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ORIGINAL ARTICLE

Out-of-pocket-payments and the financial burden of 502 cancer patients of working age in Germany: results from a longitudinal study

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Abstract

Purpose Cancer patients in Germany often face payments related to their disease or treatment which are not covered by their health insurance. The aim of this study was to analyze the amount of out-of-pocket payments (OOPPs) among cancer patients in Germany, to explore potential socioeconomic determinants of OOPPs, and to identify how cancer patients are burdened by these payments.

Methods Cancer ptients were consecutively enrolled in 16 clinics in Leipzig, Germany. Data on OOPPs for the past 3 months and on socioeconomic status were obtained at the end of their hospital stay (t0) and 3 (t1) and 15 months (t2) after t0. Financial burden was calculated by dividing the monthly OOPPs by the midpoint of the income category, and the perceived burden was assessed by using the financial difficulties scale of the EORTC QLQ-C30. A two-part regression model was used to estimate the determinants of OOPPs.

Results At baseline (t0), 502 cancer patients participated in the study and provided data on OOPPs and socioeconomic status. The mean 3-month OOPPs were the following: €205.8 at baseline, €179.2 at t1, and €148.1 at t2. Compared to the lowest income group (< €500 monthly), all other income groups (€500–999, €1000–1499, and ≥ €1500) had higher 3-month OOPPs of €52.3 ($p = 0.241$), €90.2 ($p = 0.059$), or €62.2 ($p = 0.176$). Financial burden at t0 was 6.4% (SD 9.2%) on average, 5.4% (SD 9.9%) at t1, and to 3.9% (SD 7.0%) of monthly income at t2.

Conclusion German cancer patients face relatively high OOPPs during their cancer journey. These payments may burden cancer patients, especially certain subgroups like low-income groups.

Keywords Out-of-pocket-payments · Cancer · Financial burden · Germany · Financial toxicity

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Introduction

The estimated cost for cancer care in the EU in 2014 was €83.2 billion [1], an estimate that only includes costs borne by the social systems. Direct private health expenditures made by cancer patients, so called out-of-pocket-payments (OOPPs), were not included. OOPPs are used in the health care system mainly for three reasons. First, to give financial relief to the social security systems by having patients pay for certain medical services themselves [2]. Secondly, to raise the efficiency of medical services by allocating them only to medically justified cases [3]. Third, to reduce the risk of "moral hazard," which occurs when individuals access health services without medical necessity only because they do not have to pay for it [4, 5]. On the downside, studies have shown that OOPPs may cause inequalities in the use of health care services [6] and may burden certain subgroups to different

degrees [7, 8]. Additionally, OOPPs carry the risk of preventing patients from using beneficial medical services or treatments because they might not be affordable for certain subgroups [9]. There is a certain risk that cancer patients change their adherence to the treatment plan by rationing medication, choosing more radical treatments, or skipping follow-up examinations in order to reduce their OOPPs [10, 11].

In the German health care system, around 87% of the German population is insured under statutory health insurance, while 10% have private health insurance and 3% are insured in other ways. All patients in Germany, independent of their form of insurance, are entitled to medical services, including in- and outpatient services and access to pharmaceuticals. Despite these services provided by the health insurance companies, three types of OOPPs exist. First, there are direct payments for health services or treatments which are not covered by health insurance and need to be paid by the patients themselves. Secondly, deductibles need to be paid by the patient before the insurance company steps in. Third, there are additional payments when a certain threshold, up to which the health insurance pays, is reached [12]. During the time of this study, certain regulatory affairs regarding OOPPs in Germany were in place. These regulations are described elsewhere [13].Arsenijevic et al. estimated that 12% of total health expenditure in Germany is covered by OOPPs [14]. Even though OOPPs may vary between certain types of health insurance, nearly all cancer patients in Germany use health care services (e.g., medical aids or non-medical treatments) that are not fully covered by their health insurance; therefore, OOPPs occur for most of the cancer patients in Germany.

Only a few studies have investigated the OOPPs of cancer patients in Europe. Most of the studies have been performed in the USA or in Canada and have shown high OOPPs for cancer patients [15]. These studies are not comparable to the German health care system due to the fact that those systems entail high direct payments by the patients or they have a high share of private health insurance. Studies on OOPPs in cancer patients in Europe, especially in countries with a health system similar to Germany, are rare.

Financial burden which can be measured by OOPPs and related income might not only burden patients on an economic basis; it may also influence the psychological well-being by being financially burdened. The term financial toxicity has been used to describe the financial and psychological burden perceived by cancer patients [16].

Therefore, this study aims to determine the OOPPs of cancer patients in Germany throughout their treatment course. Additionally, the distribution of OOPPs across health care sectors is investigated to gain insights on where the OOPPs arise. Also, socioeconomic and demographic determinants that influence the level of OOPPs are investigated. Finally, the economic burden of cancer patients due to OOPPs is analyzed as well as how the patients perceive this burden.

Methods

Design

Data were collected from cancer patients who were consecutively admitted in 16 clinics in Leipzig, Germany, between April 2007 and October 2009. Participants were interviewed in hospitals and in rehabilitation clinics ranging from university hospitals to small institutions, representing the whole range of levels of care. Patients were included if (1) they had been diagnosed with cancer, (2) the treatment intention was curative, (3) they were between 18 and 55 years of age, (4) they had adequate German proficiency, and (5) they gave written informed consent. Exclusion criteria were recurrent or metastatic disease and age over 55 years. The primary endpoint of the original study was return to work of cancer patients, and therefore the upper age margin was set to 55 years and only patients with curative treatment were included, since palliative patients often do not return to work after treatment. The study was a prospective cohort study using a longitudinal design with three time points. More details about the study design and rationale can be found elsewhere [17, 18].

Data on OOPPs by the participants were obtained at three time points: at the end of their hospital stay (t0), with follow-up 3 (t1), and 15 (t2) months after t0. Patients could be enrolled at t0 even if follow-up could not be completed. Therefore, a higher number of observations were obtained at t0 than at t1 and t2. Trained interviewers using standardized questionnaires performed data collection in the study.

Assessments

Data on OOPPs were obtained by using a questionnaire enquiring about the past 3 months. Patients were asked to state the amount of OOPPs paid and the reason for paying the OOPPs in six categories: (1) hospital stays, (2) rehabilitation stays, (3) non-medical treatments, (4) medical aids, (5) transportation, and (6) other services. Non-medical treatments were defined as outpatient services which are not provided by a physician, such as physiotherapy, massages, or speech therapy. Medical aids covered supportive products such as wheelchairs, support stockings, or glasses, but dental prosthesis were also included in this category. Payments for medical aids should only be stated if they were acquired outside of hospital or rehabilitation stays. OOPPs for transportation included OOPPs for the use of cars, taxis, trains, and busses if they were needed in the context of cancer treatment, rehabilitation, or aftercare. OOPPs for private car transportation were calculated assuming €0.30 per kilometer, in accordance with German legislation [19]. Other services included payments for self-help groups or domestic aids.

The following socioeconomic and sociodemographic variables were obtained and used in the analysis: age, sex,

education, health insurance, living condition, and income. Education was categorized into less than 10 years of schooling, 10 years of schooling, and more than 10 years of schooling. Patients were insured by social health insurance (SHI) or private health insurance (PHI), with the SHI representing the main type of insurance in Germany. Living with a partner, living alone, or other living conditions were the distinctions in the living conditions variable. Participants were asked to state their monthly total net household income within one of the eight following categories: below €500, €500 to < €1000, €1000 to < €1500, €1500 to < €2000, €2000 to < €2500, €2500 to < €3000 to < €3500 and over €3500. To adjust for household size, the OECD-modified equivalence scale [20] was used, resulting in four income categories used in the analysis: below €500, €500 to €999, €1000 to €1499, and over €1500. These categories were chosen so that adequate numbers of patients for each income category were available.

As an additional tool for assessing whether the cancer diagnosis resulted in financial problems, the *financial difficulties scale* from the Quality of Life questionnaire of the European Organization for Research and Treatment of Cancer, the EORTC QLQ-C30 [21] was used. This 1-item scale measures whether the physical conditions or the medical treatment of the cancer patient has caused any financial difficulties within the last week using a four-point Likert scale ("not at all," "a little," "quite a bit," and "very much"). The answers are summed up to a scale ranging from 0 to 100, with high values indicating a high financial burden perceived by the patient in accordance with the scoring manual of the EORTC [22].

Statistical analysis

Patient characteristics were expressed as mean or percentage values as appropriate. Total OOPPs were calculated by summarizing the OOPPs of each category. If a participant did not mention any OOPPs for a category or left out the question, it was assumed that no OOPPs occurred in that category for this participant. This assumption is justified since the interview was performed by trained interviewers which asked the patients every question of the questionnaire.

Univariate analysis for OOPPs and socioeconomic and sociodemographic variables was performed according to the distribution of the data. A two-part regression model was used to estimate predictors of OOPPs at t0: First, a logistic regression model was applied to calculate the probability of having any OOPPs. The second part used a generalized linear model with a gamma distribution and log link function to calculate the expected individual levels of OOPPs for positive OOPPs [23]. To determine a combined predictor for OOPPs from both models, predictive margins were used [24]; this approach is recommended for highly skewed data with a high number of zeros, which is common in cost data. To identify the average monthly burden of OOPPs for the participant, the share of monthly income spent on OOPPs per month was calculated. For this, the ratio of the middle monthly income category (OECD equivalence scale) and monthly OOPPs (3-month OOPPs divided by three) was used. The financial difficulties scale was calculated according the scoring manual of the EORTC QLQ-C30 [23]. All statistical analyses were performed using R (R version 3.2.4, R Foundation for statistical computing).

Results

Sample

For the baseline (t0) assessment, data on OOPPs and socioeconomic and sociodemographic status were obtained for 502 individuals. At the first follow-up (t1), 3 months after baseline, data from 416 participants (82.9%) were available. Seventy individuals (13.9%) withdrew their consent, and 16 individuals (3.2%) could not provide any more data because the study had ended. At t2 (15 months after baseline), 218 individuals (43.4% compared to baseline) provided data, while 61 individuals (12.2%) withdrew consent or had died and 223 individuals (44.4%) were unavailable to be interviewed because the study had ended.

Patient characteristics

Of the 502 participants at baseline, 234 (46.6%) were female and 170 (33.9%) were younger than 45 years old (mean, 45.9 years; SD, 8.0; range, 19–57). Other sociodemographic and medical characteristics are presented in Table 1. There were no significant differences in patient characteristics between baseline and t1, or t2 (Table 1).

3-month OOPP

The mean 3-month OOPP was €205.8 (SD €346.9; median €153.9) at t0. At t1, it was €180.0 (SD, €346.7; median, €104.3) and €148.1 (SD, €228.4; median, 42.35) at t2.

At t0, 46.3% (t1 14.8% and t2 1.4%) of the OOPPs were connected to hospital stays, 0.6% (t1 2.8% and t2 9.5%) for rehabilitation stays, 1.2% (t1 8.0% and t2 8.0%) for non-medical treatments, 12.7% (t1 15.9% and t2 38.7%) for medical aids, 38.9% (t1 58.1% and t2 41.3%) for transportation, and 0.4% (t1 0.7% and t2: 1.1%) for other services.

Out-of-pocket-payments and income

Higher total OOPPs were associated with higher income at all three time points (Table 2). At t0, transportation costs were significantly higher for the high income groups

Table 1 Sample characteristics at baseline, t1, and t2

Characteristic	t0 baseline ($n = 502$)		t1 (3 months after baseline) ($n = 416$)		t2 (15 months after baseline) ($n = 218$)	
	n	%	*n*	%	*n*	%
Age						
< 45 years	170	33.9	133	32.0	70	32.1
≥ 45 years	332	66.1	193	68.0	148	67.9
Sex						
Male	268	53.4	223	53.6	114	52.3
Female	234	46.6	193	46.4	104	47.7
Tumor site						
Prostate	87	17.3	81	19.5	51	23.4
Breast	79	15.7	66	15.9	25	11.5
Cervix	79	15.7	65	15.6	41	18.8
Head and neck	72	14.3	52	12.5	22	10.1
Gastro-intestinal malignancy	44	8.8	34	8.2	17	7.8
Other uro-genital malignancy	37	7.4	33	7.9	14	6.4
Testicles	29	5.8	22	5.3	8	3.7
Other gynecological malignancy	24	4.8	19	4.6	14	6.4
Lung	21	4.2	17	4.1	6	2.8
Other	30	6.0	27	6.5	20	9.2
Income*						
< €500	33	6.6	23	5.5	12	5.5
€500 to €999	134	26.7	108	26.0	63	28.9
€1000 to €1499	129	25.7	116	27.9	49	22.5
> €1500	182	36.3	151	36.3	87	39.9
Missing	24	4.8	18	4.3	7	3.2
Education						
< 10 years of school	53	10.6	42	10.1	23	10.6
10 years of school	315	62.7	266	63.9	144	66.1
> 10 years of school	128	25.5	105	25.2	50	22.9
Missing	6	1.2	3	0.7	1	0.5
Living situation						
Alone	111	22.1	87	20.9	34	15.6
With partner	371	73.9	317	76.2	176	80.7
Other	19	3.8	11	2.6	7	3.2
Missing	1	0.2	1	0.2	1	0.5
Health insurance						
Social health insurance	437	87.1	363	87.3	199	91.3
Private health insurance	52	10.4	45	10.8	15	6.9
Other	7	1.4	4	1.0	2	0.9
Missing	6	1.2	4	1.0	2	0.9

All p values for the characteristics (baseline vs. t1 and baseline vs. t2) were > 0.05

*Monthly income per person according to the OECD modified equivalence scale

(€44.7 vs. €78.7 vs. €78.0 vs. €88.6; $p = 0.004$). At t1 (€2.1 vs. €15.5 vs. €11.9 vs. €51.0; $p = 0.047$) and at t2 (€6.8 vs. €17.5 vs. €44.3 vs. €89.9; $p = 0.012$) medical aids showed the most relevant differences among the OOPPs sectors. There were no significant differences in total OOPPs by gender and age. Women reported a mean total OOPP of €190.5 compared to men with €219.2 ($p = 0.332$) at t0, €164.5 vs. €193.4 ($p = 0.386$) at t1, and €175.7 vs. €123.0 ($p = 0.206$) at t2. The older age group, which is 45 years and older, had higher OOPPs at all three time points although these differences were not statistically significant, with €218.2 vs. €181.6 ($p = 0.145$) at t0,

Table 2 Mean 3-month OOPPs (out-of-pocket-payments) stratified by income (monthly income (OECD equivalence scale) categories for sectors of OOPPs (out-of-pocket-payments)

	t0 (baseline)					t1 (3 months after t0)					t2 (15 months after t0)				
	< €500 (n = 33)	€500 to €999 (n = 134)	€1000 to €1499 (n = 129)	> €1500 (n = 182)	p value	< €500 (n = 23)	€500 to €999 (n = 108)	€1000 to €1499 (n = 116)	> €1500 (n = 151)	p value	< €500 (n = 12)	€500 to €999 (n = 63)	€1000 to €1499 (n = 49)	> €1500 (n = 87)	p value
Hospital stays	79.7[a] (87.1)	87.7 (85.9)	102.0 (74.5)	102.7 (241.7)	0.098	21.3 (41.6)	19.4 (56.7)	23.0 (54.8)	33.6 (246.4)	0.403	0	5.4 (29.5)	0	1.3 (8.3)	0.384
Rehabilitation stays	0	0	0	3.3 (44.1)	0.653	0	0.6 (4.8)	6.2 (25.1)	7.4 (27.4)	0.033	0	3.3 (26.5)	18.6 (63.5)	22.6 (68.2)	0.137
Non-medical treatments	0	3.0 (10.5)	2.8 (11.4)	1.8 (7.0)	0.331	0.8 (3.8)	3.3 (15.1)	6.8 (18.8)	31.3 (208.5)	< 0.001	6.1 (21.1)	3.3 (15.3)	8.8 (23.9)	17.0 (52.2)	0.034
Medical aids	4.9 (16.0)	9.7 (39.5)	42.4 (214.1)	29.3 (238.8)	0.933	2.1 (7.3)	15.5 (67.2)	11.9 (38.5)	51.0 (337.1)	0.047	6.8 (16.3)	17.5 (104.4)	44.3 (253.1)	89.9 (340.5)	0.012
Transportation	44.7 (63.6)	78.7 (108.0)	78.0 (88.0)	88.6 (118.6)	0.004	79.2 (133.0)	111.6 (231.2)	97.6 (117.8)	107.7 (130.8)	0.061	30.0 (32.9)	53.4 (77.8)	66.5 (144.7)	65.9 (104.8)	0.616
Other services	0	2.8 (32.8)	0.7 (8.1)	0	0.651	0	3.8 (37.1)	0	1.0 (8.6)	0.505	0	0	0	4.0 (37.5)	0.701
Total OOPPs	129.3 (117.0)	181.9 (152.8)	226.0 (245.3)	225.7 (506.8)	0.016	102.0 (141.6)	152.1 (252.4)	144.9 (133.2)	232.1 (508.6)	0.003	42.9 (38.8)	82.9 (137.8)	138.2 (300.5)	200.8 (376.9)	0.09

SD standard deviation

[a] Mean 3-month OOPPs (SD)

€193.6 vs. €148.5 (p = 0.108) at t1, and €156.3 vs. €130.9 (p = 0.492).

The results of the two-part regression model are displayed in Table 3. The model shows a positive effect of higher income in relationship to OOPPs. Compared with the lowest income group, the other income groups had additional OOPPs of €52.3 (p = 0.241), €90.2 (p = 0.059), and €62.2 (p = 0.176) at t0. All other included variables showed no significant effect on OOPPs.

Financial burden of German cancer patients

Financial burden (monthly OOPPs divided by the midpoint of income category) at t0 was 6.4% (SD 9.2%) on average, ranging from 0 to 128%, showing that there are patients where the monthly OOPPs exceeded their monthly income. At t1, the average financial burden decreased to 5.4% (SD, 9.9%, range, 0 to 79.6%) and to 3.9% (SD, 7.0%, range, 0 to 48.5%) at t2.

To evaluate how the patients perceived their financial burden, the financial difficulties scale of the EORTC QLQ-C30 was used. At t0, 21% (99 of 472 respondents) stated that their physical state or medical treatment had caused financial difficulties within the last week "very much" or "quite a bit". A total of 40.1% (140 of 349) at t1 and 30.6% (57 of 186) at t2 experienced financial difficulties on a high level. Lower income groups (< €1000) more often perceive their financial difficulties as burdensome: For the group with a net income below €1000 per month, 26.8% reported "very much" or "quite a lot" of perceived financial difficulties at t0, 59.1% at t1, and 50% at t2. In the income group over €1000, the corresponding proportions are 17.9% (t0), 31.4% (t1), and 20.5% (t2).

Discussion

This study set out to estimate the 3-month OOPPs paid by cancer patients in Germany throughout their course of treatment and to identify sectors and predictors that influence the amount of OOPPs paid. At the end of the hospital stay, almost all participants (97.8%) reported some kind of OOPP. OOPPs for transportation and medical aids had the highest share of total OOPPs, with the exception of t0, where OOPPs for hospital stays also showed a high share. The relatively high amount of OOPPs for hospital stays at the end of treatment may explain why OOPPs at baseline were the highest of all three time points. Patients with higher income had higher OOPPs compared to the lowest income group. In concordance with the reduction in OOPPs over time, the financial burden for all patients dropped from 6.4% at the end of their hospital stay to 5.4% 3 months later, and 15 months after the hospitalization, it was 3.9% of monthly income.

Table 3 Two-part regression model with OOPPs (out-of-pocket-payments) as the dependent variable

Independent variables (Reference)	Logistic regression model[1]		Generalized linear model[2,a]		Combined predictor[3]	
	Logit OR [CI]	*p* value	GLM [CI]	*p* value	Predict. Margin [CI]	*p* value
Constant			4.80 [4.17; 5.42]	< 0.001		
Female gender (male)	0.55 [− 1.27; 2.37]	0.554	− 0.10 [− 0.37; 0.16]	0.450	− 20.5 [− 75.28; 34.38]	0.465
Age 45 years and older (< 45 years)	- 1.33 [− 3.63; 0.97]	0.256	0.13 [− 0.14; 0.40]	0.336	24.7 [− 29.32; 78.77]	0.370
Education (< 10 years of schooling)						
10 years of schooling	− 0.49 [− 2.91;1.93]	0.693	0.40 [− 0.39;0.46]	0.855	6.7 [− 73.57;86.93]	0.870
> 10 years of schooling	− 0.42 [− 3.57;2.73]	0.794	0.28 [− 0.20;0.76]	0.259	59.3 [− 41.03;159.62]	0.247
Income (< €500)						
€500 to €999	2.62 [0.23; 5.01]	0.031	0.22 [− 0.33; 0.77]	0.441	52.3 [− 35.20; 139.82]	0.241
€1000 to €1499	2.58 [0.10; 5.05]	0.041	0.39 [−0.16; 0.95]	0.166	90.2 [− 3.28; 183.72]	0.059
≥ €1500	3.01 [0.33; 5.69]	0.027	0.26 [− 0.30; 0.83]	0.361	62.2 [− 27.98; 142.46]	0.176
Living with partner (living alone)	0.51 [− 1.34; 2.36]	0.587	0.16 [− 0.15; 0.47]	0.309	33.1 [− 25.98; 92.15]	0.272

[1] log OR for having any OOPPs

[2] GLM for positive OOPPs

[3] Combined expected effect

[a] Generalized linear model with log link and gamma distribution

Out-of-pocket-payments

Comparing OOPPs in cancer patients across countries is difficult due to different health insurance systems and the definition of OOPPs. Two studies among cancer patients have been performed in countries with health care system similar to Germany's. In Italy, Baili et al. [25] found that cancer survivors at 5 to 10 years post-diagnosis had mean monthly OOPPs of 160€, with large differences between the north (mean, €69; SD, €157.1) and the south (mean, €244.1; SD, €480.2) of the country. An Irish study reported [25] mean yearly OOPPs of €1589 (SD, €3827) for colorectal cancer survivors. To date, most of the studies related to OOPPs in cancer patients have been conducted in the USA and Canada. In Canada and the USA, cancer patients report higher OOPPs due to the health care systems, which are built on more self-payments by the patient. Longo et al. [27] found mean monthly OOPPs of CA$392.6 (SD, CA$830.1) and travel costs of CA$225.2 (SD, CA$387.7) for Canadian breast cancer patients and CA$149.5 (SD, CA$265.8) and travel costs of CA$ 426.3 (SD, CA$771.6) for other cancer types. A US study [28] reported OOPPs per month of US$232.7 at the end of primary breast cancer treatment. In Germany, Bock et al. [13] and Hajek et al. [29] assessed the OOPPs of patients over 65 years of age. For 3124 individuals aged 65 and older, the mean 3-month OOPPs were €119, and 3 years later, they amounted to €135, indicating that cancer patients at working age, as in our study, in Germany have higher 3-month OOPPs compared to an older age group.

In addition to the differences in the health care systems, the differences in OOPPs may be explained by several factors. First, the composition of OOPPs was different throughout the studies. In our study, as well as in Baili's [25] and Longo's [27], transportation was responsible for a high share of the OOPPs. Unfortunately, this was not assessed in the other studies as part of OOPPs. Baili et al. [25] found that transportation was the main reason for the differences in OOPPs between north and south Italy, with higher transportation OOPPs in southern Italian regions due to a paucity of oncological services. In our study, no information was available on whether the participant lived in a rural or urban area, but transportation did have one of the highest shares of all sectors, indicating that there is a possible paucity of oncologic services. Additionally, there was no information on medication for OOPPs in our analysis, which is clearly a limitation. Bock et al. [13] reported €25.60 for mean 3-month OOPPs for medication. In other studies [25, 27], medication or pharmaceuticals also had an essential share of OOPPs, which may explain the differences in OOPPs between the studies. Secondly, patients' income may be an influencing factor on the amount of OOPPs paid. Our study is in concordance with other studies showing that higher income leads to a higher amount of OOPPs [15]. This may be due to the fact that patients with a higher income have a higher willingness to pay for certain health services [30]. Also, higher income groups can use services that are not covered by the health insurance more often than patients from lower income groups [31]. Thirdly, other sociodemographic or health-related factors can influence the amount of OOPPs made. Studies have shown that age, gender, and education were associated with the amount of OOPPs paid [15]. These results could not be confirmed by our study, where no significant differences in these

subgroups were found. Cheillair et al. [26] found an association between OOPPs and cancer stage, with a higher cancer stage resulting in higher OOPPs. This result could not be verified by our analysis due to too many missing data in the cancer stage variable, which is another limitation of our study.

Financial burden

The average monthly financial burden was relatively modest for the cancer patients at all three time points. These results are in line with studies in cancer and non-cancer populations [13, 28, 31]. However, looking only at the average monthly burden does not describe the problem adequately. First, relatives or friends often cover services like household help and nursing care; these forms of help are not OOPPs but may burden the relatives and/or the patient. A study by Giorgi Rossi et al. [32] looking at end stage cancer patients revealed that almost half (44%) of the non-professional caregivers declared that it was very difficult to manage their regular employment and the care for the cancer patient. The family also often had to pay for services used by the patient, costs which are not accounted for in the patients' OOPPs. Secondly, it is important to understand how patients perceive this burden. In our study, especially the low income groups perceived the financial difficulties as burdening. A study investigating the financial burden among colorectal cancer patients showed that 94.2% at diagnosis stage and 86.2% 6 months post-diagnosis perceived their OOPPs as at least somewhat difficult [33]. This perceived burden or negative economic well-being is now referred to as another side effect of cancer treatment called "financial toxicity" [34, 35].

Limitations and strengths

A limitation of this study is that no information on medication OOPPs was available, so the OOPPs are underestimated. Unfortunately, there was not sufficient information on cancer stage, and it therefore could not be included in our analysis. Due to the setting of the original study, age was restricted to the working population. Elderly patients may have due to retirement a reduced income so therefore the low income group may be bigger and even more patients may be affected by the financial burden. Another limitation is that data was obtained 10 years ago and changes in the health care system have occurred. Since OOPPS in Germany are increasing within the last years [36] cancer patients may face even higher OOPPs today than reported here. Nevertheless, this is the only study reporting OOPPs of cancer patients in Germany until now. Also the EORTC QLQ-C30 time frame for obtaining the financial difficulties is the week before but OOPPs were calculated for the last 3 months. A strength of the study is its baseline sample size and the availability of follow-up data. The follow-up time points allowed for analyzing OOPPs from before the start of the primary treatment and throughout the rehabilitation process, ending 15 months after the primary treatment.

Conclusion

Almost all cancer patients in Germany experience OOPPs during their cancer journey. These payments are not negligible and may burden cancer patients severely. Transportation costs in particular have a high impact on OOPPs and may might burden patients living in rural areas more than those in urban areas. Also, one needs to consider that OOPPs not only pose a financial burden but also may influence the patients' and their families' well-being. For the German health care system, this means that ideas must be developed on how to support cancer patients so that they can cope better with their OOPPs, with a focus on creating equal burdens and not equal expenses.

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Compliance with ethical standards

Conflict of interest The authors confirm that they have full control of all primary data and agree to allow the journal to review the data if requested.

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