

# How much does it cost to care for survivors of colorectal cancer? Caregiver's time, travel and out-of-pocket costs

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## Abstract

**Purpose** Cancer treatment is increasingly delivered in an outpatient setting. This may entail a considerable economic burden for family members and friends who support patients/survivors. We estimated financial and time costs associated with informal care for colorectal cancer.

**Methods** Two hundred twenty-eight carers of colorectal cancer survivors diagnosed on October 2007–September 2009 were sent a questionnaire. Informal care costs included hospital- and domestic-based foregone caregiver time, travel

expenses and out-of-pocket (OOP) costs during two phases: diagnosis and treatment and ongoing care (previous 30 days). Multiple regression was used to determine cost predictors.

**Results** One hundred fifty-four completed questionnaires were received (response rate=68 %). In the diagnosis and treatment phase, weekly informal care costs per person were: hospital-based costs, incurred by 99 % of carers, mean=€393 (interquartile range (IQR), €131–€541); domestic-based time costs, incurred by 85 %, mean=€609 (IQR, €170–€976); and domestic-based OOP costs, incurred by 68 %, mean=€69 (IQR, €0–€110). Ongoing costs included domestic-based time costs incurred by 66 % (mean=€66; IQR, €0–€594) and domestic-based OOP costs incurred by 52 % (mean=€52; IQR, €0–€64). The approximate average first year informal care cost was €29,842, of which 85 % was time costs, 13 % OOP costs and 2 % travel costs. Significant cost predictors included carer age, disease stage, and survivor age.

**Conclusion** Informal caregiving associated with colorectal cancer entails considerable time and OOP costs. This burden is largely unrecognised by policymakers, service providers and society in general. These types of studies may facilitate health decision-makers in better assessing the consequences of changes in cancer care organisation and delivery.

**Keywords** Colorectal cancer · Informal care · Cost-of-illness · Out-of-pocket costs · Regression

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## Introduction

Colorectal cancer is the third most commonly diagnosed cancer in males and the second most common in females

worldwide [1]. Survival rates have been increasing due to advances in diagnosis and treatment [2] and, in common with other cancers, the treatment model has changed from predominately hospital inpatient-based to a combination of inpatient and outpatient based [3]. In Ireland—as in other developed countries—population ageing together with improved survival has resulted in an increased number of people living with colorectal cancer [4]. For many survivors, colorectal cancer is associated with a significant symptom burden and severe limitations in emotional and social functioning [5, 6]. Consequently, survivors often require intensive supportive care immediately post-treatment, followed by continuing care thereafter [7]. This support and care are often provided by a family member or friend who receives little or no financial compensation; these activities are known as informal care.

The shift in the cancer care model represents a transfer of the costs of delivery of care from the formal (i.e. health service) to the informal setting. Although informal care costs add to the already substantial health service costs engendered by cancer in the Western world [8, 9], they have rarely been quantified. Consequently, the true societal cost of cancer remains poorly understood.

Informal care tasks are multidimensional in nature and may impinge upon the carer's personal time, social activities, physical health, emotional well-being and financial resources. Carers can incur direct out-of-pocket (OOP) expenses for a range of items, including prescription drugs and cancer care supplies, in addition to travel costs to medical appointments [10–14]. Carers also give their time, often many hours per week, to caring activities; this time can be valued, but this has rarely been done [7, 10, 13]. Indeed, accurately estimating the economic impact of informal caring requires combining direct and indirect costs, but few studies have done this, either for cancer or other conditions. Most available studies relating to cancer have focussed on a single dimension of costs (for example, time costs or OOP expenses) [7, 10, 15] or costs at a single time point and/or in a single context/setting (for example those incurred during intense hospital-based activity [11]). A more holistic picture of informal care costs may be obtained by capturing and combining domestic-based time costs with hospital-based time costs and adding these to OOP expenses incurred at different times during the survivorship continuum (for example during the intense treatment period post-diagnosis and afterwards).

The aim of this study was to quantify the total economic cost of informal caring for people with colorectal cancer in Ireland during two phases of the survivorship trajectory—the diagnosis and initial treatment phase and the continuing care phase. In addition to quantifying both direct (OOP and travel) and indirect (time) costs, we identified the key drivers of costs.

## Methods

### Subjects

For this study, an informal carer was defined as a family member or friend who, on the basis of their close personal relationship, provides hospital-based and domestic-based care to recipients without receiving the market equivalent compensation for their activities. The sample of informal carers was derived from a survey of colorectal survivors in Ireland. In spring 2010, survivors with primary, invasive colorectal cancer (ICD-10, C18–C20), diagnosed 6–30 months previously, were identified from the National Cancer Registry, Ireland. Eligible subjects were invited to return a postal questionnaire that asked them to indicate whether a family member, friend or another person had been helping take care of them since their diagnosis and, if so, to provide contact details for that person. Of 495 survivors who responded, 228 provided details of a carer who could be contacted.

### Questionnaire

Details of informal care activities were obtained from carers by means of a postal questionnaire, developed from in-depth interviews with survivors and family members and literature review. The questionnaire collected information on respondents' (carer) socioeconomic and demographic characteristics and their relationship to the survivor (care recipient). Information was collected on time expended and costs incurred on caring activities during two phases: during diagnostic investigations, work-up and initial treatment and up to 3 months post-diagnosis ("diagnosis and treatment" phase) and during the last 30 days before questionnaire completion ("ongoing care" phase). In the diagnosis and treatment phase, information was collected on specified hospital-related caring activities (including travelling, waiting and visiting time during diagnosis, surgery and/or chemotherapy/radiotherapy), hospital-related OOP costs (including parking, meals and accommodation), domestic-related caring activities (extra hours spent on housework (HDL), activities of daily living (ADL), instrumental activities of daily living (IADL) and cancer-specific care [16]) and domestic-related OOP costs (including medications, household expenses and cancer-related items such as home help, private nurse and stoma expenses). Since hospital-related care activities were expected to be relatively infrequent in the ongoing care phase, only details of domestic-related activities and OOP costs were collected during that phase (Details in Online Resource 1).

The draft questionnaire was pre-tested among 20 carers from the study population for face and content validity, acceptability and ease of understanding/completion. No

major alterations were required and so the questionnaires completed during pre-testing were included in the analysis. Surveys were dispatched by post-September 2010–March 2011. Up to two reminders were sent to non-respondents at fortnightly intervals.

### Costing informal care

All costs were valued in 2008 Euro. Costs were categorised by phase of care and type of activity (hospital- or domestic-related). Ongoing care costs were adjusted for inflation using the Irish Consumer Price Index [17]. We recorded a zero cost for blanks left by respondents who reported some cost for any of the cost components in a given section.

OOP costs (excluding travel) were collected for a typical week in each phase. Valuation of travel costs (excluding time) was based on mode of transport used and number of journeys. For car users, we derived costs from miles travelled multiplied by average cost per mile for 2009 (the closest year to the base cost year for which estimates were available), assuming average car use of 10,000 miles/year and tax band C [18]. This cost includes fixed (e.g. insurance, depreciation) and variable components (e.g. petrol, tyres, servicing and repairs). For carers using public transport, we applied the cost for a day return ticket for the journey as reported by provider websites (Bus Éireann, Irish Rail and Dublin Bus). For taxis, cost was apportioned using an official fare calculator ([19]) and the reported distance travelled. Walkers, cyclists and users of hospital minibuses were assumed to incur zero travel costs.

We calculated time costs as the product of the numbers of hours spent on caring activities per week by the gross national hourly average wage in Ireland in quarter three, 2008 (€21.21) [20]. Applying a single wage to estimate time costs ensured that all respondents were treated equally, with no implied assumptions on perceived differences in productivity across different population groups [7]. We imposed a threshold of 16 h/day on care activities as an approximation of waking hours [7]. We calculated an approximate first year informal care cost by multiplying weekly estimates for hospital- and domestic-related time costs in the diagnosis and treatment phase by 13 to yield a 3-month total. Ongoing care weekly costs were multiplied initially by 4.25 to yield a monthly cost and subsequently by 9 to derive a 9-month ongoing care cost. This was added to the 3-month cost total to derive an approximate first year informal care cost. All percentages for a subcomponent of care (e.g. travel expenses) quoted in the results section are expressed as a percentage of the aggregated mean total (not the mean sum totals shown in the tables).

### Statistical analysis

Due to the skewed nature of cost estimates, a range of descriptive statistics was derived, including means per

respondent, standard deviations, medians and interquartile ranges. Multiple regression models were developed for the two phases of care (diagnosis and treatment; ongoing), and for hospital-based and domestic-based direct and indirect costs, to identify significant cost drivers. Univariate regression was undertaken on possible predictors including socio-demographic (e.g. age, gender, education, marital status), economic (e.g. employment status), carer-related (e.g. relationship to the survivor, distance resident from the survivor) and survivor/disease-related (e.g. stage at diagnosis, cancer site, stoma) variables. Those significant at the 5 % level were considered for inclusion in the multiple regression models; those significant at the 5 % level were retained in the final models. Bootstrapped 95 % confidence intervals were estimated using the bias-corrected–accelerated approach and re-sampling the data 1,000 times [21].

## Results

### Respondent characteristics

One hundred fifty-four completed questionnaires were received (response rate=68 %). Carers were predominantly female (82 %; Table 1). Their ages ranged from 21 to 83 and more than 60 % were 55 or over. Nearly three quarters were married to, or cohabiting with, the cancer survivor and lived with them. Just under half of carers were working. Slightly more than half of the survivors had colon cancer, and half had been diagnosed with more advanced disease (stage 3/4)

### Caregiver costs by phase of care

#### *Diagnosis and treatment phase: hospital-related activities and costs*

Almost all carers (99 %) incurred hospital-related costs in the diagnosis and treatment phase (Table 2). The mean weekly cost, across all subjects, was €393 (Table 2). Time costs represented 69 % of the total cost. Time costs included waiting and visiting (mean €186; 42 % of total cost) and travel time (€113; 26 %). In terms of direct costs, carers expended similar amounts on OOP costs (€79; 18 % of total costs) and travel expenses (€59; 14 %)

Costs related to surgery, reported by 98 % of carers, accounted for more than half of the cost burden associated with hospital-related activities in this phase (mean total cost, €206). Sixty-one percent reported chemotherapy costs (mean, €101). Although almost 90 % reported costs associated with diagnostic tests and investigations, the average total cost was relatively small (€45).

**Table 1** Summary of socio-demographic and economic characteristics of caregivers and colorectal cancer survivors

Characteristic	Number (154)	Percentage
<b>Caregivers</b>		
Gender		
Male	28	18.2
Female	126	81.8
Age		
<55	52	33.8
55–64	46	29.9
≥65	52	33.8
Not reported	4	2.6
Relationship to the patient		
Spouse or cohabiting partner	112	72.7
Other <sup>a</sup>	42	27.3
Living with the patient		
Yes	113	73.4
No	36	23.4
Not reported	5	3.2
Education		
Primary	17	11.0
Secondary	81	62.6
Third level	55	35.7
Not reported	1	0.6
Economic status <sup>b</sup>		
Employed	68	44.2
Looking after family/home	38	24.7
Retired	33	21.4
Other	10	6.5
Not reported	5	3.2
Marital status		
Married/living as married	135	87.7
Single	14	9.1
Other	4	2.6
Not reported	1	0.6
<b>Survivors</b>		
Cancer site		
Colon	84	54.5
Rectum	63	40.9
Unknown whether colon or rectum	7	4.5
Stage of disease at diagnosis		
Stage 1/2	55	35.7
Stage 3/4	77	50.0
Unknown stage/unstaged	22	14.3
Age at diagnosis		
≤64	64	41.6
65–74	44	28.6
≥75	39	25.3
Unknown	7	4.5
Gender		
Male	106	68.8

**Table 1** (continued)

Characteristic	Number (154)	Percentage
Female	41	26.6
Unknown	7	4.5

<sup>a</sup> Children, 29; parent, 8; friend, 3; another relative, 1; other, 1

<sup>b</sup> Immediately prior to commencement of caring activities

#### *Diagnosis and treatment phase and ongoing care phase: domestic-based activities*

Eighty-five percent of carers reported providing domestic-based care activities during the diagnosis and treatment phase and time costs were €609 per week (Table 3). The highest ranked cost activity was HDL (€305), followed by ADL (€150), IADL (€104) and cancer-specific care (€50). Nearly three quarters of carers undertook HDL and IADL; fewer indicated carrying out ADL (56 %) and cancer-specific activities (44 %).

Ongoing caregiver time costs were on average 42 % less than diagnosis and treatment costs. In total, weekly ongoing care phase costs were €353 with 66 % of carers reporting some time spent on caring activity over the period (Table 3). The largest divergence was in cancer-specific care where costs were 60 % lower in the ongoing care phase than during diagnosis and treatment. In both phases, HDL accounted for the largest percentage of costs and cancer-specific activities accounted for the smallest.

#### *Diagnosis and treatment phase and ongoing care phase: domestic-based OOP costs*

Weekly domestic-based OOP costs during diagnosis and treatment were €69 with over two thirds of carers incurring these costs. The dominant cost category was household expenses (in particular extra costs for food and drink), which comprised two thirds of the total (€47); smaller amounts were incurred for medicine and cancer-related items (Table 4).

Ongoing OOP costs were €50 per week; 72 % of the amount in the diagnosis and treatment phase. Just over half of carers incurred ongoing OOP costs, 15 % fewer than during diagnosis and treatment. Household expenses, as the largest OOP cost component, accounted for over two thirds of the total.

#### *Total economic burden of informal care*

The total economic burden of caring for colorectal cancer survivors is summarised in Table 5. The estimated first year informal care cost was €29,842 per carer. Over this first

**Table 2** Weekly cost of hospital-related activities, diagnosis and treatment phase: descriptive statistics (2008 Euro)

Type	With costs <sup>a</sup> (%)	Mean <sup>b</sup>	SD	Median	IQR <sup>c</sup>
Total (direct + indirect)	99.1	393.4	327.4	393.7	131.4–541.1
Total indirect costs	99.3	295.4	270.3	222.3	104.4–393.2
Total waiting and visiting time <sup>d</sup>	99.3	185.7	204.0	123.2	49–241
Diagnostic tests and investigations <sup>e</sup>	86.7	16.2	31.9	9.8	3.3–19.6
Surgery	98.0	99.2	138.3	53.8	31.0–107.7
Chemotherapy	51.0	54.8	105.7	5.7	0–75.1
Radiotherapy	21.9	9.2	22.3	0	0–0
Total travel time	99.3	112.9	101.2	67.4	40.8–171.3
Diagnostic tests and investigations	90.9	14.1	21.4	6.5	2.7–17.1
Surgery	96.5	57.2	66.7	37.0	19.6–71.8
Chemotherapy	59.7	21.6	30.0	8.7	0–32.6
Radiotherapy	23.8	15.6	44.1	0	0–0
Total direct costs	99.1	129.8	150.6	74.3	30.3–194.5
Total travel costs	99.2	59.1	67.9	33.6	12.7–85.7
Diagnostic tests and investigations	88.1	6.6	10.8	2.7	0.54–8.0
Surgery	94.7	28.9	42.6	17.4	6.0–32.4
Chemotherapy	59.3	12.8	28.6	2.9	0–15.5
Radiotherapy	22.5	8.8	25.9	0	0–0
Total OOP costs	93.5	79.2	151.0	30	8.0–101.6
Diagnostic tests and investigations	80.1	8.6	21.9	2.3	0.6–7.7
Surgery	86.2	39.7	117.1	10.8	3.1–25.8
Chemotherapy	44.1	15.9	36.7	0	0–13
Radiotherapy	17.7	6.6	23.3	0	0–0

<sup>a</sup>Percentage of the carers in the sample that incurred costs in this category

<sup>b</sup>Mean costs are based on the entire sample

<sup>c</sup>Interquartile range

<sup>d</sup>This includes visiting time while the person with cancer was an inpatient

<sup>e</sup>All subtotal means and summary statistics (in italics) are means of the selected variable and are not the sum of means from cost subcomponents

year, time costs accounted for 85 % of the total economic burden, OOP costs 13 % and travel costs 2 %.

### Predictors of costs

Variables which were significant predictors of carer costs are summarised in Table 6. In the diagnosis and treatment phase, significantly higher hospital-based indirect time and direct costs were incurred by carers of survivors with later stage disease. In the same phase, hospital-based direct costs were significantly lower for carers aged 55 or over, than younger carers. Domestic-based indirect costs were lower for carers aged 55–65. In the ongoing care phase, carers of older survivors had higher domestic-based costs.

### Discussion

Evidence is accumulating that cancer survivors may incur considerable cancer-related time and OOP costs [12, 22–25]. By quantifying the direct and indirect costs associated with informal caregiving, this study reveals that the economic burden of cancer extends to family and friends.

### Time costs

The majority of carer costs for colorectal cancer are engendered indirectly in the form of time lost from other activities. As might be expected, time costs were highest during the diagnosis and treatment phase but remained substantial during the ongoing care phase. The proportion of total costs due to lost time in this study was somewhat similar to that reported in a study of carers of people with colorectal and lung cancer in the USA (where time accounted for 91 % of total costs) [13] and one of carers of people with cancer in the USA (80 % of total costs due to time) [25]. However, the magnitude of time cost estimates is more heterogeneous across studies. A broad extrapolation of time costs for Irish carers in this study yielded a cost of €29,842 (43,890 USD, 2008) [26] over the first year of care. US estimates of total informal caring time costs range between 14,000 USD for carers of colorectal cancer and lung cancer patients over a 1-year period since diagnosis [13] and 45,699 USD for time associated with caring for colorectal cancer patients over a 2-year period [7].

Although time costs do not represent a direct monetary expense for carers, they are important and can impose a burden both on the individual (through time lost from other activities) and on society in general (in the

**Table 3** Time cost of domestic-related activities, diagnosis and initial treatment phase and ongoing care phase: descriptive statistics (2008 Euro)

Activity	Diagnosis and treatment phase					Ongoing care phase				
	With costs (%)	Mean	SD	Median	IQR	With costs (%)	Mean	SD	Median	IQR
Total	85.1	608.7	522.5	487.8	169.7–975.7	66.2	352.7	428.8	169.7	0–593.9
HDL <sup>a</sup>	76.1	304.5	284.8	233.3	21.2–487.8	56.4	217.5	278.4	0	0–381.8
Preparing food and drinks	66.9	123.5	130.4	106.1	0–212.1	48.2	78.1	117.4	0	0–127.3
Cleaning the house	57.0	66.1	79.3	42.4	0–106.1	44.4	59.0	94.1	0	0–84.8
Washing, ironing and sewing	57.0	46.9	61.2	79.5	0–79.5	44.8	34.3	52.1	0	0–53.0
Shopping	57.7	34.4	46.5	21.2	0–42.42	44.4	29.6	57.6	0	0–42.4
Maintenance work, odd jobs and gardening	42.7	35.1	61.7	0	0–42.4	31.7	21.7	39.6	0	0–42.4
ADL	56.3	150.4	221.5	42.4	0–212.1	30.6	76.2	179.4	0	0–42.2
Personal care	45.1	63.6	100.7	0	0–127.3	22.2	29.5	85.0	0	0–0
Moving around the house	23.6	23.7	61.2	0	0–0	11.1	10.8	38.0	0	0–0
Eating and drinking	18.1	17.6	45.1	0	0–0	11.8	14.1	45.8	0	0–0
Moving and travelling outside the house	37.5	45.4	80.8	0	0–63.6	16.0	21.8	66.6	0	0–0
IADL	71.5	104.4	136.1	63.6	0–127.3	50.0	51.5	79.4	10.6	0–84.8
Making trips or visiting family or friends	41.7	39.9	76.1	0	0–42.4	24.3	19.1	42.4	0	0–0
Health care contacts	66.0	40.4	51.8	21.2	0–53.0	41.0	19.0	34.9	0	0–21.2
Organising help, taking care of financial matters, arranging house adaptations	37.5	24.1	53.9	0	0–21.2	27.1	13.4	32.1	0	0–21.2
Cancer specific	43.8	49.6	97.9	0	0–63.6	19.4	19.6	60.6	0	0–0

Overall total and subtotal means and summary statistics presented in italic

form of productivity losses). For example, other studies have shown an adverse impact on work due to caregiving for cancer survivors [27, 28]. The considerable time costs found in this study suggest that these might explain the adverse effect of caregiving on employment.

#### Direct costs

OOP costs impose a direct cancer-related monetary burden on carers. Although OOP costs peaked in the diagnosis and treatment phase (at a mean of €138 per week), they were still considerable during the ongoing care phase (€50 per week). For low income households, the unemployed and/or retired individuals such additional expenses may cause considerable financial and psychological stress and strain. Previous studies have demonstrated a link between increased cancer-related OOP costs and increased financial burden, stress and strain [11, 29] and a link between increased cancer-related financial burden and psychological well-being [30], but these studies have mainly concentrated on individuals with cancer. It is possible that similar associations exist for cancer caregivers and tentative evidence would suggest that this is the case [31]; this area requires further investigation.

It is worth noting that an approximate first year accumulation of OOP costs incurred by carers amounted to €3,830 on average per person, which is not an insignificant amount. In the first 3 months of care alone, 9 % of carers incurred OOP costs of more than €2,000. While the average OOP costs due to caring may not constitute an onerous burden for moderate to high income households, some carers do experience considerable expenses over the course of the survivor's treatment and may struggle with this additional financial burden.

Direct comparison of OOP cost estimates between studies is difficult and depends on cost subcategories included and the nature of the provisions available in the health and social welfare system (e.g. whether supportive medications are available free of charge). A US study reported that caregivers of colorectal and lung cancer patients incurred OOP costs of \$1,243 over a 1-year period [13], lower than in our study. However, the US study included fewer OOP cost categories than we did. Transportation was a significant burden in the US study, similar to our study, where travel costs were incurred by 99 % of carers in the diagnosis and treatment phase at a mean cost of €726. A Canadian study estimated family and patients incurred OOP costs of \$213 over a 30-day-period [11], a considerable proportion of

**Table 4** OOP cost of domestic-related expenses, diagnosis and treatment phase and ongoing care phase: descriptive statistics (2008 Euro)

Category	Diagnosis and treatment phase					Ongoing care phase				
	With costs (%)	Mean	SD	Median	IQR	With costs (%)	Mean	SD	Median	IQR
Total OOP expenditure	67.8	69.2	89.0	35	0–110	52.1	49.7	85.4	5.3	0–63.7
Medicine	49.3	14.2	21.7	0	0–20	34.2	7.3	14.0	0	0–10.6
Prescription medicine	21.2	5.8	13.9	0	0–0	13.7	2.6	7.8	0	0–0
Over-the-counter medicine	32.9	4.6	9.0	0	0–5	19.2	2.2	5.3	0	0–0
Vitamins and food supplements	27.4	3.9	8.4	0	0–4	20.5	2.5	6.3	0	0–0
Household expenses	56.8	46.8	73.4	10	0–60	39.0	35.5	72.3	0	0–26.5
Telephone	40.4	6.6	14.5	0	0–10	30.1	4.6	10.2	0	0–5.3
Electricity and heating	40.4	10.3	17.7	0	0–12.5	28.1	8.2	17.3	0	0–9.6
Food and drink	47.3	20.1	44.0	0	0–20	22.6	15.9	43.7	0	0–0
Clothes	26.0	6.2	13.4	0	0–4.5	15.8	5.1	16.6	0	0–0
Childcare	4.8	3.6	19.7	0	0–0	0.0	1.7	14.3	0	0–0
Cancer-related items	23.3	8.2	26.7	0	0–0	16.4	6.8	37.0	0	0–0
Home help	4.1	2.1	13.6	0	0–0	4.1	4.0	35.6	0	0–0
Private nurse	0.0	0	0	0	0–0	0.0	0	0	0	0–0
Stoma expenses	12.3	2.0	7.1	0	0–0	7.5	1.0	4.4	0	0–0
Other expenses	10.3	4.1	22.1	0	0–0	6.2	1.8	9.9	0	0–0

Overall total and subtotal means and summary statistics presented in italic

which was accounted for by drugs, accommodation and food. This is somewhat similar to our study where the largest cost components were household expenses and in particular food and drink, electricity and heating bills and medications.

#### Phase of care

We found that informal care costs were higher in the diagnosis and treatment phase than in the ongoing care phase. The consistency in the reduction across various activities and OOP costs is striking and suggests a definite reduction in care activities following the intensive diagnosis and treatment period. In contrast to us, Van Houtven [13] found that the caregiver economic burden increased from the initial phase to the continuing phase of care for lung and colorectal cancer patients, but these authors used

a different definition of phases of care (initial phase up to 1 year post-diagnosis; continuing phase,  $\geq 1$  year post-diagnosis but not within 6 months of the patient's death).

#### Cost predictors

Similar to previous studies, stage of disease was a key predictor for carers' costs [7, 13]. This seems intuitive for the diagnosis and treatment phase as survivors with later stage disease are likely to have more extensive treatment and longer inpatient stays after surgery. Our other findings with regard to drivers of costs, including the age of the carer and the care of the care recipient, are novel (as far as we are aware) and provide some initial clues regarding subgroups who might be at greatest risk of adverse financial or economic consequences of cancer caregiving.

**Table 5** Summary of indirect costs and direct costs by phase of care (2008 Euro)

	Diagnosis and treatment phase		Ongoing care phase	First year informal care costs <sup>a</sup>
	Hospital-related costs (per week)	Domestic-related costs (per week)	Domestic-related costs (per week)	
Total informal care costs	–	–	–	29,842
Indirect costs	295.4	608.7	352.7	25,244
Direct costs	129.8	69.2	49.7	4,598

<sup>a</sup> Approximate first year informal care costs consist of 9 months of aggregated ongoing care costs plus a total cost for the first 3 months of care

**Table 6** Significant predictors of carer costs, by phase of care and type of cost; coefficient and 95 % confidence interval

Phase and cost	Variable	Coefficient	SE	95 % CI	
Diagnosis and treatment phase					
Hospital based					
Indirect costs	Stage				
	1 and 2	Ref <sup>a</sup>	–	–	–
	3/4/unknown	137.9	40.8	63.8	219.6
Direct costs	Carer age				
	<55	Ref	–	–	–
	≥55	–79.8	31.2	–150.0	–26.0
	Stage				
	1,2 and unknown	Ref	–	–	–
	3 and 4	67.6	25.4	20.5	119.0
Domestic based					
Indirect costs	Carer age				
	<55 or >65	Ref	–	–	–
	55–65	–277.3	82.3	–426.5	103.2
Direct costs	No significant variables				
Ongoing care phase					
Domestic based					
Indirect costs	Survivor age				
	≤75	–	–	–	–
	>75	248.4	85.9	94.7	438.0
Direct costs	No significant variables				

<sup>a</sup>Ref reference category,  
SE standard error

### Strengths and limitations

This is one of the few studies to quantify direct and indirect costs associated with informal caregiving. Although the survey response rate was relative high (68 %), the sample size was relatively small and we cannot exclude the possibility that non-responders and responders may differ. The characteristics of the care recipients for respondent and non-respondent carers were reasonably similar for most factors except stage: survivor gender (percentage of male carer respondents, 69 %; carer non-respondents, 67 %); survivor site (percentage of colon, 55 vs 54 %); and survivor stage (36 and 44 % for stages I and II, respectively).

Cost estimates were based on self-reports of time and expenses. Cancer survivors tend to underreport their use of health care resources [24]. If this holds for carers, cost estimates, particularly for the diagnosis and treatment phase, may be underestimated. Costs estimated for the previous 30 days of care (ongoing care) provide only a snapshot of continuing costs due to caring activities. Whether these costs decrease, stay the same or increase over time is unknown. Nevertheless, the inclusion of survivors at different times after diagnosis ensures that the cost estimates from the ongoing care phase represent a spectrum of post-treatment care.

We did not distinguish between different types of carer time foregone because previous studies have shown that respondents can find this difficult [32]. We used a base wage rate to value time foregone irrespective of the employment status of the carers; this was in part driven by the fact that almost half of the carers were not working and we preferred not to allocate zero opportunity costs for their time. Using different approaches to cost time can produce different estimates: we report on this elsewhere.

### Potential policy implications

Our results suggest that consideration should be given to the development of strategies and services to support carers in managing the economic burden of colorectal cancer. In addition, policymakers should take the carer burden into account when making service decisions. Although the drive towards centralisation of cancer services and more outpatient and community-based treatment and follow-up are likely to deliver many benefits, these may be at the expense of patients'/survivors' family and friends. Policymakers need to better recognise these consequences. In time, this recognition may lead to informal care costs being routinely



integrated into economic evaluations of new health care interventions.

## Conclusion

To date, the economic burden of cancer-related informal care has been largely overlooked in both the economic and survivorship literature and from a policy and service perspective. We have shown that significant time and OOP costs are borne by informal carers who provide support and care to colorectal cancer survivors. While costs were highest in the diagnosis and treatment phase, ongoing care costs are not insignificant. Estimates like these may facilitate policymakers and service providers in better assessing the consequences of changes in organisation and delivery of cancer care.

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**Conflict of interest** None

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