Cost of Treatment for Cancer: Experiences of Patients in Public Hospitals in India

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Abstract

Background: To assess the treatment pattern and expenditure incurred by cancer patients undergoing treatment at government tertiary hospitals in India. Materials and Methods: A cross-sectional study of 508 cancer patients randomly selected from tertiary cancer hospitals funded by central/state governments located in major cities of five states in India, namely Kerala, Maharashtra, Rajasthan, West Bengal and Mizoram, during March - May 2011 was conducted. Information related to direct costs, indirect costs and opportunity costs incurred on investigations and treatment, major source of payment and difficulties faced by patients during the course of treatment was collected. Results: About 45% of the patients used private health facilities as the first point of contact for cancer related diseases as against 32% in public hospitals. About 47% sought private health facilities for cancer investigations, 21% at district/sub-district hospitals, and about 4% contacted primary health care facilities. A majority of the patients (76%) faced financial problems while undergoing treatment. Conclusions: The results highlight the importance of involving the primary health care system in the cancer prevention activities.

Keywords: Cancer - cost of treatment - investigations - direct cost - indirect cost

Introduction

Cancer is the second leading cause of death and disability around the world. More number of people now die of cancer than from all cases of AIDS, tuberculosis and malaria put together. According to World Cancer Report, there is a high incidence rate of cancer throughout the world and it may reach about 20 million by 2030 (WHO, 2008). More than half of new cancer patients and two-thirds of cancer-related deaths now occur in developing countries. Cancer has become one of the major causes of death in India. Every year, about 0.4 million deaths occur in India due to cancer (Government of India, 2010). It is estimated that nearly one million new cases of cancers will be diagnosed by 2015 and nearly 0.67 million people are expected to die. Cancers of oral and lungs in males, and cervix and breast in females account for over 50% of all cancer deaths in India (Government of India, 2005). Most cases of cancers are detected only in the advanced stages, when they are untreatable. This is especially true in developing countries like India.

Most cancer patients in India reel under the pressure of the astronomical cost of treatment. What hits them even harder is the exorbitant amount of money paid for the drugs that are crucial for a cancer patient’s survival at an advanced stage. It can be a huge drain on the resources of families belonging to middle or lower income group. The mounting cost of cancer care can drive most families to the brink of bankruptcy. Although both the Central and State Governments provide free/subsidized treatment at the tertiary cancer centers, patients often use expensive advanced-level treatment to increase their chances of survival. As relatively low percentage of the population going in for health insurance, much of the money spent comes from the people themselves. Emergence of new technologies and treatments protocols for cancer coupled with a rapid rise in cases of the disease mean cancer care is rapidly becoming unaffordable to a majority of population.

The treatment of the commonest form of cancer in India – head and neck cancer – usually costs between Rs. 15,000-20,000 a month in government hospitals. A study, conducted in 2006-07 by the All India Institute of Medical Sciences (AIIMS) which is super-speciality government hospital in India aimed at estimating the costs of treatment borne by cancer patients and family during the course of radiotherapy found that the average cost across all treatment plans is Rs. 1,062 per week. Patients end up paying around Rs 8184/- for a seven-week course in radiotherapy; as much as 59 per cent of this is spent on transportation and food and lodging. The average economic burden to a patient being treated at AIIMS amounted to Rs. 14,031 (before start of radiotherapy), add to that Rs. 8,184 totalling up to Rs. 22,215/-. If the average expenditure of Rs. 14,597 made before coming to AIIMS is added, an average cancer patient surveyed in the study would have to bear an economic burden of Rs. 36,812 for the entire cancer therapy course (which is equivalent to US$669 considering 1 US$=INR 55/-) (Mohanti et al., 2011).

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The cancer treatment in private hospitals is forbiddingly expensive in India. The costs of treating non-Hodgkin’s lymphoma a lymph node biopsy, a bone marrow test, an endoscopy, a PET scan, special anticancer drugs and six cycles of chemotherapy may cost INR 10,00,000/- (US$18182). Each chemotherapy sitting costs INR 90,000 (US 1636). The main reason is the staggeringly high cost of imported equipment for setting up a cancer hospital and expensive cancer treatment drugs (Sharma, 2013).

A recent study on cost of oral cancer conducted at one of the super-speciality private hospital in Delhi found that the mean expenditure for treatment was Rs. 1,49,995.29/- for stage 1 patients, Rs. 1,41,621.36/- for stage 2 patients and Rs. 1,82,859.75 for stage 3 patients. It may be seen that there is not much difference between the costs incurred in treatment of stage 1 and stage 2 patients but the cost has risen significantly for stage 3 patients (Sandeep et al., 2013).

A web search on ‘cancer treatment costs in India’ (http://india.gov.in/sectors/health_family/national_cancer.php) showed only the price list of one particular corporate hospital group charging between USD 1350-2600 for Radio Therapy course of 4-8 weeks. It is to be highlighted that this cost range does not take into account the costs of other cancer treatments like surgery, chemotherapy, supportive medicines and indirect costs (transport, lodging, food etc.) borne by the patient.

In China, a detailed study was conducted on exclusively 456 oral cancer patients including 176 females and 280 males to analyze the cost of treatment. The primary goal of cost analysis in the study was to identify the relationship of differences in medical hospital days (MHD) and cost per patient (CPP) with pathology, clinical stage, gender, smoking habit, medicare and census register. This study examined the detailed MHD and CPP of patients in different clinical stage and with different pathology. Findings indicate that the MHD and CPP of patients in early clinical stages (I & II) were lower than those in late stages (III & IV). The CPP and MHD of Adenocarcinoma group were evidently lower than that of Squamous Cell Carcinomas (SCC) and Sarcoma group. There were no significant difference in MHD and CPP between SCC and Sarcoma group. The study showed that the cost for diagnosis, treatment and hospitalization in early stage were significantly lower than the costs incurred in late stage. The data indicated that the cost for diagnosis in each pathology group had no evident differences (p>0.05). The treatment cost in Adenocarcinoma group was significantly lower than that of SCC groups. The hospitalization cost of Adenocarcinoma group was significantly lower than that of SCC and Sarcoma group. Study findings demonstrate that the MHD and CPP of smokers were significantly higher than those of non-smokers (p=0.018). This study indicates that the treatment cost of the male patients was significantly higher than the female patients (p=0.015). It is noticeable that the diagnosis and treatment cost for patients with medicare was significantly lower than those without medicare. Comparing the cost of smokers with non-smokers, the smokers had significantly higher cost for treatment and hospitalization than those non-smokers (Han et al., 2010).

A study in Vietnam estimated the direct medical cost of a 5-years treatment course for women with primary breast cancer. Retrospective patient-level data from medical records at the Hue Central Hospital between 2001 and 2006 were analyzed. Various direct medical cost categories were computed for a 5-year treatment course for patients with breast cancer. Costs, in USD, discounted at a 3% rate, were converted to 2010 prices after adjusting for inflation. The total direct medical cost for a 5-year treatment course for breast cancer in central Vietnam was estimated at $975 per patient (range: $11.7-$3,955). The initial treatment cost, particularly the cost of chemotherapy, was found to account for the greatest proportion of total costs (64.9%). Among the patient characteristics studied, stage at diagnosis was significantly associated with total treatment costs. Patients at later stages of breast cancer did not differ significantly in their total costs from those at earlier stages, but their survival time was much shorter. The absence of health insurance was the main factor limiting service uptake. The long treatment course was significantly influenced by out-of-pocket payments for patients without health insurance (Lan et al., 2013).

Elaborate costing studies to estimate direct and indirect costs of cancer treatment in public hospitals in India and other countries in Asia are limited in the public domain. There is huge difference in cost of treatment in government and private hospitals and cost increases with higher stage of cancer. In this context, an effort has been made to estimate both direct and indirect costs including opportunity costs incurred by the cancer patients who were undergoing treatment in government tertiary hospitals in India during the past one year.

**Materials and Methods**

This was a cross-sectional study conducted among cancer patients who were availing investigations and treatment in tertiary hospitals of the Government (funded by centre or state) located in five major cities in India namely; Thiruvananthapuram (Kerala), Mumbai (Maharashtra), Bikaner (Rajasthan), Kolkata (West Bengal) and Aizawl (Mizoram) during March 2011 – May 2011. Ethical approval for the study was given by the Institutional Review Board of National Institute of Health & Family Welfare, New Delhi. A total number of 508 cancer patients (at least 40 inpatients and 60 out-patients from each hospital except in Mizoram, which is a small state) were randomly selected for interview.

The technical advisory committee formulated for the study provided all necessary inputs for finalization of study instruments. An in-depth interview schedule for patients was developed and pretested for data collection. Interview schedule contained questions related to socio-economic and demographic characteristics, awareness about cancer diagnosis and treatment facilities, stages of cancer, direct and indirect costs including wage loss incurred by families during investigations and treatment, source of payment, assistance received, constraints faced during the course of treatment etc. Interview of patients were conducted by the research team in collaboration with the medical colleges/
other health training institutions in the selected state. All participants were fully informed of the nature of the study for their cooperation and completed consent forms. After thorough scrutiny of data collected from the patients, it was analyzed using SPSS 16.0 to generate various tables.

**Results**

Almost two-thirds of cancer patients were between the age of 35-64 years. Male and Female patients constituted almost equal proportion. Nearly 60% of the patients were residing in rural areas. Educational status of the cancer patients varies significantly across cities; 55% of the patients in Bikaner (Rajasthan) were illiterates, as against only 3% in Thiruvananthapuram (Kerala). About 30% of females were house wives, 28% of all patients were agricultural labourers/daily labour and only 10.3% were in government service. Almost 29% of all patients belonged to families living Below Poverty Line (BPL).

Early diagnosis and initiation of appropriate treatment help in higher survival among patients and reduces cost on treatment. The findings reveal that almost 46% of the cancer patients were diagnosed at second stage or at earlier stage, whereas around 18% were in the third or above stages. About 37.3% did not know their cancer stage at the time of diagnosis. Around 18% of cancer patients have reported of delaying treatment even after they were diagnosed for cancer. About 27% percent reported financial barriers as the reason for delaying decision for treatment.

The health seeking behaviour of patients in terms of first point of contact was also assessed. Surprisingly it was noted that for about 45% of the cancer patients, the first point of contact was private hospitals/practitioners. This was followed by Government run hospitals (42%) including tertiary level institutions. While, about 47% of the patients have undergone investigations at private hospitals, others had their investigations at district hospitals/medical colleges or other tertiary institutions of government. The role of primary health care facilities is negligible in conducting investigations.

As far as treatment is concerned, about 34% were referred from district hospitals or primary health facilities and 28% of patients were from private hospitals. Region wise figures reveal that 42% in Mumbai and 38% in Kolkata respectively were referred by private providers. About 25% of the cancer patients were advised by their family members or friends to avail treatment from the concerned tertiary hospitals. Except in Aizawl (Mizoram) where 57% of cases were referred by primary health care facilities, there exist poor referral practices by the facilities below district levels in other states.

It is difficult for hospitals to provide free services to all the poor patients as many times BPL cards are not available with them. Tertiary hospitals in Mumbai and Thiruvananthapuram assess the economic status of the patients with the help of social workers and decide whether the patients to be given free/subsidized treatment, where as in other hospitals such systems were not in place.

About 34% of the cancer patients were reported of receiving investigations like X ray, CT scan, MRI, ultrasound, biopsy, hematological & cytological investigations free of costs. The proportion of patients who received free investigation was relatively higher in Kolkata (72.6%) followed by Bikaner (36%) (Table 1). On an average of Rs.16,739 was spent on investigations, which is highest in Thiruvananthapuram (Rs. 37,670/-) and Mumbai (Rs.16,739/-). 33.6% cancer patients received entire treatment free of cost. While rest of the patients on an average spent Rs.41,311/- for cancer treatment including medicines. Cost of treatment also highest in Thiruvananthapuram (Rs.66,725/-). Indirect cost incurred by cancer patients comes to an average of Rs.27,248/-, which includes transportation, stay arrangements, food etc. Cancer patients in Thiruvananthapuram and Mumbai have reported highest indirect and opportunity costs (wage loss to the family) respectively.

All the tertiary health facilities were providing free or subsidized treatment to certain proportion of patients, but among the various treatment procedures, chemotherapy was provided free of cost to less number of patients except hospital in Bikaner (Rajasthan) where about 50% of the patients who received chemotherapy were provided completely free or subsidized treatment.

Cancer treatment is quite expensive in all hospitals and for almost 41% of the patients treatment cost was unaffordable. Treatment includes surgery, radiotherapy, chemotherapy, palliative care, follow up care etc. About 31% of the cancer patients have spent more than Rs. 50,000 for investigations and treatment during the last one year. In Thiruvananthapuram treatment expenditure was unaffordable to more than 70% of patients. However, in Bikaner more than half of the cancer patients agreed that it was affordable to them because charges were low as per the policy of subsidised treatment of Government of Rajasthan.

Nearly one half of the patients were aware about health insurance schemes. Health assistance schemes like Jeevan Dai was more popular scheme (51.7%) among the cancer patients followed by Rashtriya Swasthiya Bima Yojana (RSBY), a national health insurance scheme fully subsidized for BPL families and Prime Minister’s/Chief Minister’s/Health Minister’s funds for financial assistance. However, only few of the patients received benefits under these schemes. National Cancer Relief Fund was utilised by 28% of the patients and 26 % utilized RSBY.

Friends and relatives were the major source of information about the various schemes (28.4%). In Aizawl 70% of the patients came to know about the financial assistance/health insurance schemes from friends and relatives. Radio/TV/Newspapers were not a main source of information in any of these states.

Among those who utilised health insurance schemes, only one fifth received the full payment from various health insurance schemes. Almost one-third of the cancer patients (38.3%) spent more than Rs. 50,000 as out-of-pocket expenditure, yet variations exist among patients treated in various institutions. For instance in Thiruvananthapuram (Kerala) about 58% of patients spent more than Rs. 50,000, as against only 28% in Bikaner (Rajasthan).

About 39% of the patients had to borrow money
from various sources to meet the cost of treatment. Table 2 shows patient’s major sources of funds for treatment. Nearly 37% of patients sources of fund was their ‘own saving’. The main concern is for the patients who sell their asset for the treatment (12.4%).

Cancer patients face various hardships and difficulties during investigations and treatment for cancers. About majority of cancer patients faced various types of hardship/difficulties. Almost 75% of them faced financial problems, 44% faced difficulties in travelling long distance to hospitals, as cancer treatment required repeated visits to the hospital. The problem of non-availability of beds in hospitals was also faced by almost 17% of patients.

### Discussion

Nearly one-half of patients reported private health facilities as the first point of contact for cancers related diseases. This clearly reveals lack of involvement of the primary health system in the cancer control activities particularly in rural areas forcing patients to visit private facilities. More than three-fourths of the cancer patients faced financial problems in treatment. Poor families usually delay their treatment decision due to financial problem. The treatment of cancer has become a major reason for indebtedness for patients belong to poor families. The poor become poorer due to the disease, it would be desirable if higher proportion of poor is provided with free/subsidised charge for the high cost diagnostic tests.

The patients have to sell off property and borrow heavily to keep treatment going. Mahal et al. (2010) showed that almost 50% of households having a member with cancer experiences catastrophic spending and 25% are driven to poverty by health care costs.

In the context of high out-of-pocket payments, it is important to provide financial protection to the poor patients, thereby enabling them to access treatment services. Currently only a limited financial protection is available through the government funded health insurance schemes in India and in particular, the RSBY, a national health insurance scheme that now covers about 33 million poor families. However, except for a few state funded health insurance schemes that cover about 5% of the Indian population, these schemes do not cover outpatient care.

Patient has to pay for transportation and child-care especially in Indian scenario where patient has to travel long distance to the tertiary care facilities. Hospitalization may well require another adult to accompany the patient and that person’s time is a direct cost. Family and friends also provide informal assistance to the patient including child-care.

Patients requiring other form of treatment including surgery and chemotherapy incur a higher expenditure. Most often, depending on their type and stage of cancer, patients would require more than one form of treatment. This pushes the families to deep financial crisis when cancer treatment is expensive and is also long term with no surety of cure.

Though the tertiary hospitals provide free/subsidised treatment to the poor, the study reveals that only a low proportion of patients were given free/subsidised diagnostic services on costly procedures like MRI (15%). But, a higher proportion of patients were given free/subsidized charges for less costly services like X-ray (28%). Due to insufficient grants from the Government of India and the state governments, the hospitals collect high charges from the patients belonging to all categories for investigation and treatment. In order to lessen the burden by the poor due to the disease, it would be desirable if higher proportion of poor is provided with free/subsidised charge for the high cost diagnostic tests.
There are various financial assistance, available in different states, especially for the poor patients. However, the awareness of the schemes among the poor families is limited; and even if they are aware, they do not know the procedure to avail the benefit under the scheme.

Sufficient awareness on the importance of subscribing to health insurance scheme must be propagated. The study shows the lack of proper communication activities about the health insurance/financial support schemes in the outpatient counter of hospitals. Lack of awareness has been the major reason for not availing the financial support by many of the poor patients. Except hospitals in Thiruvananthapuram and Mumbai, other hospitals found to be helping poor patients in submitting applications for financial support schemes run by the Central, State Governments or Non-Governmental Organisations.

Non-profit making hospitals or philanthropic organizations could subsidise the premium costs of a community or group of people who may not be able to afford the annual expense. While health insurance companies do not find it ‘practical’ to underwrite new patients who have already been detected with cancer, health insurance remains the strongest support mechanism for people battling the disease.

Cancer Care for Life scheme (3rd series) is a scheme sponsored by Regional Cancer Centre, Trivandrum to provide advanced cancer treatment free of cost to all those who join the scheme up to a prescribed limit. When the scheme was introduced in 1986 membership fee was kept at the barest minimum Rs.101/- and later it was raised to Rs.500/-. As there was enormous escalation in cost of drugs, diagnostic procedures and treatment modalities, the enrolment in the scheme had to be discontinued. The center has now revived the scheme with slight modifications in deference to requests from the public.

The Yashaswini health insurance scheme, conceived for cooperative workers in Karnataka, is increasingly being adopted in states like Andhra Pradesh and Tamil Nadu. These schemes cover cancer treatment for people living below the poverty line. In few states different schemes for diagnosis and treatment of cancer is initiated by the Government. Cancer treatment is also included in the Rashtriya Swasthya Bima Yojana (RSBY). Kerala government has introduced a new scheme of Comprehensive Health Insurance for all BPL card holders of Kerala, known as “CHIS PLUS”.

Under the scheme, additional treatment facility for BPL card holders of RSBY/CHIS for critical care patients of cardiac, cancer and kidney problems is available. This scheme is implemented through insurance company, but fully funded by state government. At the national level, in 2009, the Health Minister’s Cancer Patient Fund was created within the Rashtriya Arogya Nidhi Scheme. It proposed to establish the revolving fund in the Regional Cancer Centres (RCC) to speed up financial assistance to needy patients.

In India, the burden of cancer is likely to increase if urgent actions are not initiated on priority basis. Currently implemented programmes that address cancer prevention, care and treatment have not been able to reduce the burden due to limited scale of implementation. Failure of the programme for screening and early detection results in late diagnosis of cancer leading to more expenses on the part of patients. A recent study in India has revealed that knowledge of cancers other than the tobacco related cancers is very low among the community and there exist poor knowledge of warning sign and symptoms of cancers (Raj et al., 2012). Further factors like long distances from homes, psychological shock and difficulties in arranging money for the treatment may lead to delaying treatment decision by poor families. The Twelfth Five Year Plan (2012-2017), Government of India has recognized the magnitude of cancer in the country and envisaged a package of policy interventions which include raising taxes on tobacco, enforcing bans on tobacco consumptions in electronic media, counseling for quitting tobacco, screening for common and treatable cancers (Government of India, 2012).

The study has clearly highlighted the financial burden faced by the cancer patients, especially the poor. In order to deal with the financial burden of the poor families, it is inevitable to set up a good referral system and a mechanism to provide free diagnosis, treatment and support the travel expenses of the poor patients. Most importantly, it is imperative to strengthen the cancer control activities at the community level as most of the common cancers are preventable. It is time to implement evidence based strategies for cancer prevention, early detection and the management of patients with cancers.

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