

Impact of cancer on Nepalese patients and their caretakers

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Abstract

Introduction: Cancer is today's burning healthcare issue. Disease itself as well as side effects from treatment has massive impact on patients' lives. Tragic disease consequences happen, further worsened by inevitable adverse reactions of treatment. This study attempts to measure the various impact of disease among Nepalese cancer patients and their caretakers.

Methods: This was a hospital based descriptive cross sectional study conducted in Bhaktapur Cancer Hospital for two months on 198 adult cancer patients and 20 caretakers. Face to face interview was done with semi structured interview schedule, 0-10 Numeric Pain Intensity Scale, Kuppuswamy's Socioeconomic Status Scale and Beck's Depression Inventory. Data entry and analysis was done on IBM SPSS V20.

Results: Disease was seen in advanced age group with no sex wise variations. Majority was married, literate, from rural area, of upper caste and upper lower socioeconomic status. Cancer of lung, rectum and bile duct were more frequent in male in contrary to that of breast, ovary and cervix in female. Majority suffered from various impact of disease and side effects of the treatment like pain, depression, fatigue, weight loss, diminished physical activity and financial burden. Family members were equally prone to depression.

Conclusion: Patients and their families are cosufferers in the battle against cancer. To confront the mounting impact of cancer epidemic in Nepal, cancer should be given high priority in national health programs, and population based cancer registry should be immediately established.

Key words: Cancer, Caretakers, Depression, Nepalese patients, Pain, Physical activity, Side effects

Introduction

Cancer is today's burning global healthcare issue and Nepal is not an exception. Cancer morbidities and mortalities are on rise due to abundance of risk factors as well as rapid growth and unprecedented aging of human population. In 2012, 14.1 million new cases and 8.2 million deaths occurred globally. In the same year, 19 thousands new cases and 14 thousands deaths occurred in Nepal.¹ These values are extrapolated from some hospital based data as well as data from neighboring countries. Actual information on cancer morbidity and mortality is possible only from population-based registry, which unfortunately is lacking in Nepal.

Disease itself as well as side effects from treatment has massive impact on patients' lives. Cancer caused 208.3 million DALYs worldwide in 2015 for both sexes combined.² Cancer brings tremendous social distress; physical and psychological suffering, economic losses, hardship to patients and their caretakers.³ Cancer is a costly illness. It can take a toll on patient's health, emotions, time, relationships and wallet. The condition is really serious for people from poor countries like Nepal where health insurance is not popular. So the treatment expenses come from patients' out-of-pocket. The rate of depression in persons with cancer is higher than in healthy populations. Similarly, the caretakers will have massive psychological impact like depression, anxiety and many others. So family members have been frequently described as cosufferers in the battle against cancer.⁴

Number of physical symptoms like pain, weight loss, loss of appetite and many more arise because of disease and treatment as well. Physical functioning will compromise and poor quality of life will prevail. So the present hospital based study has been carried out to measure the various impact of disease among Nepalese cancer patients and their caretakers.

Methods

This was a hospital based descriptive cross sectional study conducted in Bhaktapur Cancer Hospital, Bhaktapur, Nepal. The study duration was of two months. Written consent was taken from patients, approval from Bhaktapur Cancer Hospital and ethical clearance from Institutional Research Committee. All adult cancer patients aged 18 and above, admitted in that center during the study period and willing to participate in this study were enrolled. All invasive cancers in categories (C00-C99), precancerous lesions and in-situ carcinomas in categories (D00-D48) from International Classification of Diseases 10th Revision⁵(ICD-10), diagnosed by histopathology or radiology or other methods, were included in the study. Those who were seriously ill or in terminal stage or were unable to answer the questions were excluded. A total of 198 admitted patients were available during two months duration after being selected by convenience sampling. Twenty caretakers (10% of 198) were selected similarly to assess their depression status. Face to face interview was done with semi structured interview schedule, 0-10 Numeric Pain Intensity Scale⁶, Kuppaswamy's Socioeconomic Status Scale⁷ and Beck's Depression Inventory.⁸ Kuppaswamy's Socioeconomic Status Scale considers education, income and occupation as a measure of social class. Score less than 5 means lower class, 5-10 upper lower class, 11-15 lower middle class, 16-25 upper middle class and 26-29 is upper class.⁷ Pain measurement was done with 0-10 Numeric Pain Intensity Scale. Zero means no pain at all and 10 means the worst possible pain one can imagine, 1-3 means mild pain, 4-6 moderate pain and 7-10 severe pain.⁶ Status of depression was assessed with Beck's Depression Inventory which contains 21 questions with options ranging from zero to four, which are summed up to know the status of depression.⁸ Data entry and analysis was done on IBM SPSS V20 for descriptive statistics.

Results

Among the total 198 patients, 51%(101) were male and 49%(97) were female. The median age was 54 years within terquartile range(IQR)= [62(third quartile

Q3)-45(first quartile Q1)=17 years]and the age range was 62 years (81-19). Since the study was carried out in adult patients above 18 years, 162(81.8%) were married, 17(8.6%) single and 19(9.6%) widowed. Majority of the patients, 136(69%), were from rural area and the rest 62(31%) were from urban area as per their permanent residence status. Out of total patients, 77(39%) were of upper caste. Disadvantaged non-dalit caste were 3(1.5%), dalit 10(5%), relatively disadvantaged janajatis 50(25%), relatively advantaged janajatis 54(27%) and religious minorities 4(2%).

Regarding literacy status, 119(60%) of the patients were literate and the rest 79(40%) illiterate. Among the literates, majority had completed secondary education, followed by primary and higher secondary. When their socioeconomic status was assessed, none of them were from the upper socio economic class. Majority 105(53%) was from the upper lower class, followed by lower middle class 78(39%), lower class 11(5%) and upper middle class 4(2%) respectively.

Among 101 male, lung cancer was the most common cancer in male 15(15%), followed by cancer of rectum 10(10%) and cancer of bile duct 6(6%). Among 97 female, breast cancer was the most common 22(23%), followed by cancer of ovary 13(13%) and cancer of cervix 12(12%).

Most of the cancer patients suffer from various impact of disease and side effects of the treatment. Only 18(9%) of the total patients denied any noticeable effects. Among the rest, majority complained of fatigue 156(79.3%), followed by weight loss 137(68.7%) and loss of appetite 133(67.2%). So apart from the tragic disease consequences and expensive treatment, their sufferings and poor quality of life were further worsened by these inevitable side effects. (Figure 1)

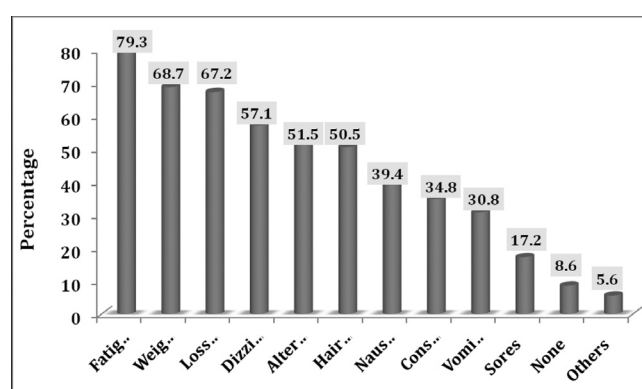


Figure 1: Distribution of treatment related side effects in cancer patients.

Table 1: Physical activity of cancer patients before and after disease occurrence

		Physical activity (Before disease)		Total
		Fully active	Light work	Number (%)
		Number (%)	Number (%)	
Physical activity (After disease)	Fully active	3(1.51)	0(0)	3(1.51)
	Light work	63(31.81)	0(0)	63(31.81)
	Self care	61(30.80)	4(2)	65(32.82)
	Limited self care	58(29.29)	7(3.53)	65(32.82)
	Completely disabled	0(0)	2(1)	2(1)
	Total	185(93.43)	13(6.56)	198(100)

Regarding physical activity, 185(93.43%) out of the total 198 patients were fully active and the remaining 13(6.56%) could do only light work, before the onset of disease. After the infliction of cancer, only 3(1.51%) patients could perform full range of physical activity while the rest had to compromise more or less with their physical activity. So this disease, cancer, caused disability in significant proportion of the sufferers. (Table 1)

Table 2: Level of pain in cancer sufferers

Level of pain	No pain	Mild	Moderate	Severe
Number (%)	50(25.3%)	115(58%)	31(15.7%)	2(1%)

No pain was felt in any body part even after disease occurrence in 50(25.3%)and among the rest 128 who felt some sort of it,115(58.1%) complained of mild pain, followed by moderate and severe pain.(Table 2)

Considering both sex, 64(32.2%) patients were not found to be depressed and among those depressed, majority 52(26.5) had moderate depression. More male had mild mood disturbance and borderline clinical depression compared to their female counterparts. While considering normal status as well as moderate and severe depression, female outnumbered male.(Table 3)

Table 3: Depression status of cancer patients

Depression status	Male(N=101)	Female(N=97)	Total
	Number (%)	Number (%)	Number (%)
Normal	30(29.7)	34(35.1)	64(32.2)
Mild mood disturbance	26(25.7)	17(17.4)	43(21.6)
Borderline clinical depression	20(19.8)	15(15.5)	35(17.7)
Moderate depression	24(23.8)	28(28.9)	52(26.5)
Severe depression	1(1)	3(3.1)	4(2)
Total	101(100)	97(100)	198(100)

Table 4: Depression status in caretakers

Depression status	Normal	Mild mood disturbance	Borderline clinical depression	Moderate depression	Total
Number (%)	8(40)	9(45)	2(10)	1(5)	20(100)

While assessing the status of depression in 20 caretakers of the cancer patients, 12(60%) were depressed among whom majority 9(45%) had mild mood disturbance and none were found to be severely depressed.(Table 4)

Table 5: Source of treatment expenses

Financial source	Loan	Relatives	Property sale	Other
Number (%)	113(57.1%)	111(56.1%)	25(12.6%)	5(2.5%)

Regarding total sum of money incurred during diagnosis and treatment of disease, median value till the study date was found to be 127500 (Q1=70000, Q3=262500) Nepalese Rupees (NRs). Minimum and maximum amount spent were NRs 6000 and 900 000 respectively. Since majority of the patients belong to lower socioeconomic status, apart from their own savings, to meet the high treatment expenses, cancer patients were obliged to take loan, ask relatives and in substantial cases, even sell properties like land or own home. Other sources like donations supported a few. (Table 5)

Discussion

In this hospital-based study, disease was more frequent in advanced age group with no sex wise variations in disease frequency. Majority was married, literate, from rural area, of upper caste and upper lower socioeconomic status. Binu VS et al in a study from Manipal, Nepal reported similar findings regarding sex and age of patients.⁹ On contrary, El-Akad SM et al reported in a study from Jordan that male to female ratio was 1.5:1; the median age for males was 43 years and for females it was 45 years.³ Cancer of lung, rectum and bile duct were more frequent in male in contrary to that of breast, ovary and cervix in female. Pradhananga KK et al found that the most common site in males was the lung, followed by the oral cavity and stomach; while the first three in females were cervix uteri, breast and lung.¹⁰

Almost all patients suffer from various impact of disease and side effects of the treatment like pain, depression, fatigue, weight loss and more. They had to compromise more or less with their physical activity. Smets EM et al found that the majority of cancer patients, about 70%, reported feelings of fatigue during radio-or chemotherapy.¹¹ About two-third of the patients from this study complained of pain and 68% of the total patients were suffering from depression. KC B et al found mild pain in 66.7% of the patients, moderate pain in 7.1% and severe pain in 26.2%. Pain affected the normal daily life activities in almost all of the patients. Sleep was affected in 88% of the patients and the normal physical activity was affected in 92.9% of the patients. Similarly, the pain decreased the appetite in 78.6%

of the patients; it affected the personal relationship in 35.7%, emotion in 71.5% and visual activity in 33.6% of the patients.¹²

Thapa P et al found depression in 28.0% of cancer patients.¹³ On contrary Mhaidat NM et al found that the prevalence of depression in cancer patients was 81.9%.¹⁴ Mashhadi MA et al measured the prevalence of depression with Beck's Depression Inventory (BDI) scale in 400 patients with cancer in Iran. The prevalence of depression was 24.8 % and 28% in males and females and those with depression had mild to moderate depression.¹⁵ This study found depression in 60% of caretakers. However Pitceathly CA et al found that most caregivers coped well with the caregiving role, but an important minority became highly distressed or develop an affective disorder mainly in female caretakers and those with a history of psychiatric morbidity.¹⁶ Patients approaching the Bhaktapur Cancer Hospital were mainly from the low and middle socioeconomic background as affluent ones seek treatment in private institutions. Because cancer is an expensive disease, it is costly to treat even in government hospitals. Many of the times, when the disease inflicts on the productive age group or the only adult member who does the earning, the whole familial life is ruined into grave misery, assaulting their livelihood and dwelling.

This study suffered from some limitations like being a single hospital based study even though patients from all around the country approached there for treatment. Non-probability sampling method and single site of study made generalization of the findings not possible.

Conclusion

Cancer is a global public health challenge with immense impact on patients and their families. In the absence of population-based cancer registry, the present hospital based study attempted to measure the same and found that majority of patients suffered from tragic disease consequences like pain, diminished physical activity, financial burden and depression, which were further worsened by inevitable adverse reactions of treatment. Similarly majority of caretakers fell victim to depression. In order to confront this mounting impact of cancer epidemic in Nepal, cancer should be given high priority

in national health programs, and population based cancer registry should be immediately established to strengthen the fight against cancer.

Conflict of Interest: None declared

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