

Out-of-pocket costs for cancer patients treated at the Brazilian public health system (SUS) and for their caregivers: A pilot study

Custos adicionais para pacientes tratados pelo sistema público de saúde brasileiro (SUS) e seus cuidadores: Um estudo piloto

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| Abstract

Background: The economic burden of cancer care extends beyond public or private payors to patients and caregivers. Additional out-of-pocket costs (OPC) include drugs, supplies, transportation, in addition to lost hours of work. Our goal was to evaluate the amount and nature of these costs from the perspective of caregivers and patients treated at the Brazilian Public Health System (SUS). **Patients and Methods:** We conducted this cross-sectional study at the oncology clinics of the ABC Foundation School of Medicine. We included patients older than 18 years with a confirmed diagnosis of cancer and their caregivers who responded to a questionnaire that assessed the time spent and financial costs incurred with transportation, medicines, food and other supplies. **Results:** From February to May 2015, we included 57 non-consecutive patients with various types of tumors and their 47 caregivers. The average age of patients was 57 years (23-92) and of caregivers 46 years (21-83). The average monthly income of both groups was approximately two times the minimum wage (R\$ 1,576.00). We estimated that the mean OPC for patients was R\$290,41 and R\$312,65 for their caregivers (One US dollar = R\$2.89). In multivariate analysis, the only variables related to higher patient OPC were younger age ($p = 0,0079$) and receipt of active treatment ($p = 0.0321$). We also observed significant correlation between the OPC incurred by patients and caregivers ($p = 0.0022$). **Conclusion:** patients and caregivers OPC represent a substantial portion of their income. Public health officials need to recognize and cover OPC, especially for low-income patients.

| Introduction

In 2012, about 14.1 million cancer cases occurred worldwide¹. In Brazil, the estimate for 2015 is of approximately 576 000 new cancer cases, including cases of skin non-melanoma¹.

The economic burden of cancer extends beyond health services to also affect patients and their families. These additional out-of-pocket costs (OPC) not covered by private insurance or by the public health system involve drugs, cancer treatment supplies, and travel expenses to medical appointments. In addition, we should also consider as part of these costs, the time spent by patients and their caregivers in the process of patient treatment or follow-up^{2,3}. Such costs are a source of emotional stress for patients and their caregivers who often must dispose of assets and seek loans from financial institutions, friends, family or employers². Also, these costs can be prohibitive for the treatment of cancer patients who cannot afford it.

| Keywords

Cancer, health expenditures, healthcare economics and organizations, caregivers, costs and cost analysis

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In Brazil, the Public Health System (SUS) provides universal coverage for all citizens for chronic and acute diseases, including cancer⁴. However, additional aforementioned out-of-pocket costs (OPC) associated with cancer treatment are not covered by SUS. Therefore, in this paper, we sought to analyze from the perspective of a sample of cancer patients and their caregivers, the nature and magnitude of these additional expenses.

| Patients and Methods

This study was cross-sectional and conducted at the medical oncology clinics of the ABC Foundation School of Medicine at the Mario Covas State Hospital in Santo André and Padre Anchieta Teaching Hospital in São Bernardo do Campo.

We included patients older than 18 years of age, provided they had a good understanding of Portuguese and a confirmed diagnosis of neoplasia. We included patients both in the treatment as in follow-up phases. We considered patients in active treatment when they were still receiving chemotherapy and radiation therapy. Otherwise, we considered patients as being in follow-up. Hormone Therapies because of its lower complexity was not considered an active treatment for the purposes of OPC calculations.

We also included caregivers of these cancer patients, whenever they were 18 years old or older, able to understand Portuguese and were accompanying the patient during cancer treatment (consultations, chemotherapy sessions).

Patients and caregivers who agreed to participate signed the Informed Consent forms (protocol number in CEP: 26640714.0.0000.0082) and provided their socioeconomic and demographic data. Subjects also answered to a detailed questionnaire regarding the time spent and the financial costs incurred with transportation, not covered oral medications or any other supplies not provided by the SUS during the last month before inclusion. Questionnaires were applied by medical students directly to patients and respective caregivers.

The questionnaire evaluating the time and costs incurred by patients and caregivers had two parts: time and cost. Regarding costs, we asked what were the amounts spent on transportation, not covered medicines, food and supplies. To estimate the time they spent, we asked about the minutes or hours dedicated to activities related to cancer treatment. We also converted this time into money, by calculating the average value of each hour as a function of the median salary received by patients and caregivers. For example, we assumed a typical work week of 44 hours. Therefore, a month would have approximately 182 working hours. As patients received an average of 2.09 minimum wages per month and assuming the value of the minimum salary at the time of this study of R\$ 788.00, we arrived at an average value of R\$ 8.77 per hour spent. We did a similar procedure to calculate the cost of time for caregivers, obtaining a value of R\$9,02 per hour. This conversion of hours in money allowed us to include hours spent as part of the total OPC.

Regarding transportation, for patients we used the conversion of the estimated car mileage from their homes to our Hospitals and converted it to fuel cost using the average cost of fuel. As for public transportation (bus, train, subway) the value considered was the fare rate multiplied by the number of trips undertaken. For taxi, we used the amount reported for each trip. We did not compute any costs for those patients or caregivers who came walking or used a bike.

We only considered the costs relating to drugs effectively purchased by the patients; those taken within health facilities or otherwise covered have been disregarded. The currency used for all items was the Brazilian real (R\$). For reference purposes, the value of one US dollar at the time of this study R\$2,89.

We also applied to caregivers the same questionnaire of costs incurred and time spent. Similarly to patients, time was converted to money using the average salary received by caregivers divided by the total hours of work in a hypothetical month to find the average value of an hour. This value was then multiplied by the number of hours spent by each caregiver.

Statistical Methods

We evaluated correlations between continuous and categorical variables by the ANOVA or Kruskal-Wallis tests. If variables were both continuous, we employed linear regression methods. All statistical calculations were conducted with the NCSS package (<http://www.ncss.com/>).

| Results

From February to May 2015 we included 57 patients and 47 caregivers. The average age of patients was 57.54, ranging 23 to 92 and 46.29 for caregivers, ranging from 21 to 83 years of age. Most of the included patients and caregivers were women (61.4% of patients and 61.7% of caregivers). Regarding marital status, 49,12% of the patients and 38,3% of caregivers were married or lived together with a significant other (Table 1). The average monthly income of the patients was 2.03 times the minimum wage and for caregiver it was of 2.09 times the minimum wage, with an average value received by the working hours estimated in R\$ 8.77 (patients) and 9.02 (caregivers).

The largest amount of time spent by patients related to treatment (8.46 hours) whereas the highest costs incurred by patients related to transportation (R\$51,18) (Table 2). Patients OPC represented 21,6% of their total income.

For caregivers, the most hours were spent accompanying treatment (11,31 hours) and the largest cost incurred related to transportation (R\$ 74,68) (Table 2). Caregivers OPC represented 25% of their monthly income.

When we evaluated the possible predictors of the total OPC incurred by patients, we observed in a univariate analy-

Table 1. Socioeconomical and disease data

	Patients	Caregivers
People included	57	47
Gender		
Female	61,40%	61,70%
Male	38,60%	38,30%
Age		
Mean	57,54	46,29
Standard-deviation	15,81	14,55
Race		
White	61,40%	63,83%
Others	38,60%	36,17%
Marital Status		
Engaged	49,12%	38,30%
Single	31,58%	48,94%
Widowers	19,30%	12,76%
Schooling		
Didn't study	8,78%	2,13%
Elementary School 1	45,61%	34,04%
Elementary School 2	28,07%	42,55%
High School	17,54%	21,28%
Job		
Employed	45,61%	51,06%
Retired	31,58%	6,38%
Housewife	10,53%	17,02%
Unemployed	12,28%	25,54%
Professional Status		
Employee	52,63%	27,66%
Autonomous	47,37%	72,34%
Birth Place		
São Paulo State	50,88%	27,66%
Other States	47,37%	70,22%
Other country	1,75%	2,12%
Residence		
São Paulo State	98,25%	0%
Other States	1,75%	100%
Monthly Income		
No income	7,03%	21,28%
1 minimum wage	36,84%	23,40%
2-3 minimum wages	40,35%	31,92%
3-6 minimum wages	12,28%	17,02%
6-9 minimum wages	1,75%	4,26%
9-12 minimum wages	1,75%	2,12%

Family Income		
No income	3,51%	
1 minimum wage	26,32%	
2-3 minimum wages	49,12%	
3-6 minimum wages	17,55%	
6-9 minimum wages	1,75%	
9-12 minimum wages	1,75%	
Retired		
Yes	36,84%	38,30%
No	63,16%	61,70%
Own a car		
Yes	22,81%	51,06%
No	77,19%	48,94%
Dependents		
Mean	0,81	1,02
Comorbidities		
Yes	45,61%	44,69%
No	54,39%	55,31%
Use of Meds		
Yes	80,70%	40,43%
No	19,30%	59,57%
Type of tumor		
Breast	27,66%	
GYN or GU	23,40%	
Gastrointestinal	31,91%	
Hematologic	10,64%	
Lung	6,39%	
Clinical Stage		
1	6,98%	
2	20,93%	
3	34,88%	
4	37,21%	
Treatment Status		
Under Treatment	84,21%	
Follow-up	15,79%	

sis significant inverse correlation with younger patient age ($p = 0.0005$, $R^2: 0,1976$) and positive correlation with being under active treatment ($p = 0.016$). We noted as well a tendency to a statistical significance of an association of patients' OPC with the marital status of the patient ($p = 0,07786$) (Table 3). By multivariate analysis, the only statistically significant independent variables that remained in the model were younger age ($p = 0.0079$, $R^2: 0,1059$) and whether or not the patient was on active treatment ($0,0321$, $R^2: 0,0673$).

Regarding the OPC spent by caregivers, we observed a significant inverse association with patient age ($p = 0,0028$,

Table 2. Patients and Caregiver’s costs and time allocation. OPC: out of pocket costs

	Patients	Caregivers
Time (in hours/month)		
Transportation	7,60	9,11
Clinical Visits	2,87	2,67
Chemotherapy and/or Radiotherapy	8,46	11,31
Acquiring Medications	0,67	0,54
Other activities	0,86	0,44
Total	20,48	24,09
Total in R\$	179,62	217,32
Costs (in R\$)		
Transportation	51,18	74,68
Medicines	36,92	7,00
Supplies	0,53	0,64
Food	22,17	13,01
Total	110,80	95,32
Global Costs (OPC) (Time + costs)	290,41	312,65
Monthly Income (Mean)	1340,98	1251,53
Global Costs/ Month Incomes (Mean)	21,60%	25%

R2: 0,1823). We found no other correlations between the total OPC incurred by patients and any of the other patient or caregiver’s variables evaluated (Table 3). By multivariate analysis, both patient age ($p = 0,0079$) and marital status ($p = 0,0321$) remained in the model. We also observed significant correlation between the total OPC incurred by patients with that spent by caregivers ($p = 0.0022$, R2: 0,1903) (Figure 1).

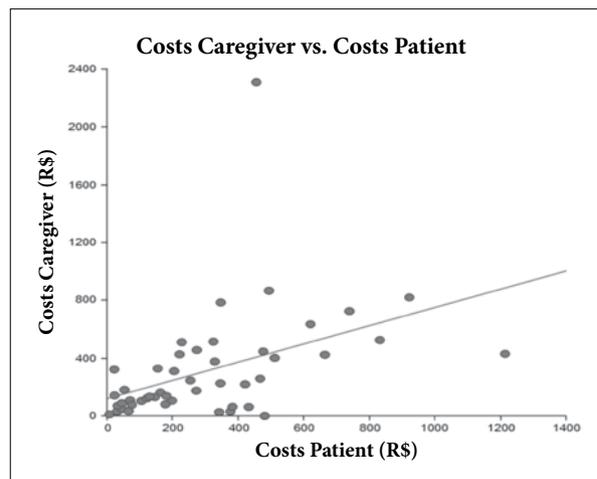


Figure 1. Correlation between Patients and Caregivers’s OPC ($p = 0.0022$, R2: 0,1903).

| Discussion

The total monthly spending on average to a patient in treatment or follow-up for cancer is approximately R\$290,41

Table 3. Univariate analysis of patients and caregivers’ OPC and demographic and clinical variables. OPC: out of pocket costs

Patient Clinical Status	OPC Patients	OPC Caregivers
	Mean ± SD	Mean ± SD
Under treatment	318,25 ± 260,10	318,38 ± 393,10
Follow-up	141,99 ± 158,20	273,48 ± 272,45
<i>p</i>	0,01607	0,97457
Patient’s Marital Status		
Married or living with someone	285,19 ± 238,47	260,92 ± 221,8129
Single	380,80 ± 305,36	435,00 ± 575,5802
Widow	155,81 ± 121,48	225,53 ± 162,5287
<i>p</i>	0,07786	0,85173
Caregiver’s Marital Status		
Married or living with someone		272,68 ± 237,46
Singles		271,67 ± 249,10
Widowers		589,64 ± 861,55
<i>p</i>		0,8482

Patient's Job Status		
Employed	259,29 ± 154,74	233,27 ± 193,07
Retired	112,31 ± 108,95	183,82 ± 112,73
Housewife	250,87 ± 157,58	349,56 ± 279,29
Unemployed	369,04 ± 322,69	382,38 ± 504,79
<i>p</i>	0,11162	0,73114
Caregiver's Job status		
Employed		943,32 ± 1200,22
Retired		238,37 ± 233,01
Housewife		221,91 ± 244,38
Unemployed		301,20 ± 241,18
<i>p</i>		0,55242
Comorbidities		
None	329,60 ± 304,21	361,32 ± 473,56
Diabetes	494,29	866,95
Hypertension	222,64 ± 184,04	267,38 ± 197,32
Dyslipidemia	316,61 ± 145,20	
Others	215,80 ± 163,12	117,23 ± 108,202
Hypertension + Dyslipidemia	324,49	514,76
Hypertension + Diabetes	231,68 ± 204,11	161,66 ± 84,22
<i>p</i>	0,81991	0,2045
Patient's Dependents		
0	236,18 ± 228,26	296,29 ± 428,04
1	343,86 ± 253,58	297,69 ± 258,57
2	269,65 ± 309,35	635,16
3	608,54 ± 123,30	341,07 ± 117,00
4	383,50 ± 404,67	263,032 ± 231,60
5	467,59 ± 384,18	725,7492
<i>p</i>	0,12027	0,42012
Caregiver's dependents		
0		264,84 ± 221,52
1		383,80 ± 690,29
2		258,33
3		342,60 ± 298,39
4		108,16
5		785,63
<i>p</i>		0,67744
Use of Medications by Caregiver		
No		343,70 ± 454,93
Yes		266,89 ± 224,60
<i>p</i>		0,9309
Use of Medications by Patient		
No	274,37 ± 179,50	260,74 ± 262,67
Yes	294,25 ± 270,37	323,30 ± 399,13
<i>p</i>	0,85559	0,69189

Patient Family Incomes expressed in multiples of minimum wage		
0	197,32 ± 179,84	
1	316,14 ± 224,63	311,46 ± 287,51
1 to 3	281,77 ± 224,63	312,74 ± 184,85
3 to 6	239,38 ± 179,16	248,59 ± 260,64
6 to 9	922,01 ±	420,06 ± 720,53
> 9	211,55 ±	820,72
<i>p</i>	0,56791	0,38954
Patient monthly Incomes expressed in multiples of minimum wage		
0	180,54 ± 106,62	223,01 ± 194,92
1	339,61 ± 288,10	
1 to 3	254,94 ± 232,16	315,30 ± 215,45
3 to 6	243,23 ± 176,39	232,28 ± 254,71
6 to 9	922,01	520,92 ± 882,02
> 9	211,55	820,72
<i>p</i>	0,47328	0,3564
Patient's Birth Place		
São Paulo (SP)	195,74 ± 146,27	159,99 ± 160,67
São Bernardo do Campo	314,33 ± 303,74	319,34 ± 219,43
São Caetano do Sul	817,68 ± 560,41	324,68 ± 149,30
Santo André	328,91 ± 164,74	942,94 ± 1200,64
Other states	273,86 ± 239,85	298,91 ± 270,10
Other countries	346,03	225,82
State of São Paulo	281,70 ± 274,12	279,65 ± 265,56
<i>p</i>	0,50858	0,72388
Patient's residence		
São Paulo (SP)		
São Bernardo do Campo		317,83 ± 452,54
São Caetano do Sul		147,21 ± 23,08
Santo André		443,17 ± 228,15
Other states		785,63
Other countries		
State of São Paulo		215,82 ± 221,99
<i>p</i>		0,144
Caregiver's birth place		
São Paulo (SP)		225,99 ± 165,23
São Bernardo do Campo		567,23 ± 719,84
São Caetano do Sul		147,21 ± 23,08
Santo André		175,28 ± 127,55
Other states		354,17 ± 283,96
Other countries		133,64
State of São Paulo		203,93 ± 192,02
<i>p</i>		0,87376
Caregiver's residence		
São Paulo (SP)		
São Bernardo do Campo		248,23 ± 215,71
São Caetano do Sul		147,21 ± 23,08
Santo André		415,61 ± 254,99
Other states		
Other countries		
State of São Paulo		395,23 ± 606,24
<i>p</i>		0,42712

Patient's race		
White	274,17 ± 226,25	302,38 ± 456,17
Non-white	316,26 ± 296,88	326,52 ± 245,56
<i>p</i>	0,83125	0,3017
Caregiver's race		
White		257,82 ± 218,83
Non-white		409,41 ± 554,79
<i>p</i>		0,72315
Patient's schooling		
No school	215,53 ± 166,03	331,50 ± 144,44
Unfinished elementary school	236,99 ± 226,82	271,23 ± 262,79
Finished elementary school	169,95 ± 135,72	160,55 ± 131,67
Unfinished High School	313,70 ± 226,82	74,38 ± 68,12
Finished High School	451,20 ± 321,99	349,53 ± 228,21
Unfinished College	93,27 ± 98,83	153,06 ± 14,80
Finished College	366,43 ± 287,48	540,47 ± 827,04
<i>p</i>	0,15871	0,58061
Caregiver's Schooling		
No school		785,63
Unfinished elementary school		310,45 ± 323,78
Finished elementary school		251,09 ± 133,17
Unfinished High School		155,89 ± 163,72
Finished High School		309,11 ± 253,90
Unfinished College		76,45 ± 41,96
Finished College		480,95 ± 753,84
<i>p</i>		0,44362
Patient's Gender		
Male	235,64 ± 177,70	378,28 ± 557,07
Female	324,84 ± 289,25	275,46 ± 226,11
<i>p</i>	0,44105	0,92943
Caregiver's Gender		
Male		363,21 ± 277,43
Female		281,27 ± 430,11
<i>p</i>		0,09627
Clinical Stage		
1	214,85 ± 228,33	302,85 ± 38,67
2	259,24 ± 233,94	419,87 ± 836,33
3	320,52 ± 254,67	375,21 ± 296,63
4	314,97 ± 220,58	282,39 ± 232,90
<i>p</i>	0,72553	0,41473
Type of Tumor		
Breast	266,38 ± 259,35	222,63 ± 255,73
Gyn and GU	362,34 ± 234,55	597,19 ± 686,46
GastroIntestinal	294,52 ± 216,96	244,05 ± 171,73
Hematologic	195,07 ± 212,37	374,71 ± 437,24
Lung	160,05 ± 98,28	289,16 ± 232,52
<i>p</i>	0,46154	0,37826

per month and R\$312,65 for your caregivers. For a population with an average family income of two times the minimum wage salary (R\$1,576), this represents a high impact to their personal financial organization. This situation makes difficult for patients to meet treatment OPC and simultaneously fulfill their other financial obligations resulting in stress^{5,6}. Also, financial stress can adversely impact on the quality of life of patients and their caregivers. Additionally, OPC can lead patients do not adhere properly to their treatment with possibly harmful consequences for their anti-tumor treatment^{7,8}.

In our study, we found that younger patients had higher total OPC than older patients. In this line of research, interesting results were reported by Timmons and colleagues⁶. These authors undertook several interviews with cancer patients and social workers. In this study, the authors reported that patients more susceptible to financial difficulties were those very old or young, actively employed at diagnosis, with low social support and little savings.

In our study, we also noted that caregivers of patients under active treatment as well as patients who received active treatment had more OPC as compared with patients in follow-up and their caregivers. We believe that this finding reflects a greater intensity of care given to patients on active treatment, including transportation and time needed to go to more frequent doctor visits, more need for medications and other supplies.

Another interesting finding is the significant correlation we found between OPC of caregivers and patients. Interestingly, we found no significant correlations between any of the demographic or clinical variables of patients with OPC incurred by their caregivers. Perhaps there is some form of financial aid between caregivers and patients with higher expenses, but our study did not investigate this possibility.

The most striking finding in our study, however, was the high percentage represented by OPC in relation to the average wages received by patients (21%) and caregivers (25%). In agreement with our study, Mahal and colleagues evaluated⁹ several cancer patients' households in India and found that these families spent 36 to 44% of their annual income on the care of these patients. Furthermore, Zafar reported that ⁷ for 42% of insured cancer patients, OPC were deemed substantial. Given the low income of the population we studied, consideration of expenses not covered

by the Brazilian Public Health System for cancer patients is of fundamental importance.

The main limitation of this pilot study is its small sample size. Future larger studies should be conducted to better describe OPCs in our cancer population.

We conclude that the OPC related to the treatment of cancer account for substantial part of the salaries commonly paid to cancer patients and their caregivers. For patients, these costs are more pronounced in the younger and those under active treatment. These data should serve to alert policy-makers to formulate health policies that help patients and caregivers defray uncovered costs involved in cancer treatment.

| Disclosures

None.

Zaremba, G. *et al.* Out-of-pocket costs for cancer patients treated at the Brazilian public health system (SUS) and for their caregivers: A pilot study. **Clinical Oncology Letters**. 2016;2(1):23-30.

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