

The socio-economic burden of cancer: An observation from the palliative care OPD

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ABSTRACT

A cross-sectional study was planned to assess the socio-economic burden of cancer among patients referred for palliative care. Patients referred within 6 months of diagnosis were grouped as early while others were late referrals. The socio-economic status, out-of-pocket expenditure (OOPE), and budget adjustments were noted and compared between the two groups using SPSS v 23.0. A total of 96 patients were included among which 57 were referred late. Most patients belonged to middle- and lower-income groups but only 22/96 had some kind of social security. The demographic profiles of the two groups were comparable. Although the patients referred late had more OOPE compared to the early ones, the difference was not statistically significant. Patients receiving chemotherapy had a significantly higher OOPE ($P = 0.001$). Job interruptions and loss of family income leading to budget adjustments were reported by 50 patients. The study indicates that there is a significant economic impact and OOPE that needs to be addressed in our patient population.

Keywords: Budget, cancer, out-of-pocket-expenditure, palliative

Introduction

Early integration of palliative care is a conscious decision at our Regional Cancer Centre (RCC) where approximately two-third of all patients are treated with palliative intent. Over the years, several attempts have been made to document physical and psychological symptoms of cancer patients.^[1] Unfortunately, the socio-economic burden is still sparsely documented. The cost of cancer treatment even in the public sector can be prohibitive. Although the available government schemes and insurance policies may reimburse, some of these expenses, the out-of-pocket-expenses (OOPE) for indirect cost of

expenses is seldom discussed. The clinician in an attempt to provide the best possible therapy can prescribe the high-end treatment without explicitly discussing the cost-benefit ratio. The caregivers, in their concern for the patient, ask for the best possible treatment without realizing the chances of “Catastrophic Health Expenses” (CHE) and “Distress Financing” (DF). The present study was conducted to get a preliminary idea about the magnitude of the socioeconomic burden of disease among cancer patients and their families and how they meet the costs of therapy.

Methods

All newly registered patients attending the palliative care OPD during December 2019 and January 2020 were asked to share the details of their treatment-related expenses. Consenting patients were asked about the details of treatment, expenses incurred, availability of insurance/financial aid, loss of family income,

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and budget adjustments required as a direct consequence of the disease and treatment thereof. Particular attention was given to family size, education, OOPE, and work interruptions. Patients who were referred for palliative care within 6 months of diagnosis were grouped as “early” while all other patients were grouped as “late.” An attempt was made to compare the burden between these two groups.

All data were entered in MS Excel and then the datasheet was transferred to SPSS, version 23. A descriptive analysis was performed initially. All qualitative data were analyzed using Chi-square test and quantitative by *t*-test. Diagrammatic representation to explain the OOPE was done. The factors affecting expenditure were estimated using univariate analysis and those which were found significant were compared using multivariate analysis. A *P* value of <0.05 was considered significant.

Results

During the period of study, 205 patients were registered in palliative care OPD among which 96 patients consented to be part of the study. The sociodemographic profile of the study population is depicted in Table 1.

There were 53 male and 43 female patients. Almost 60% (57/96) of them were referred “late” to palliative care. However, the “early” and “late” groups were comparable in terms of income, education, family size, and occupation.

The median family size of the entire cohort was five. The patients were divided into various income groups as per the World Bank classification.^[2] Our patients predominantly belonged to the lower-middle-income group with 45 patients reporting a family income between Rs 70,137 and Rs. 2,73,098. A significant 26 patients (27.1%) were even worse off and belonged to the low-income group.

Only 14 patients had a “Below Poverty Line” card issued by the government and 8 others had some form of medical insurance. Most patients received multimodality cancer-directed treatment in a government hospital. The mean expenses incurred for treatment in rupees were 1.938 lakhs in the early group and 3.382 lakhs for the late group (*P* = 0.052). For most patients, the expenses covered treatment cost, travel, and stay away from home. Significantly more money (Rs. 3,86,111 vs Rs. 1,46,363) was spent by patients receiving chemotherapy (*P* = 0.001).

Loss of family income was reported by 50 patients who were employed and had work interruptions. Among the 96 interviewed patients, 54 made budget adjustments, 38 incurred loans, and 15 sold their belongings to cover medical expenses and ancillary costs. Figure 1 outlines the various adjustments made in household budget. These adjustments were comparable in the early and late groups of patients.

Table 1: Table depicting the sociodemographic profile of study population

Characteristics	Early n=39 (40.6%)	Late n=57 (59.4%)
Mean Age (in years)	58.74	52.86
Residence: Rural	17 (17.71%)	30 (31.25%)
Urban	18 (46.15%)	23 (23.96%)
Education: Illiterate	17 (17.71%)	16 (16.55%)
Primary	12 (12.5%)	21 (21.87%)
Secondary	8 (8.33%)	11 (11.46%)
Graduate	0	6 (6.25%)
Post graduate	2 (2.08%)	3 (3.13%)
Marital Status: Married	38 (39.58%)	55 (57.29%)
Unmarried	1 (1.04%)	0
Widow	0	2 (2.08%)
Household size: up to 4	12 (12.5%)	21 (21.87%)
5-8	22 (22.92%)	28 (29.17%)
>=9	5 (5.21%)	8 (8.33%)
Head of family		
Yes	2 (2.08%)	7 (7.29%)
No	37 (38.54%)	50 (52.08%)
Income: Low	11 (11.46%)	15 (15.62%)
Lower middle	16 (16.67%)	29 (30.21%)
Upper middle	10 (10.42%)	10 (10.42%)
High	0	3 (3.13%)
Occupation		
Unemployed	14 (14.58%)	24 (25%)
Student	0	1 (1.04%)
Retired	3 (3.13%)	5 (5.21%)
Service	3 (3.13%)	2 (2.08%)
Skilled laborer	1 (1.04%)	3 (3.13%)
Unskilled laborer	18 (18.75%)	21 (21.87%)
Social security/Insurance		
Yes	2 (2.08%)	6 (6.25%)
No	37 (38.54%)	49 (51.04%)
Partial	0	2 (2.08%)

Discussion

The success of Universal Healthcare depends on the availability, accessibility, and affordability of healthcare facilities. Our RCC has consistently reported advanced-stage disease at the time of presentation in majority of patients. An earlier analysis indicated that distance and economic factors probably influenced stage of malignancy at the time of presentation.^[3] The study also mentioned the lack of structured healthcare support. Palliative care is a holistic approach that improves the quality of life of patients and their caregivers through the prevention and relief of suffering by means of early identification and diligent assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual. In 2009, World Health Assembly reaffirmed the principles of PHC: equity, solidarity, social justice, universal access to services, decentralization, and community participation – as the basis for strengthening health systems,^[4] all of which are also principles of palliative care. The present study was conceived to get better idea of the economic burden faced by cancer patients and their caregivers to propose cost-efficient

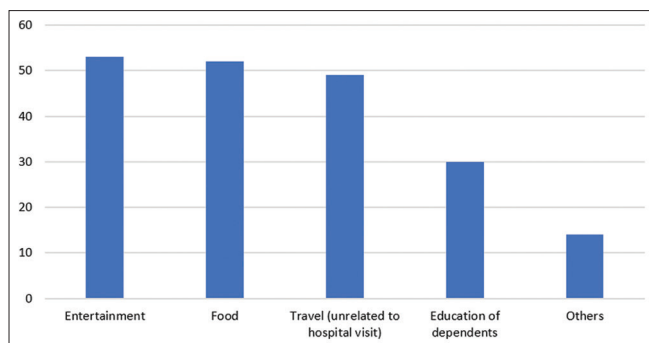


Figure 1: Budget adjustment made to meet medical expenses

treatment protocols in the future. Our study reveals that only a few patients could avail the benefit of insurance schemes.

This cohort had 74% patients belonging to low and lower-middle-income groups. Despite various schemes launched by State and Union Governments, only 14 patients were eligible to avail them. Another 8 patients had some kind of health insurance/social security. Thus, most patients paid from their pockets for the treatment. This study not only included newly diagnosed cancer cases, but also dealt with old cases, who were actively suffering from the disease. Though not statistically significant, patients referred late to palliative care had more OOPE. The addition of chemotherapy increased OOPE significantly. Even when the treatment is given free of cost or reimbursed, patients have to bear the indirect costs of treatment. This leads to an increased burden for the caregivers and may adversely affect compliance with treatment. Although our study was not planned to look into treatment compliance, a cross-sectional study from Argentina did quantify the effect of loss of family income on treatment compliance.^[5] Sneha *et al.*^[6] reported the significant financial burden of families of children with malignancies due to OOPE. The situation is similar even in western countries such as Germany and the United States where OOPE significantly worsened their quality of life.^[7,8] Palliative care service integration into primary care is beneficial for improving access to early palliative care, and subsequently, improving symptom control, compliance with cancer treatment, quality of life, and overall satisfaction.

Our study revealed job interruptions due to disease and treatment, and diminished family income requiring budget adjustments. The maximum reduction was expenditure on food, a direct blow to patients who require nutritious diet while fighting the disease. Rajpal *et al.*^[9] found high incidence of distressed financing among cancer patients attending public and private hospitals. The economic burden was evident across all wealth quintiles. In addition, they found catastrophic OOPE where households spent 10, 20, and 40% of their annual per capita expenditure for availing inpatient treatment.

Quantification of OOPE for cancer treatment is a relatively new concept at our center. We documented distress health financing in our study when 39.6% of households incurred financial loans

and 15.6% sold their assets to meet medical expenses. Cancer has been identified to have the highest CHE (79%) and DF (43%) among all hospitalized patients.^[10] Even when much of the treatment was delivered in a public sector hospital, our patients and their families did encounter distress due to OOPE.

Conclusion

In modern times, diagnosis and treatment of cancer have improved remarkably but facilities are mostly concentrated in the cities. Delay in diagnosis and overall delay leads to a change of intent from radical to palliative.^[11] Till we have an effective structured healthcare system, the treating physicians need to discuss the cost of cancer care in policy papers as well as oncology clinics.^[12] Every attempt should be made to make patients and caregivers aware of the existing benefit schemes. Another major task for clinicians is to avoid expensive but potentially futile therapeutic choices. Early integration of palliative care with cancer-directed therapy through PHC often gives patients and caregivers a chance to choose wisely and avoid catastrophic OOPE.

This study was approved by the Institute Ethics Committee, PGIMER, Chandigarh.

All authors have contributed equally in data collection, analysis and shaping the manuscript.

Declaration of patient consent

Written informed consent was obtained from all participants.

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Conflicts of interest

There are no conflicts of interest.

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