



## **Differentiation of Out-of-Pocket Expenditures in Cancer Patients; A Case Study in the Cancer Institute of Iran**

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### **ABSTRACT**

**Background:** The Cancer Institute of Iran, located in Tehran (Iran's capital city), is a national specialized center for cancer. Cancer patients from all over the country refer to it. This study compared the out-of-pocket (OOP) expenditures of patients from Tehran and patients from other parts of Iran who were hospitalized in this center.

**Methods:** This cross-sectional study included all patients over 18 years of age with head and neck or digestive system cancer who were actively undergoing primary treatment in the Cancer Institute of Iran located in Tehran (the capital city). Data was collected through a structured interview with the patients themselves and/or their companions and then analyzed using SPSS<sub>16</sub> software.

**Results:** Direct medical costs of patients from Tehran were much higher than those of patients from other provinces. In contrast, the average direct non-medical costs including transportation, accommodation, food, etc. of patients from other provinces were significantly higher than those of patients from Tehran, and 53% of patients borrowed money for their treatments.

**Conclusion:** It seems necessary to develop new supportive policies to alleviate financial costs for cancer patients and help them manage their cancers effectively. Patients from the provinces faced additional costs for travel, food, and accommodations which complicated their access to special services. Establishing and improving specialized cancer centers in other cities can reduce the burden of out-of-pocket expenditures for patients from remote areas.

**Keywords:** Out-of-Pocket Expenditures, Direct Medical Costs, Cancer Patients

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## Introduction

Cancer is a leading cause of morbidity and mortality in the world (1), and its global burden will increase in future decades (2, 3). It is expected that the number of new cancer cases will increase from 10 million in 2000 to 15 million in 2020, and about 60% of such new cases will occur in underdeveloped countries (3, 4).

The impact of a cancer diagnosis extends beyond the patient, changing the lives of spouses, children, and other family members and relatives. Treatment for cancer imposes a variety of physical, emotional, and financial costs on patients as well as their families and loved ones (5).

Cancer care generally requires that a large amount of resources be used. It involves periods of hospitalization, the use of physician and other professional services, diagnostic tests, and chemotherapy. Such a variety of treatments together with expensive surgery, radiotherapy, and other pharmaceuticals sometimes results in an unbearable cost to be paid by patients or their families (6, 7).

The costs of cancer care are likely to increase in the future with expected increases in cancer prevalence; the growth and aging of populations; the promotion of national screening services; advances in oncology pharmaceuticals and the potential for prolonged treatment regimes caused by multiple courses of chemotherapy; highly specialized and expensive equipment being limited to hospitals/specialist centers, requiring patients to travel for treatment; and the possible rationing and centralization of health services by state and territorial governments (8, 9).

Cancer care costs are sorted into different categories, direct medical and non-medical costs being two of them (10). Direct medical costs refer to sources used for patients by the health sector during assessment, treatment, and follow-up services (10-13). These costs are related directly to medical services provided to patients and incurred by healthcare centers (e.g., hospital, outpatient clinic), staff (doctors, nurses, and other professionals), medical services, alternative and complementary care, and the cost of any other

medications. Direct medical costs may have undesirable effects on both patients and healthcare institutions (5, 14, 15).

Another category is known as direct non-medical costs. These costs are directly associated with the patient receiving the care. In other words, they pertain directly to the care that is delivered to the patient, but are considered non-medical in nature (14). The centralization of specialist cancer services in major cities is the chief cause for such costs. Most patients from rural and remote areas are often required to relocate or at least travel considerable distances to receive treatment. Thus, out-of-pocket (OOP) costs such as travel, accommodation, and communication costs can be particularly troublesome for people living in distant regions (16).

The categorization of direct costs as medical or non-medical is very important, because it helps us consider health sector-related costs and other kinds of costs separately and it facilitates decision-making and interventions (15). In this study, direct medical and non-medical costs of care provided for patients are analyzed from the perspective of patients and their families. Other kinds of indirect costs, such as productivity cost which includes time away from work for both patients and their companions, are not considered in this study (6, 14).

Cancer is the third major cause of mortality and morbidity in Iran. According to the National Cancer Registration Report, more than 30,000 people die each year from cancer. It is estimated that more than 70,000 new cases of cancer occur annually in Iran. With the increasing life expectancy and the percentage of aging in the population, it is expected that the number of cancer cases will increase in future decades (3). The high prevalence of cancer in Iran as well as the decreasing age of morbidity due to this costly and dangerous disease has forced oncologists to coin the term “cancer tsunami” to emphasize the human and financial losses brought on by this fatal disease.

Access to effective healthcare is usually limited for patients that live in rural and remote areas.



Necessary treatments and the associated financial pressure for many patients and their families can be very stressful, especially for low-income patients (9). Well-timed estimates of the costs of care for cancer patients are important factors in the formulation of national cancer programs and policies (8).

The Cancer Institute of Iran (CII) is a national referral center located in Tehran, and cancer patients from all over Iran refer to it. This study analyzed and compared direct medical and non-medical costs paid out-of-pocket by cancer patients (including patients from Tehran and other districts) who referred to the CII so as to identify influential factors imposing such costs and the extent of them. Estimating these costs can be useful and applicable for both policy makers and insurance companies in making policies that ultimately lead to improving patients' access to vital services.

### Materials and Methods

This analytic-descriptive, cross-sectional study was performed in the CII from August to November, 2013.

According to CII statistics and available documents, patients with head and neck or gastrointestinal (stomach, esophagus, colon, rectum, pancreas) tumors were selected as the study population due to the high prevalence of these kinds of cancer in Iran (17). Based on patient hospitalization costs, 177 patients were selected as the study sample. Patients above the age of 18 years who had head and neck or gastrointestinal tumors and were in the primary stage of treatment were asked to participate in the study. Primary treatment refers to a set of medical procedures (including surgery, chemotherapy, and radiotherapy) planned and performed completely for the patients after the diagnosis of cancer by the cancer care unit. Patients with recurrent disease and metastatic treatment were excluded.

It is said that the amount of money spent for treatment differs among various tumors. Hence, limiting the scope of the study to the above-mentioned types of tumors can increase the chances of finding possible expenditure patterns.

US studies have shown that cancer treatment costs are the highest in the first 6 months and just before death, whereas they diminish dramatically in the time between these two periods (18). Several approaches have been used to estimate the costs of cancer care, including prevalence and disease phase. The disease phase approach divides care clinically into three periods: the initial period after diagnosis, the last year of life, and the intervening or continuing period (8). Based on this and to have a more comprehensive cost estimation, all patients in their first stage of disease treatment, generally known as primary treatment, were included in the study sample.

Data was collected with the use of a questionnaire derived from two other questionnaires used in similar studies, one developed by Longo in Canada in 2005 (6) and the other by Gordon in Australia (9). For the purpose of the face validity, the newly-developed questionnaire was studied and revised by the study's supervisors and oncologists. A 'pilot' study was initially conducted on ten patients to refine the questionnaire, and some questions were revised to make them more understandable.

The questionnaire sought information on the patients' demographics, general health condition, insurance coverage, occupational situation, and the number of sick leave days of both the patients and their companions. The primary objective of this questionnaire was to determine the amount of direct OOP payments patients had to make during their primary cancer treatment.

The two groups of direct medical costs and direct non-medical costs were analyzed in this study. Direct medical costs included doctor visits, emergency visits, diagnostic tests (laboratory, radiology, endoscopy, and colonoscopy services), physiotherapy, medications, surgery, chemotherapy, radiotherapy, home care services, complementary and alternative treatments, vitamins and nutrients, medical equipment (wig, corset), and informal payments to providers. Direct non-medical costs, on the other hand, included travel costs to healthcare centers, accommodations and food, costs for taking



care of family members such as adults or children in the absence of the patient, and other costs (e.g., telephone). All payments that patients had previously made to other medical centers for their primary treatment were included.

The questionnaires were completed by the patients themselves or by their families at the time of discharge from hospital. A significant amount, especially outpatient costs, had been paid to medical centers other than CII. Though a major portion of the OOP costs had been expended outside of the cancer center (as mentioned above), these costs were taken into account in the calculations for this study. SPSS<sub>16</sub> for Windows and descriptive and inferential statistics including chi-square, one-way ANOVA, two-way ANOVA, and *t*-test were employed for data analysis.

Further, in the current study all ethical issues were observed based on the Helsinki Declaration.

## Results

Of the total 170 cancer patients that participated in the study, 112 and 58 of them were male and female, respectively. Among the participants, 60 were inflicted with cancer of the head and neck, 56 with cancer of the colon/rectum, 48 with stomach cancer, and 6 with esophageal cancer. Although the costs of esophageal-cancer patients were included in the data analysis, no comparison was made between the costs associated with this type of tumor and the other kinds of cancer in the study population mainly because of the small sample size.

The average age of patients was 52 years; no significant age difference was found between patients in the different studied groups (*P*-value = 0.736). About 51% of patients lived in Tehran, while the rest (49% percent) hailed from other parts of the country.

The costs of cancer patients were divided into the two categories of direct medical costs and direct non-medical costs. The average OOP expenses paid directly during primary treatment were 745 and 70 \$ (1\$ = 11,000 Rials) for direct medical and non-medical costs, respectively, totaling costs equal to 815 \$ for each patient.

Direct medical expenses were almost 91% of the total costs, and the remaining amount (9%) was associated with direct non-medical costs.

As Table 1 indicates, differences across the three cancer categories were statistically significant at *P*-value < 0.001.

Studies have found that in some cases, households consume their savings, sell their properties, and borrow money from relatives or friends to pay the catastrophic OOP costs of cancer (19). In the present study, 53% of patients had borrowed money from their family members, relatives, banks, charities, or other available sources for their treatment with the average amount borrowed being 734 \$. The minimum and maximum amounts of money borrowed by patients for their treatment were 14 and 2429 \$, respectively.

Table 2 shows that the average direct medical costs for borrowing patients from Tehran and other provinces were 1007 and 666 \$, respectively. For patients from Tehran and from other provinces who had not borrowed, the average direct medical costs were 883 and 358 \$, respectively. Average direct medical costs for patients from Tehran and those from other districts, regardless of loans, were 947 and 534 \$, respectively. On the whole, direct medical costs were much higher for patients from Tehran than for patients from other provinces, and the difference was statistically significant (*P*-value = 0.001). The average direct medical cost was higher for borrowing patients than for non-borrowing ones, but this difference was not statistically significant (*P*-value = 0.069).

As shown in Table 3, the average direct non-medical costs for patients from Tehran and from other provinces who borrowed money were 50 and 130 \$, respectively. Moreover, for non-borrowing patients living in Tehran, direct non-medical costs equaled 27 \$, while for their counterparts from other areas it was estimated to be 66 \$. The average direct non-medical costs for patients from Tehran and other provinces were 39 \$ and 103, respectively. Average non-medical costs for borrowing and non-borrowing patients was higher for those from other provinces than for those from



Tehran at a significant level (P-value < 0.001). Moreover, average costs were higher for borrowing patients than for non-borrowing patients from both Tehran and other provinces. ANOVA proved a statistically significant difference between the two groups (P-value < 0.001).

**Various factors that contribute to total costs paid OOP based on patients' residence location**

Figures 1 and 2 display five important factors in the structure of costs directly paid OOP by patients from Tehran and those from other provinces. For patients from Tehran, approximately half of the total OOP costs (48%) were associated with chemotherapy pharmaceuticals. However, all services provided patients (other than chemotherapy pharmaceuticals) are free at CII, because it is a public referral and teaching hospital.

One quarter of total OOP costs was allocated for surgery. On the whole, 75% of the total OOP costs of patients from Tehran was allocated for chemotherapy pharmaceuticals and surgery. The findings revealed that 8.6% of the total OOP costs of patients from Tehran was spent on diagnostic services (laboratory, radiology, endoscopy, and colonoscopy). For patients from other districts, the

major part of OOP payments went for chemotherapy medications, surgery, and diagnostic services, respectively. Therefore, the ratio of OOP to total cost for the mentioned items for patients from other provinces was different from that of patients from Tehran. For patients from outside of Tehran, chemotherapy medications and surgery costs were the first and second highest cost categories accounting for 34% and 18.5% of total costs, respectively. Diagnostic services was recognized as the third highest cost category for total costs; 18% of total costs directly paid OOP was 10% higher for them than for patients living in Tehran.

For patients from other provinces, the cost of transportation was the fourth factor contributing to total costs. This category formed 12.7% of total OOP costs, while for their counterparts from Tehran, transportation was the fifth contributing factor, accounting for only 3.4% of their total costs. Cost of visits was the fifth factor for patients from other provinces (5.2% of total costs), while for patients from Tehran it was not among the first five categories of OOP payments.

**Table 1.** Average OOP costs for patients according to types of their cancer

Type of tumor	Average total OOP (\$)	P
Colon/Rectum	1306	< 0.001*
Stomach	713	< 0.001*
Head and Neck	431	< 0.001*

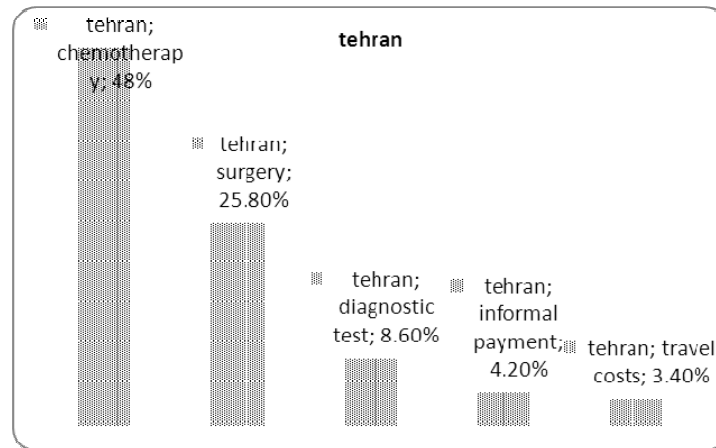
\*Significant at the 0.05 level

**Table 2.** Distribution of direct medical costs paid OOP based on place of residence and borrowing for treatment

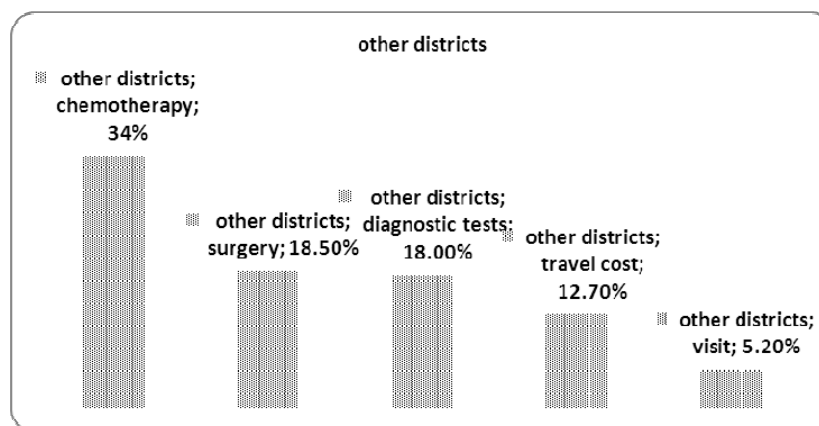
Province	Borrowed (\$)	Non-borrowed (\$)
Tehran province	1007	883
Other districts	666	358

**Table 3.** Distribution of direct non-medical costs paid OOP based on patients' lodging and loan conditions

Province	Borrowed (\$)	Non-borrowed (\$)
Tehran province	50	27
other districts	130	66



**Figure 1.** Five highest contributing factors to total OOP costs among patients from Tehran



**Figure 2.** Five highest contributing factors to total OOP costs among patients from other provinces

## Discussion

This study aimed to analyze and compare direct medical and non-medical costs for cancer patients from Tehran and other provinces of the country referring to CII in Tehran. Based on the findings, the average direct medical cost for patients from Tehran was higher than that of patients from other provinces. Having studied the details of the factors contributing to the direct medical costs, the authors found that OOP costs for visits and diagnostic services (including laboratory, radiology, endoscopy, and colonoscopy services) were much higher for patients from the provinces than for patients from Tehran. However, for items such as chemotherapy and surgery costs, OOP costs were much higher for patients from Tehran than for patients from other provinces; this difference was statistically significant ( $P$ -value  $< 0.001$ ). Generally, the total direct medical costs for

patients from Tehran were higher than those for patients from other provinces. Chemotherapy medications and surgery services formed a huge part of total costs for patients from Tehran compared to those from other provinces. Conversely, diagnostic services and doctor visits formed a large part of total costs for patients from other provinces. The average visit costs for patients from Tehran and other provinces were 26 and 42 \$, respectively, but the difference wasn't statistically significant ( $P$ -value = 0.23). The average costs for diagnostic services for patients from Tehran and patients from other provinces were 85 and 115 \$, respectively. The results of inferential statistics indicated that the difference was significant ( $P$ -value = 0.05).

One main reason for the high expenses that patients from outside of Tehran had to pay for diagnostic services and doctor visits can be the



unavailability of experienced doctors and specialists, well-equipped centers for the treatment of cancer, and the lack of modern diagnostic services in their home cities. Despite receiving diagnostic and treatment services, patients not living in Tehran frequently refer to big cities like Tehran for better quality services. However, since specialists do not trust the diagnostic services performed by their colleagues in towns outside of Tehran, they repeat diagnostic and treatment stages, imposing doubled and even tripled costs on patients.

The greater costs for patients from Tehran compared with those from districts, especially for costly treatments such as surgery and chemotherapy can be attributed to the active and highlighted presence of the private sector in Tehran; however, patients in districts use affordable public services. Patients from Tehran sometimes receive surgery and chemotherapy services from the private sector where the service quality is most likely better but more expensive than the public sector.

The study results showed that there was a significant difference in direct non-medical costs dependent upon the patient's place of residence; patients from provinces other than Tehran spent nearly 2.5 times more than their counterparts living in Tehran. The findings also demonstrated that patients who referred to specialized centers in big cities faced more extra costs which could impose enormous pressure on them. On average during primary treatment, patients from other provinces and those from Tehran paid 81 and 34 \$, respectively, directly out-of-pocket for transportation ( $P$ -value  $< 0.001$ ).

There was also a significant correlation between distance to the cancer center and transportation costs. Those who referred to the cancer center from greater distances paid more ( $P$ -value = 0.005). In the present study, there was no significant correlation between type of tumor and transportation costs; however, in Longo's study in Canada, this correlation appeared to be significant, and patients with colon or breast cancer paid higher transportation costs than others. Based on

the findings of Longo's study, the reason for these costs lied in the number of clinical visits, as patients with prostate or breast cancer had the most (14 per month) and the least (6.4 per month) visits, respectively. In Longo's study (6), transportation costs formed the largest part of costs paid directly out-of-pocket. According to Gordon's study in Australia, transportation costs comprised 70% of total OOP payments (9), while in the present study transportation costs formed only 12.7% and 3.4% of total OOP costs for patients from areas outside Tehran and those from Tehran, respectively. In Canada and Australia, transportation costs are not covered by insurance companies or any other special programs, and this leads to high transportation costs, whereas medical services are totally free, imposing no OOP expenditures on patients.

There was a significant correlation between accommodation and food costs and distance to the cancer center. Patients referring to the cancer center from greater distances paid more for accommodation and food ( $P$ -value  $< 0.001$ ). Average accommodation and food costs for patients less than 200 kilometers away and more than 600 kilometers from the cancer center were 4 and 46 \$, respectively. Also based on the descriptive statistics, 54% of traveling patients were accommodated in the houses of their relatives or friends, while 17% of patients and their companions had to stay in commercial lodging establishments.

The remaining 29% of patients used other facilities such as a bed next to the patient or the hospital campus, and some of them even stayed in parks close to the center. As mentioned above, 54% of patients in need of housing stayed with friends or relatives, indicating that patients who do not have friends or relatives in big cities may not refer to specialized centers due to the high costs of accommodation and food, and this may provoke problems regarding health equity. In comparison, the study on cancer patients' OOP costs in Australia showed that 33% of 92% of patients needing housing were accommodated in relatives' or friends' houses, while 19% stayed at Cancer Council Queensland's Gluyas Lodge (9). In



Australia, there are some organizations that provide accommodation facilities near the cancer center for patients who come far distances (16). In Iran, too, there is a charitable institution for children suffering from cancer that delivers the same type of service for relatives accompanying patients for treatment.

In the present study, six patients had changed their place of residence in order to improve their access to medical services. Three patients (one from outside of Tehran and two others from Tehran) mentioned their reason for changing location was to improve physical access to medical services. Three others from Tehran moved their residences to improve financial access to medical services. Generally, patients had to exchange their expensive houses for cheaper ones around Tehran so they could use the remaining money for treatment.

Half of the patients (both those from Tehran and those from other provinces) were forced to take out loans. The average OOP costs were higher for patients taking loans than for non-borrowing patients. This result indicates that, while OOP costs for cancer increase, it is more likely that patients will borrow money for continuing their treatment. Therefore, banks can possibly provide special facilities for these patients, so that by receiving appropriate and emergency loans, patients can manage their disease effectively. In some countries like Canada, there are programs that provide emergency financial support for patients who need it. These programs are designed as an income source for patients who have no other source of income and should pay costs higher than their income capacity (6).

Relocation for six patients and indebtedness for half of the patients due to the catastrophic OOP costs associated with the initial steps of cancer treatment indicate that cancer patients face a lot of financial difficulties in accessing vital healthcare. Needless to say, subsequent costs and treatment follow-up will impose an even higher pressure on patients and their families.

The results of the present study showed that chemotherapy medications comprise a major part of total OOP costs for cancer patients. Again, there

was a significant correlation between chemotherapy costs and borrowing money ( $P$ -value  $< 0.001$ ). Therefore, steps should be taken to prevent cancer patients (compared with non-cancer patients) from experiencing a delay in receiving treatment or from withdrawing from their treatment procedures because of financial difficulties.

### **Conclusion**

Study results indicate that cancer patients face catastrophic direct medical and non-medical costs during their medical procedures. Since CII is a public center and people from the poor and low-income strata of society refer there, large OOP costs are troublesome and impose great burdens on patients and their families, forcing nearly half of them to borrow money to continue their treatment processes. Chemotherapy medications, surgery, and diagnostic services imposed most costs on patients than other services. Moreover, patients from districts outside of Tehran faced additional costs such as travel, food, and accommodation costs which complicate access to special services. It is necessary to adopt new supportive policies that prevent the imposition of extreme costs on patients who need necessary treatment (compared with non-cancer patients) so they do not delay or even withdraw from their treatment procedures because of weak financial backing.

### **Conflicts of interest**

There are no conflicts of interest to be declared.

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### **Authors' contributions**

Pourreza A and harirchi I contributed in study design and supervised the process of research. Bazyar M contributed in conducting the study, analyzing the data, performing the statistical analysis and writing the article. Ranjbar M helped with the analyzing the data and writing and editing the article.





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