)	19 (15.8)	<0.001
		No	86 (64.5)	15 (51.7)	101 (84.2)	
	BPL card	Yes	19 (20.1)	3 (0.00)	22 (18.3)	0.275
		No	72 (79.9)	26 (100.0)	98 (81.7)	
	Ayushman card	Yes	17 (18.7)	1 (3.4)	18 (15.0)	0.069
		No	74 (81.3)	28 (96.6)	102 (85.0)	

#chi-square test

percentage in bracket is column percentage

Among the total participants, only 1/3rd of the participants could avail financial aid by a cancer relief scheme while 2/3rd could not avail any financial aid. Out of those who could avail financial aid 55.0 percent took financial benefit under the Asadhya card (Rashtriya Arogya Nidhi) and rest by other government schemes. However, we observed that 98.3 percent of participants

had awareness of some or other cancer financial relief schemes. Out of the total participants, 15.0 percent had an Ayushman card and 18.3 percent had BPL cards.

The majority 74 percent of those who availed concession in income tax did not experience OOPE as catastrophic whereas only 5 percent of those who experienced OOPE

as a catastrophic availed concession in income tax and it was statistically significant.

Majority of participants who had BPL/ Ayushman cards had to experience OOPe as catastrophic. (Table 1, Figure 1).

Table 2: Association of coping up mechanism and a different socio-economic classes of participants.

Effect		Class I (n=11)	Class II (n=16)	Class III (n=12)	Class IV (n=28)	Class V (n=53)	#P value
Borrow money from social net	Yes	0 (0.0)	4 (25.0)	6 (50.0)	20 (71.4)	47 (88.7)	<0.001
	No	11 (100.0)	12 (75.0)	6 (50.0)	8 (28.6)	6 (11.3)	
Taken any loan	Yes	0 (0.0)	0 (0.0)	0 (0.0)	2 (7.1)	2 (3.8)	0.620
	No	11 (100.0)	16 (100.0)	12 (100.0)	26 (92.8)	51 (96.2)	
Mortgage any assets	Yes	0 (0.0)	0 (0.0)	2 (1.7)	2 (7.1)	8 (15.1)	0.251
	No	11 (100.0)	16 (100.0)	10 (83.3)	26 (92.8)	45 (84.9)	
Sold any assets	Yes	0 (0.0)	0 (0.0)	2 (1.7)	6 (21.4)	14 (26.4)	0.073
	No	11 (100.0)	16 (100.0)	10 (8.3)	22 (78.7)	39 (73.6)	
Delay in paying bills, EMI etc.	Yes	0 (0.0)	2 (12.5)	6 (50.0)	8 (28.7)	23 (43.4)	0.012
	No	11 (100.0)	14 (87.5)	6 (50.0)	20 (71.4)	30 (56.6)	

#Fischer exact test

percentage in bracket is column percentage

Table 3: Association of socio-demographic characteristics of participants and benefits of financial aid schemes to them.

Socio-demographic profile		Financial Aid			#P value
		Yes (n=40)	No (n=80)	Total (n=120)	
Age (in completed years)	0 to 14 years	2 (5.0)	0 (0.0)	2 (1.7)	0.165
	15 to 30 years	2 (5.0)	12 (15.0)	14 (11.7)	
	31 to 45 years	16 (40.0)	32 (40.0)	48 (40.0)	
	46 to 60 years	14 (35.0)	24 (30.0)	38 (31.7)	
	61 to 80 years	6 (15.0)	12 (15.0)	18 (15.0)	
Gender	Male	17 (42.5)	43 (53.8)	60 (50.0)	0.245
	Female	23 (57.5)	37 (46.3)	60 (50.0)	
Current marital status	Never married	2 (5.0)	6 (7.5)	8 (6.7)	0.542
	Married	36 (90.0)	66 (82.5)	102 (85.0)	
	Divorced/separated/ widow	2 (5.0)	8 (10.0)	10 (8.3)	
Residential address	Less than 100 km from Lucknow	14 (35.0)	41 (51.3)	55 (45.8)	0.092
	More than 100 Km from Lucknow	26 (65.0)	39 (48.75)	65 (54.2)	
Type of residence	Rural	32 (80.0)	48 (60.0)	80 (66.7)	0.028
	Urban	8 (20.0)	32 (40.0)	40 (33.3)	
Religion	Hindu	34 (85.0)	68 (85.0)	102 (85.0)	1.00
	Muslim	6 (15.0)	12 (15.0)	18 (15.0)	
Category	General	22 (55.0)	30 (37.5)	52 (43.3)	0.187
	OBC	10 (25.0)	29 (36.25)	39 (32.5)	
	SC/ST	8 (20.0)	21 (26.25)	29 (24.2)	
Type of family	Nuclear family	16 (40.0)	40 (50.0)	56 (46.7)	0.301
	Joint family	24 (60.0)	40 (50.0)	64 (53.3)	

chi-square test/Fischer exact test

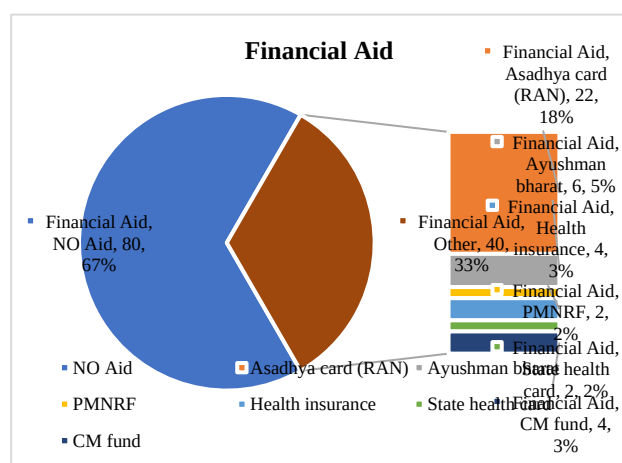
percentage in bracket is column percentage

Table 4: Association of details of diagnosis of cancer and benefits of financial aid schemes to participants.

Details		Financial Aid			#p-value
		Yes (n=40)	No(n=80)	Total (n=120)	
Site of cancer	Oral	10 (25.0)	39 (48.8)	49 (40.8)	<0.001
	Breast	10 (25.0)	3 (3.8)	13 (10.8)	
	Ovary	2 (5.0)	12 (15.0)	14 (11.7)	
	tongue	2 (5.0)	10 (12.5)	12 (10.0)	
	Gall bladder	4 (10.0)	4 (5.0)	8 (6.7)	
	Others	12(30.0)	12 (15.0)	24 (20.0)	
Facility at which Cancer diagnosed	District hospital	0 (0.0)	2 (2.5)	2 (1.7)	0.575
	Medical college	24 (60.0)	49 (61.3)	73 (60.8)	
	Pvt hospital/Clinic	16 (40.0)	29 (36.3)	45 (37.5)	
When was cancer diagnosed	During screening	12 (30.0)	10 (12.5)	22 (18.3)	0.020
	Symptomatic for cancer	28 (70.0)	70 (87.5)	98 (81.7)	
Time lost from first symptoms to making diagnosis	Within 1 month	24 (60.0)	31 (38.75)	55 (45.8)	0.172
	2 to 5 months	12 (30.0)	36 (45.0)	48 (40.0)	
	6 to 12 months	2 (5.0)	5 (6.25)	7 (5.8)	
	More than 1 year	2 (5.0)	8 (10.0)	10 (8.3)	
Delay in treatment after diagnosis	No delay	26 (65.0)	62 (77.5)	88 (73.3)	0.144
	Yes	14 (35.0)	18 (22.5)	32(26.7)	
Treatment plan	Surgery + radiotherapy	2 (5.0)	14 (17.5)	16(13.3)	0.002
	Chemotherapy + radiotherapy	6 (15.0)	4 (5.0)	10 (8.3)	
	Surgery + chemotherapy+ Radiotherapy)	20 (50.0)	24 (30.0)	54 (45.0)	
	Only surgery	4 (10.0)	28 (35.0)	32(26.7)	
	Surgery + Chemotherapy	8 (20.0)	10 (12.5)	12 (10.0)	

chi-square test/Fischer exact test

percentage in bracket is column percentage

**Figure 2: Financial benefits availed by study participants.**

The 88.7 percent of those who borrowed money from the social net belong to class V of socio-economic class, and it was found to be significant. The maximum number of participants who mortgaged or sold any asset or delay their bill payment also belong to class V, although statistically non-significant (Table 2).

About 2/5th of rural participants got financial aid related to cancer while 4/5th of urban participants could not avail financial aid and it was statistically significant. More of the participants who were educated till postgraduate and above got financial aid than others who were not educated till postgraduate, it was statistically significant. Most of the agricultural workers/unemployed/housewives got financial aid, although statistically non-significant (Table 3).

Table 3. Association of socio-demographic characteristics of participants and benefits of financial aid schemes to them. Almost 77 percent of the breast cancer participants could avail of the financial benefit and this was statistically significant. Most of the participants who were diagnosed while screening for cancer could get the benefit of a financial scheme. More of the participants who were given all three interventions i.e., surgical, chemical, radiotherapy got financial aid under the cancer relief scheme than others who received either one or two types of interventions and were statistically significant (Table 4).

Most of the participants belonging to class IV and Class V participants got the benefit of financial aid from any of

the cancer relief schemes, although statistically non-significant (Table 5).

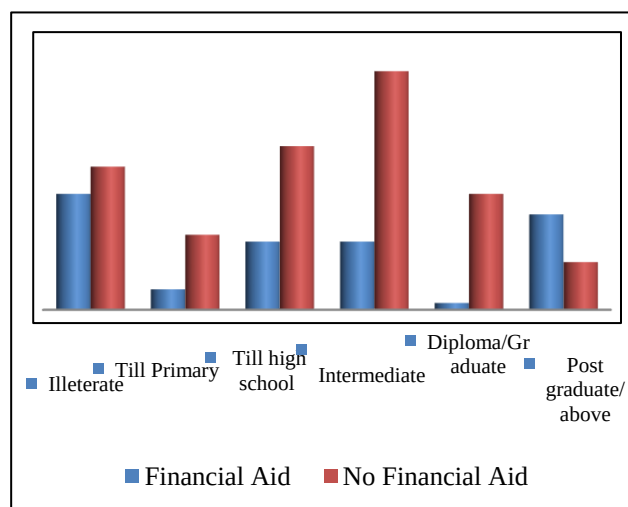


Figure 3: Association of financial aid availed with highest education qualification of patients.

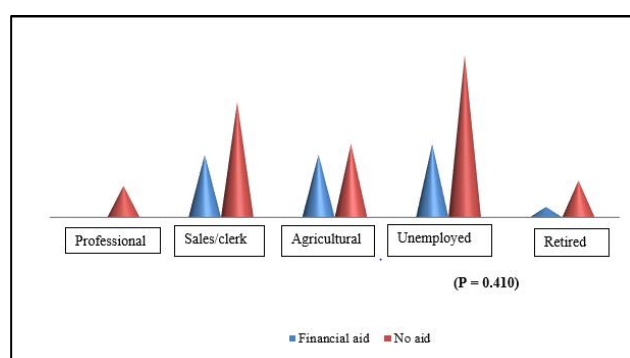


Figure 4: Association of financial aid availed with occupation of participants.

Table 5: Association of benefits of financial aid scheme to participants and economic class.

Economic class	Financial Aid			# p-value
	Yes (n= 40)	No (n=80)	Total (n=120)	
Class I	4 (10.0)	7 (8.8)	11 (9.2)	0.079
Class II	2 (5.0)	14 (17.5)	16 (13.3)	
Class III	2 (5.0)	10 (12.5)	12 (10.0)	
Class IV	8 (20.0)	20 (25.0)	28 (23.3)	
Class V	24 (60.0)	29 (36.3)	53 (44.2)	

chi-square test

percentage in bracket is column percentage

We have found that no significant variables were either positively or negatively correlated with the financial aid given. However, negative correlation between socio-economic class and borrowing money from the social net was noticed ($p < 0.001$). This means the lower the socio-economic class higher the chance to borrow money.

DISCUSSION

The ultimate concern for which the study was conducted was that Indian population had to spend a huge amount of money on cancer treatment as well as management which most of the time lead to subsequent impoverishment, although some options and financial benefits are available for cancer patients but 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.

High OOPe or catastrophic expenditure not only leads to economic burden but also mental stress among the patient household. But with the main motive of proper treatment of cancer and saving lives of loved ones, one strives hard to collect the required amount of money. Among various ways of coping up mechanism patient household prioritize the methods according to accessibility and acceptability. The simplest way is just by borrowing money from relatives or friends or in the market on interest. Chakrabarty et al reported that 55% of the household with cancer patients in Punjab borrowed money and 39% of the households in region of Major cities of Kerala, Maharashtra, Rajasthan, West Bengal and Mizoram borrowed money for expenses.⁸ Maneeta Jain et al showed that the percentage of borrowing was greater among the households who had sought treatment in private sector (17%) as compared to the public sector (14%).⁹ They also showed that the strategies adopted by the rural households was mainly of borrowing (91%) followed by social nets (76%). In the present study, about 65 participants borrowed money from one or another source. About 1/3rd of the total participants who face catastrophic expenditure had to borrow money. Most of them borrowed from the social net and although have pressure to repay it early, but is far better than paying high interest to loan givers. In the present study about 3 percent of participants took loans and many of them used the money they took as a loan from KCC (Kishan credit card). Although very disheartening as last option left is selling or mortgaging whatever assets one has made or have. About 10 percent of participants mortgage assets and 20 percent of participants had to sell their assets. Our findings are also supported by Dror et al.¹⁰

Chakrabarty et al reported that selling assets for coping the expenses was used by 30% in Punjab and 12.4% in major cities of India.⁸ Maneeta Jain et al study shows that 30 percent of the participants who were insured sold their assets while among those who were not insured 55.7 percent sold their assets.⁹ The family has to prioritize whatever money is left, they have to look first for patient treatment then the basic needs of the family, so sometimes they have to delay paying back the bills at local grocery shops, EMI, paper, electricity bill, rent, etc. They also showed 54 non-insured participants had to delay paying EMI of loans, many of them had to reduce their expenditure on education and food. In the present study 32.5 percent of participants had to delay paying

back bills. Not only this study also shows that almost all those who mortgage/ sold assets or delay their bill payment were the participants facing catastrophic expenditure. The majority of participants who used one or another coping up mechanism for OOOPE belong to class V and class IV socio-economic class and those among Class I and Class II hardly had to use any of the methods.

There are also several Government and non-government schemes providing financial benefits for cancer patients. But their accessibility and reach to needful have always been the problem. Some of them found paperwork difficult, many of them don't know where and how to avail the benefits. In the present study, only 1/3rd of participants could avail themselves of financial benefits more than half of them avail benefit under Arogya card (Rashtriya Arogya Nidhi) for which BPL card or Income certificate was necessary. Although 18 percent of total participants had Ayushman cards only 1/3rd of them could avail the benefits with the card. But good thing was that most of them were aware of one or the other government financial benefit schemes. Chakrabarthy Jyosthi et al. study shows that utilization of schemes was not common like the National cancer relief fund by 28 and RSBY by 26.

The present study shows that 77 percent of those who got financial benefit were those who had experienced catastrophic OOOPE that is a financial benefit scheme that could benefit those who needed it and is a positive sign of good governance. About 80 percent of those who got financial aid belong to a rural area as their MPCII is less and could easily get a BPL card or low-income certificate issued by tehsil. The majority (2/3rd) of postgraduate participants could avail of financial benefits. This was because these participants were more aware of schemes and know how to avail it themselves plus can do all paperwork easily. Most of the participants who got financial aid were either agricultural worker/ unemployed or housewife as they have mostly low-income. Almost 77 percent of breast cancer patients got financial aid. The majority of participants who were diagnosed during screening could avail financial benefits. This may be due to more time they got to perform all required procedures to apply and get financial aid. The majority of participants who belong to the class V socio-economic group got the financial benefits. Except for direct financial schemes, there are also other benefits provided by the government. About 20 percent of participants avail concession in rail/road fare while traveling and 15 percent of them avail deduction in income tax. It was observed in the study that although financial aid and concession in travel was availed by the majority of the participants who faced catastrophic OOOPE but concession in income tax was mostly availed by participants who did not face catastrophic expenditure. This is because most of those who did not face catastrophic expenditure were those whose income was more and came under income tax slab, thus had to pay income tax. Chauhan et al study in North India shows only 36 percent of participants were

insured and Ranjbar et al study in Tehran city shows that among a total 70 percent of participants were insured (had health insurance).^{11,12} There is a huge gap in the proportion of health-insured people in India and abroad. And also, in the present study, it's worse only 10 percent of participants had health insurance.

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.

CONCLUSION

We concluded that for coping up mechanism 64 % of participants borrowed money, 3% took loans, 10% mortgage assets, and 20% sold their assets. Participants who borrowed money are positively correlated to catastrophic expenditure. More participants who faced catastrophic expenditure more the participants borrowed money. Participants who borrowed money are negatively correlated to socio-economic class. Lower the socio-economic class higher chance of borrowing money. About 33 percent variability in borrowing money is explained by economic class. Financial benefit was availed by about 1/3rd of participants. 20% availed concessions in rail/road travel fare and 16% availed concessions in income tax. Financial aid was availed maximally to participants who faced catastrophic expenditure. Participants who availed financial benefit depends on the type of residence, highest education qualification, site of cancer, when was cancer diagnosed, and treatment plan.

We recommend increase the coverage of beneficiaries and empanelled hospitals for Ayushman Bharat with one-stop online portal where all schemes for cancer relief are enumerated and the patients can apply online. We also recommend the provision of reimbursement of money spent in the treatment of cancer till they are able to get benefit from cancer relief schemes which takes many weeks or even months to materialize.

Funding: No funding sources

Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Verma R, Ahmad N, Singh VK, Akhtar N. Coping up mechanism and financial aid scheme for cancer treatment at a tertiary care hospital in Lucknow. *Int J Community Med Public Health* 2023;10:1788-95.