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Research Article

Treatment Seeking Behaviour and Cost of Care among Cancer Patients in Nepal

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Abstract

Introduction: The major challenge observed in oncology service in Nepal is the high cost of the treatment and because of the lack of insurance, and a proper health policy, people have to bear all burden by themselves. Early diagnosis of cancer results in lower stages of the cancer, less intensive treatment and improved survival.

Objectives: To study the distribution of cases, past and future treatment seeking behaviour of diagnosed cancer cases and to assess the economic burden of cancer of cases treated at hospitals.

Methods: The study was conducted at Bhaktapur Cancer Hospital, Nepal. The sampling technique for the study was Systematic random sampling of our patients of inpatients available during the study period. The data was analyzed using the SPSS Version 16. The data has been analyzed using mean and percentages, and krushkall Wallis test.

Results: 54 percent had visited only one facility and 34 percent had visited two facilities and 11 percent had visited three facilities and 1 percent had visited up to six facilities. There is no significant difference between the stages of Cancer in the cost of care on different aspects. There is no significant difference in the cost of care between the types of cancer.

Conclusion: Treatment seeking behaviour of person and the expenditure pattern which is very costly for the people suffering from cancer in developing countries like Nepal.

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- Treatment seeking behaviour

INTRODUCTION

National Cancer Institute estimates that the financial costs of cancer care are a burden to people diagnosed with cancer, their families, and society as a whole. National cancer care expenditures have been steadily increasing in the United States. Costs also are likely to increase as new, more advanced treatments are adopted as standards of care [1]. In 2002 3.5 million people died of cancer in Asia. This is expected to increase to 8.1 million by 2020. As the death rate and prevalence of cancer hits hard in Asia; specific concerns have been raised about the economic toll of the disease on patients and their families. Ongoing treatments are expensive and can impose a considerable financial burden. This is felt most strongly in socio economically disadvantaged groups particularly in low and middle income countries where social safety nets, such as health insurance and access to health care, are less likely to be present. In such settings, poverty is a real consequence of the costs associated with cancer treatment and its impact on people's ability to work [2].

The major challenge observed in oncology service in Nepal

is the high cost of the treatment and because of the lack of insurance, and a proper health policy, people have to bear all burden by themselves. Considering cost of cancer treatment, as per capita income of an individual is only US\$ 600, majority of the population finds it difficult to bear expensive cancer treatments since people have to pay from their pocket due to lack of health insurance system [1]. One of the most important prognostic factors for cancer is how early the disease is detected and how far it has spread. Early diagnosis of cancer results in lower stages of the cancer, less intensive treatment and improved survival [3].

In Nepal, most of the cancer patients have been reported diagnosed at advanced stage indicating the long duration between disease onset and final diagnosis of the disease. Delays may occur at different stages of the cancer diagnostic journey and have been commonly defined as being either patient focused or healthcare provider focused. Commonly, delay is found further categorized into different component delays such as patient delay, health care provider delay, referral delay and system delay. Calculation of the total economic burden of a particular cancer or cancer in

general, provides information to decision makers for mobilizing political and financial support for cancer care and research. Since resources are not unlimited and costs do matter delay, referral delay and system delay [2].

METHODOLOGY

The study was conducted at Bhaktapur Cancer Hospital, Dudhpati, Bhaktapur, which was established by Nepal Cancer Relief Society in 1992 with the support of Sahid Smriti Cancer Service. Now, it has become a model hospital of first Public Private Partnership & most highly regarded hospitals. The study design selected for the study was combination of cross sectional and retrospective data collection. The population for the study consisted of all cancer patients visiting hospital for the first time or for follow up & inpatient care at Bhaktapur Cancer Hospital in Kathmandu, Nepal. Samples of only 100 cases of respondents were taken as stated above from the hospital during December 2013. The sampling technique for the study was Systematic random sampling of our patients of inpatients available during the study period.

Data was collected using a semi structured questionnaire and also from records of the hospital. Interview and pretested questionnaire method was used to collect information on: I. Treatment seeking behaviour from onset of symptoms till they finally reached the hospital (including the delays, duration of treatment at each facility if they had gone through it before reaching the hospital) was elicited retrospectively.

II. Economic burden of care comprised of information on all aspects of care. Economic burden data was collected from all cases in the sample for the last one year or from the date of diagnosis for cases diagnosed within one year. But after collection of data it was observed that there was memory lapse on different components of care for a long duration like one year. As such the data analysis was restricted to three months period from October to December 2013. All analysis on cost of care was done for the above quarter only.

All Cancer patients who are visited the Hospital for treatment or as in patients during the study period. Information on treatment seeking behaviour was taken & analysed. Cost of treatment for only last three months was calculated for the reasons stated above. Cost analysis was done according to type and stage of cancer and Krushkal Wallis test was used to see the significance in difference in the cost between types of cancer or stages of cancer by using SPSS 16. Ethical permission was taken from ethical board of Bhaktapur Cancer Hospital. Data was collected after taking written Inform consent from each patient and confidentiality of the data was maintained. Ethical Approval was obtained from Padmashree School of Public Health. Consent was taken from the Medical Superintendent of the hospital.

RESULTS

It is presented from the study that mostly the respondents were in the age group to 45-54 years (23%) & majority of the respondents i.e. 65% of the respondents were Females while the Males were 35%. About half (51%) of the respondents were illiterate & those having primary education were 19 % & followed by secondary level of education by 15%, undergraduates by

6%, higher secondary by 5% & post graduate 4% respectively. Regarding the economic status, 67.7% of the respondents were in middle economic level while respondent with high economic level were only 1.6%. Most of the respondents (27%) were agriculturists followed by Housewives 33.7%, business 12.6%, student 3.6% & service 3.2% & labour 1% (Table 1).

DISCUSSION

In the present study most of the respondents (93%) did not have insurance & only 7% had insurance facility. And according

Table 1: Socio-demographic factors.

Socio-demographic factors	Responses	N=100	Percentage (%)	
Age in years	14-24	8	8	
	25-34	7	7	
	35-44	16	16	
	45-54	23	23	
	55-64	19	19	
	65-74	22	22	
	75+	5	5	
Sex	Male	35	35	
	Female	65	65	
Religion	Hindu	79	79	
	Buddhist	20	20	
	Christian	1	1	
Marital status	Married	92	92	
	Unmarried	8	8	
Education status	Primary	19	19	
	Secondary	15	15	
	Higher Secondary	5	5	
	Undergraduate	6	6	
	Post graduate	4	4	
	None	51	51	
Monthly income	20001-40000	15	24.2	
	40001-60000	3	4.8	
	60001-80000	1	1.6	
	100001-120000	1	1.6	
	Total	62	100.0	
Occupation	Agriculture	26	27.4	
	Business	12	12.6	
	Service	3	3.2	
	Labour	1	1.1	
	Teaching	5	5.3	
	Student	6	6.3	
	Housewife	32	33.7	
	others	10	10.5	
	Total	95	100	

Most of the respondents (93%) did not have insurance & only 7% had insurance facility. It is presented that .54% had visited only one facility & 34% had visited two facilities & 11% had visited three facilities & 1% had visited up to six facilities.

It is presented that 59.5% visited the first health facility within 30 days after the symptoms & 18.9% visited after 31-80 days &12.2% visited after 81-130. Only 5.4% visited after 131-180 days. There was a delay of 180+ days in 4.1% respondents visited health facility.



Table 2: Health facility visit.

Days	N=100	Percentage (%)
up to 30	44	59.5
31-80	14	18.9
81-130	9	12.2
131-180	4	5.4
180+	3	4.1
Total	74	100.0

It is presented that 79.3% respondents were diagnosed with cancer after visiting the health facility up to 60 days, followed by 9.8% in between 61-120 days, 4.3% more than 365 days & another 4.3% between 121-180 days. While 1.1% respondents had diagnosed after visiting health facility in between 121-180 days & 1.1% again in between 241-300 days.

Table 3: Total days of health facility visit.

Days	N	Percentage (%)
Up to 60	73	79.3
61-120	9	9.8
121-180	4	4.3
181-240	1	1.1
241-300	1	1.1
360+	4	4.3
Total	92	100.0

to Cancer Facts & (Figures) 2014, "Uninsured patients and those from ethnic minorities are substantially more likely to be diagnosed with cancer at a later stage, when treatment can be more extensive and more costly [5]." In fact, this leads not only to higher medical costs, but also poorer outcomes and higher cancer death rates. The present study shows that Majority of the respondents (87.8%) had visited General /Specialist hospital, as their first consultation place and only 7.1% visited the Cancer hospital. Out of those who visited General/Specialist hospital as the first facility, 80.5% still visited another or same General /Specialist hospital, as their second place of consultation and only 12.2% visited the Cancer hospital. There were only 8 cases who visited some general/specialist hospital as their third consultation place. This was because of lower knowledge about disease as they keep on visiting health facilities & also due to system delay also the treatment got delayed. A similar study done in Nepal, shows that Medical shops (33.6%) and private hospitals (31%) were major first contact points of patients with health care providers (HCP) [6]. Greater proportions (80.9%) of the patients had late diagnosis and 68.2% of total patients were diagnosed in cancer hospitals.

In the present study, 59.5% visited the first health facility within 30 days after the symptoms & 18.9% visited after 31-80

Table 4: Association between types of cancer and cost.

Types of	cancer	Medicine	Consultation	Travel	Accommodation	Investigation	Diet	Wages	Specialized Treatment	Supportive Services	Total Cost
Breast	N	15	15	15	15	15	15	15	15	15	15
	Median	24000	600	4000	8550	10000	4500	0	49000	0	142800
	Minimum	0	150	1050	0	2850	0	0	14000	0	38600
	Maximum	100000	850	33000	33000	16000	24000	48000	125000	90000	230000
	N	9	9	9	9	9	9	9	9	9	9
D ' 4	Median	45000	700	6000	14500	9700	2000	0	64000	0	164100
Respiratory	Minimum	22500	150	420	0	500	0	0	20400	0	84000
	Maximum	240000	1500	12000	19500	35500	17500	2600	185000	60000	380000
	N	9	9	9	9	9	9	9	9	9	9
D:	Median	67000	600	3000	4200	13000	6000	1800	83000	0	221600
Digestive	Minimum	27000	250	300	0	3650	0	0	0	0	57600
	Maximum	300000	3000	10000	20100	28100	18900	8100	488000	0	541000
	N	8	8	8	8	8	8	8	8	8	8
Head &	Median	56000	525	3050	5700	17000	5425	0	110020	0	191720
Neck	Minimum	12000	100	0	0	0	0	0	0	0	88700
	Maximum	90000	1050	14000	23000	63000	18000	3500	148000	0	260000
	N	11	11	11	11	11	11	11	11	11	11
	Median	35000	650	2400	6000	9000	1600	0	70000	0	145950
Cervical	Minimum	4800	200	170	0	3600	0	0	20000	0	70700
	Maximum	81000	1800	31000	23300	41000	41000	7700	148000	16500	188000
	N	16	16	16	16	16	16	16	16	16	16
0.1	Median	54000	425	1875	6800	10500	4350	0	50500	0	130520
Others	Minimum	8500	200	0	0	3150	0	0	0	0	64800
	Maximum	210000	1350	9000	37500	35000	22000	45000	210000	12000	359000
Total	N	68	68	68	68	68	68	68	68	68	68
	Median	41750	600	3050	6900	10800	4100	0	61525	0	149700
	Minimum	0	100	0	0	0	0	0	0	0	38600
	Maximum	300000	3000	33000	37500	63000	41000	48000	488000	90000	541000
Chi-Sq	luare	8.790	2.243	7.394	3.067	3.278	2.848	5.212	4.272	2.356	7.018
D	f	5	5	5	5	5	5	5	5	5	5
P		0.118	0.815	0.193	0.690	0.657	0.723	0.391	0.511	0.798	0.219

There is no significant difference in the cost of care between the types of cancer.

Table 5: Association between types of cancer and cost.

Stage o	f Cancer	Medicine	Consulta- tion	Travel	Accommodation	Investiga- tion	Diet	Wages	Specialized treatment	Supportive Services	Total cost
stage 0& I	N	31	31	31	31	31	31	31	31	31	31
	Median	31000	550	3000	6800	13200	4500	0	75000	0	162520
	Minimum	4800	150	0	0	0	0	0	14000	0	70700
	Maximum	210000	3000	33000	37500	63000	24000	7700	210000	90000	359000
	N	10	10	10	10	10	10	10	10	10	10
ata aa II	Median	61500	675	1650	8200	13700	3050	750	54500	0	140450
stage II	Minimum	13500	250	0	3050	3600	0	0	0	0	92400
	Maximum	155000	1350	30300	25800	41000	24000	45000	270000	6000	396000
	N	3	3	3	3	3	3	3	3	3	3
Stage III	Median	68000	600	1200	8550	3650	0	0	105000	0	199170
	Minimum	27000	200	800	3100	3150	0	0	40000	0	144000
	Maximum	90000	1200	1720	20100	10000	7000	5300	488000	0	541000
	N	8	8	8	8	8	8	8	8	8	8
Ctogo IV	Median	78000	500	3800	6325	10100	7200	0	38500	0	171680
Stage IV	Minimum	13500	100	600	0	3000	0	0	0	0	88700
	Maximum	185000	1500	14000	22300	35000	18000	48000	100000	60000	230000
	N	16	16	16	16	16	16	16	16	16	16
Unknown	Median	33500	600	6000	7925	8750	4450	0	40800	0	135150
Ulikilowii	Minimum	0	150	0	0	500	0	0	0	0	38600
	Maximum	300000	1500	12000	23300	35500	41000	8100	90800	0	335000
Total	N	68	68	68	68	68	68	68	68	68	68
	Median	4.1750E4	6.0000E2	3.0500E3	6.9000E3	1.0800E4	4.1000E3	.0000	6.1525E4	.0000	1.4970E5
	Minimum	.00	100.00	.00	.00	.00	.00	.00	.00	.00	3.86E4
	Maximum	3.00E5	3000.00	3.30E4	3.75E4	63000.00	4.10E4	4.80E4	4.88E5	9.00E4	5.41E5

days & 12.2% visited after 81-130. Only 5.4% visited after 131-180 days. There was a delay of 180+ days in 4.1 % respondents visited health facility. A study done by E.R. Saloma et al, shows that the median delay in patient presentation from first symptoms to first appointment with a general practitioner was 14 days. The median delay by the general practitioner before writing a referral was 16 days, the median referral delay was 8 days, the median delay from the first visit to a specialist until the diagnosis was 15 days, and the median treatment delay was also 15 days. Thirty percent of patients received treatment within 1 month from the first hospital visit, and 61% received treatment within 2 months. The median symptom to treatment delay was almost 4 months. The delay in seeing a specialist was shorter in patients with advanced cancer and small cell lung cancer [7].

The present study reveals that there is not any significance difference between the types of cancer & cost of cancer care. A study done in US conducted by Yabroff.k et al shows that across tumour sites Mean 5-year net costs varied widely, from less than \$20 000 (NRs.188000) for patients with breast cancer or melanoma of the skin to more than \$40 000 (NRs. 3760000) for patients with brain or other nervous system, oesophageal, gastric, or ovarian cancers or lymphoma. For elderly cancer patients diagnosed in 2004, aggregate 5-year net costs of care to Medicare were estimated to be approximately \$21.1 billion (NRs. 19, 84, 56, 0500000). Costs to Medicare were highest for lung, colorectal, and prostate cancers, reflecting underlying incidence, stage distribution at diagnosis, survival, and phase specific costs for these tumour sites [8]. While comparing these stages according to the cost of cancer was found that there is no any significant difference between the stages of Cancer.

According to a study conducted by B. Mohamed et al, shows that Overall approximately 1,978 new cases of cervical cancer occur each year in Morocco. The majority (82.96%) of these cases were diagnosed at a late stage (stage II or more). The cost of one case of cervical cancer depends on stage of diagnosis; the lowest cost is \$382 for stage C is followed by the cost of stageIA1 for young women (< 40 years) which is \$2,952. The highest cost is for stage IV, which is \$7,827. The total cost of cervical cancer care for one year after diagnosis is estimated at \$13,589,360 [9].

CONCLUSION

The present study suggests those strategies that could improve treatment seeking behaviour of person and the expenditure pattern which is very costly for the people suffering from cancer in developing countries like Nepal. They visit more than 3 health facility for diagnosing cancer which is more because of ignorance about the disease. And also they had visited India either for continuing their treatment or for doing medical tests due to the lack of adequacy & availability of the services in Nepal. These findings reveal the need of addressing these issues which made cancer patients delay in seeking health care at a prompt time. In some of the developed countries government there is provision of health insurance to the cancer patients but in countries like Nepal where even the expenditure on health as % of GDP is low i.e. 5.5, the health insurance was of far concern. Screening Programmes for cancer was found insufficient as most of the patients visit to hospital at first. As the burden of care due to high cost is always there & the income of people are not sufficient to treat the disease so the Government and public efforts both are required to make services accessible in terms



of expenditure & to improve health seeking behaviour. And this study might form an important basis for future planning for help to focus on reducing the burden of cancer care considering the expenditure beard by people which is major challenge in health sector now & will be in future.

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