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ORIGINAL ARTICLE

Counting the cost of cancer: out-of-pocket payments made by colorectal cancer survivors

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Abstract

Purpose Cancer places a significant cost burden on health services. There is increasing recognition that cancer also imposes a financial and economic burden on patients but this has rarely been quantified outside North America. We investigate out-of-pocket costs (OOPCs) incurred by colorectal (CRC) survivors in Ireland.

Methods CRC survivors (ICD10 C18-20) diagnosed 6–30 months previously were identified from the National Cancer Registry Ireland and invited to complete a postal questionnaire. Cancer-related OOPC for tests, procedures, drugs, allied medications and household management in approximately the year following diagnosis were calculated. Robust regression was used to identify predictors of OOPC; this was done for all survivors combined and stratified by age (<70 and ≥70 years) and employment status (working and not working) at diagnosis.

Results Four hundred ninety-seven CRC survivors completed questionnaires (response rate = 39%). Almost all (90%) respondents reported some cancer-related OOPC. The average total OOPC was €1589. Stage III at diagnosis was associated with significantly higher OOPCs than other stages in the all-survivor model, in those not working in the employment model and in those under 70 years in the age-stratified model. In all-survivor model, those under 70 also had higher OOPCs, as did those in employment. Having one or more children was associated with significantly lower OOPCs in those under 70 years.

Conclusions Almost all CRC survivors incur cancer-related OOPCs; for some, these are not insignificant. Greater attention should be paid to the development of services to help survivors manage the financial and economic burden of cancer.

Keywords Colorectal cancer · Patient costs · Survivorship · Outcomes

Introduction

There are approximately 32 million cancer survivors worldwide [1]. Increasing incidence and survival means that this number will rise [2, 3]. Colorectal cancer is the second and third most commonly diagnosed cancer in women and men, respectively [4]. In Europe, 5-year relative survival is around 50–55% [3]. Five-year prevalence is in excess of 3.2 million survivors; second only to breast cancer [1]. Cancer is increasingly recognised as a chronic condition, with survivors undergoing follow-up and engagement with health and other support services over an extended period of time; this has implications not only for survivors and their families but also for the society and economy.

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In terms of economic impact, the American Cancer Society estimated that in 2010, the total cost of all cancers was $260 billion in the USA [5]. A European study estimated that cancer cost the EU €126 billion in 2009 [6]. For colorectal cancer, a 2009 report estimated that the worldwide cost associated with new cases diagnosed in that year alone was $33.4 billion [7]. Most of these estimates are based primarily on costs borne by the health services for the management of the disease and those borne at the societal level as a result of premature cancer-related mortality. This means that they are only partial estimates of the total cost of cancer in that they do not (generally) consider costs incurred by survivors in the form of out-of-pocket costs (OOPCs) for tests, medications and treatment-related travel and food.

Some evidence exists on costs incurred by survivors and their families, but this is mainly on breast and prostate cancer [8–11]. The socio-economic status of colorectal patients tends to be more heterogeneous than either breast or prostate cancer. Therefore, the costs faced by colorectal survivors might be very different to those of breast and prostate cancer survivors. A few studies have examined the costs of the condition to patients and their families [12, 13] with one American study estimating that the time and travel costs alone over a patient's lifetime were in excess of $4500 [14]. These studies pertain to health care systems that are either strongly based on public provision or on a private health insurance (PHI) model. Very little evidence exists concerning survivors' costs in a more mixed setting (i.e. one with both public and private elements) which is typical across much of the western world [15].

In Ireland, a universal access health system coexists with private health insurance and patients are free to move between the two, where entitlements and ability to pay allow this. Within the universal public system, most patients make relatively modest co-payments for hospital inpatient care. For primary care, and prescribing, a complex mixed system, with potentially high OOPC, operates. Against this background, we aimed to measure the OOPCs borne by colorectal survivors from the point of initial diagnosis to completion of initial follow-up.

Materials and methods

Setting

All citizens of Ireland are entitled to treatment within the public system. Those with modest incomes and older people may also qualify for a means-tested medical card. At the time of this study, the medical card entitled holders to free prescription medications, inpatient hospital care and free-at-the-point-of-access GP consultations. Those aged 70+ were automatically entitled to a medical card. Approximately 1.8 million people currently qualify for this card, representing 40% of the population [16]. Those without a medical card must pay a contribution towards inpatient visits and the full cost of visiting a GP (approximately €60 per GP visit and €75 per night in hospital). They must also pay the costs of prescription medications up to a monthly ceiling of €144. PHI is held by roughly 50% of the population. Twenty-five percent have neither health insurance nor a medical card [17].

Subject recruitment

All cases of primary, invasive colorectal cancer in Ireland (ICD10: C18-C20) diagnosed October 2007–September 2009, and who were believed still to be alive, were identified from the National Cancer Registry (NCRI) in January 2010. The NCRI has at least 97% coverage of all cancers diagnosed in Ireland [18].

Managing clinicians[1] were approached with a list of their potentially eligible patients and asked to confirm if any were ineligible. The ineligibility criteria were the following: having died, poor understanding of English, cognitive impairment and being too ill to participate (e.g. in palliative phase). Eligible survivors also needed to be aware of their diagnosis. Survivors whom clinicians deemed ineligible, and those whose clinicians did not respond, were excluded. Ethical approval was obtained from research ethics committees covering participants' treating hospitals. These included large tertiary centres of excellence, regional and local hospitals.

Questionnaire development

The patient economic impact questionnaire[2] was developed by the research team and informed by review of existing instruments, in-depth interviews with survivors [19], focus group discussion with a colorectal cancer patient support group (all of whom were survivors) and consultation with cancer health professionals. The survey asked about the OOPCs survivors had incurred as a result of their diagnosis, and which were not recouped from PHI or other sources. These related broadly to the first-year post-diagnosis and included the period of the initial diagnosis, treatment through to completion of the initial clinical follow-up. The survivors were asked to provide information on a range of potential OOPCs, including costs of consultations with clinicians or GPs, prescription medications, appliances and treatment-related sundries such as travel and subsistence. Other cancer-related costs such as alterations to survivors' homes and supportive medication were also collected. All costs were measured in 2008 Euros.[3] The questionnaire was distributed by mail. Potential respondents were sent a reminder letter 2 weeks

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[1] In a small number of cases, where clinicians were unable to give a clear indication to the study team, the survivor's GP was approached.

[2] Available from the authors on request

[3] Health-related OOPCs were adjusted to 2008 Euro terms using the Central Statistics Office's CPI sub-index for health while all other OOPCs were adjusted using the headline CPI.

after the questionnaire pack and a further reminder, together with a new questionnaire, was mailed 2 weeks after that again.

Socio-demographic data relating to age, gender, children, health insurance/medical card status and presence of a stoma were collected by questionnaire whilst clinical information on site, stage, date of diagnosis and treatment were abstracted from the NCRI.

Statistical analysis

Analyses were conducted in Stata 10 [20] and MS EXCEL [21]. The OOPC per survivor was estimated, and then disaggregated by phase of care (pre-diagnosis, surgery, radiotherapy, chemotherapy, follow-up) and cost category (GP costs, tests and procedures, clinical consults, medications and indirect costs). Averages related to participants who experienced them only (e.g. the average for chemotherapy relates only to those respondents who underwent it) with the exception of the global OOPC average, which was an average for all participants of all costs. Whilst respondents were asked to report full costs, in some instances, they provided the cost of one episode only (such as a parking fee for one radiotherapy visit); these were aggregated by the number of episodes to provide a total. One observation was dropped from the analyses as it constituted an exceptional case.[4] Those survivors with an unknown stage were retained in the analysis and were not combined with any other stage.

Robust regression analysis was employed to identify predictors of OOPC, allowing for the skewed nature of cost data [22, 23]. Univariate ANOVA was used to inform variables for inclusion in the regression models. A model was developed initially for all survivors. Then, the sample was stratified by age (<70 and 70+) and employment status at diagnosis (working or not working) and models developed within strata to shed light on whether costs varied between subgroups. Variables were retained in the models if they were significant ($p < 0.05$) after adjusting for other variables in the model. Responders and non-responders were compared in terms of age, sex, cancer site and stage at diagnosis using *t* tests or chi-square tests as appropriate.

Results

Sampling, response and characteristics of the study sample.

Two thousand eight hundred eighty-nine survivors were identified from the NCRI. Based on additional information on deaths obtained from the Central Statistics Office, 159 were excluded. During eligibility 'screening', 121 clinicians provided information on the status of 1609 cases. Based on this, a further 283 cases were excluded, leaving 1326 who were invited to participate. Fifty-three survivors were subsequently excluded because they had recently died or indicated they were too ill to participate. Four hundred ninety-seven completed questionnaires were returned (response rate = 39%). Socio-demographic, clinical and treatment characteristics of respondents are shown in Table 1. Responders and non-responders did not differ by sex or site, but non-responders were slightly older (mean age 67 versus 70; $p < 0.001$).

Univariate results

Four hundred forty-eight survivors (90%) reported some cancer-related OOPC. The average OOPC was €1589 (*SD* = €3827, median €638, inter-quartile range €100–€1450). Mean OOPCs for those with stage III disease were significantly higher than for those with other disease stages ($F = 5.34$, $p = 0.0212$) (Table 2). Those aged 70+ had a significantly lower mean OOPC than those <70 (€1160 versus €1948) ($F = 5.27$, $p = 0.0221$). Those in employment at diagnosis had a slightly higher OOPC than those who were not (€1963 versus €1367; $F = 2.81$, $p = 0.0943$). There were no statistically significant differences in mean OOPC by gender, site, medical card status, PHI status and between those who did, and did not, receive chemotherapy or radiotherapy.

OOPCs by phase of care

Amongst those who reported paying for GP consultations ($n = 217$; 44%), the average OOPC on pre-diagnosis GP visits relating to their symptoms was €108 (Fig. 1). During surgical management, the mean OOPC was €528 ($n = 306$; 62%). For those who received (neo-) adjuvant treatment and reported incurring costs, the mean chemotherapy-related OOPC was €239 ($n = 172$; 35%) and for radiotherapy was €489 ($n = 56$; 11%). For the majority, these costs were comprised of payments for the parking and purchase of meals; however, for more than a third ($n = 172$; 35%), OOPCs related directly to their care or to overnight stays during (neo-) adjuvant treatment that they were required to pay for either as a co-payment or in full.

OOPCs by cost category

The mean OOPC of tests and procedures was €620 (*SD* = €756) for the 130 survivors (26%) who reported on it (Fig. 2). Clinical consults and GP visits (both pre- and post-diagnosis) averaged €467 (*SD* = €352, $n = 145$; 29%) and €249 (*SD* = €470, $n = 228$; 46%), respectively, whilst mean OOPCs for medications (both over-the-counter and prescription) and dietary supplements were €483 (*SD* = €909, $n = 165$;

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[4] This case was a self-employed survivor who had to take on relief workers during his treatment. This cost him €76,000.

Table 1 Participants by socio-demographic, clinical and treatment characteristics: numbers and percentages ($n = 497$)

Characteristic	Number (%)				
Gender	Male	Female			
	310 (62)	187 (38)			
Age	<70	70+			
	270 (54)	227 (46)			
Site	Colon	Rectum			
	307 (62)	189 (38)			
Stage	Stage I	Stage II	Stage III	Stage IV	Unknown
	90 (18)	141 (28)	175 (36)	36 (7)	55 (11)
Treatment	Surgery	C/therapy	R/therapy		
	464 (93)	284 (57)	118 (24)		
Private health insurance	Yes	No			
	257 (52)	240 (48)			
Medical card	Yes	No			
	255 (51)	242 (49)			
Working	Yes	No			
	185 (37)	312 (63)			
Children	Yes	No			
	423 (85)	74 (15)			

33%). OOPCs on other indirect factors (e.g. clothing, childcare and support at home) came to €510 (*SD* = €672, $n = 83$; 17%). A few people made home modifications ($n = 22$; 4%) with a mean outlay of €4802.

Regression analysis

Table 3 presents the results of the full and stratified regression models. In the all-survivor model, those with stage III at diagnosis experienced OOPCs that were €226 higher than those of other stages (95% confidence interval (CI) €89.55 to €362.88, $p = 0.001$). Those aged 70+ had OOPCs that were €373.91 less than those aged <70 ($p < 0.0001$, 95% CI −€531.12 to −€216.69). Being employed or self-employed was associated with OOPCs that were €179.88 higher than those of not working (95% CI €17.86–€341.90 $p = 0.030$). When the sample was stratified by employment status, in those who were not working at diagnosis, stage III disease was a significant predictor of higher costs (€156.35, 95% CI €22.83

Table 2 OOPCs by socio-demographic, clinical and treatment characteristics ($n = 497$): univariate analyses

Characteristic	Mean (SD)				
Gender	Male	Female			
	€1476 (€3462)	€1779 (€4368)			
Age**	<70 years	70 years+			
	€1948 (€3828)	€1160 (€3789)			
Site	Colon	Rectum			
	€1435 (€3043)	€1927 (€5135)			
Stage**	Stage I	Stage II	Stage III	Stage IV	Unknown
	€1524 (€3935)	€1075 (€2153)	€2138 (€5087)	€1216 (€1661)	€1519 (€3162)
Treatment	Surgery	C/therapy	R/therapy		
	€1563 (€4274)	€1610 (€3461)	€1516 (€3042)		
Private health insurance	Yes	No			
	€1472 (€4250)	€1983 (€4250)			
Medical card	Yes	No			
	€1590 (€3253)	€1397 (€3923)			
Working at diagnosis*[a]	Yes	No			
	€1963 (€3615)	€1368 (€3936)			
Children	Yes	No			
	€1639 (€4061)	€1451 (€2091)			

**Significant at the 5% level, *Significant at the 10% level

[a] Working is defined here as employed OR self-employed

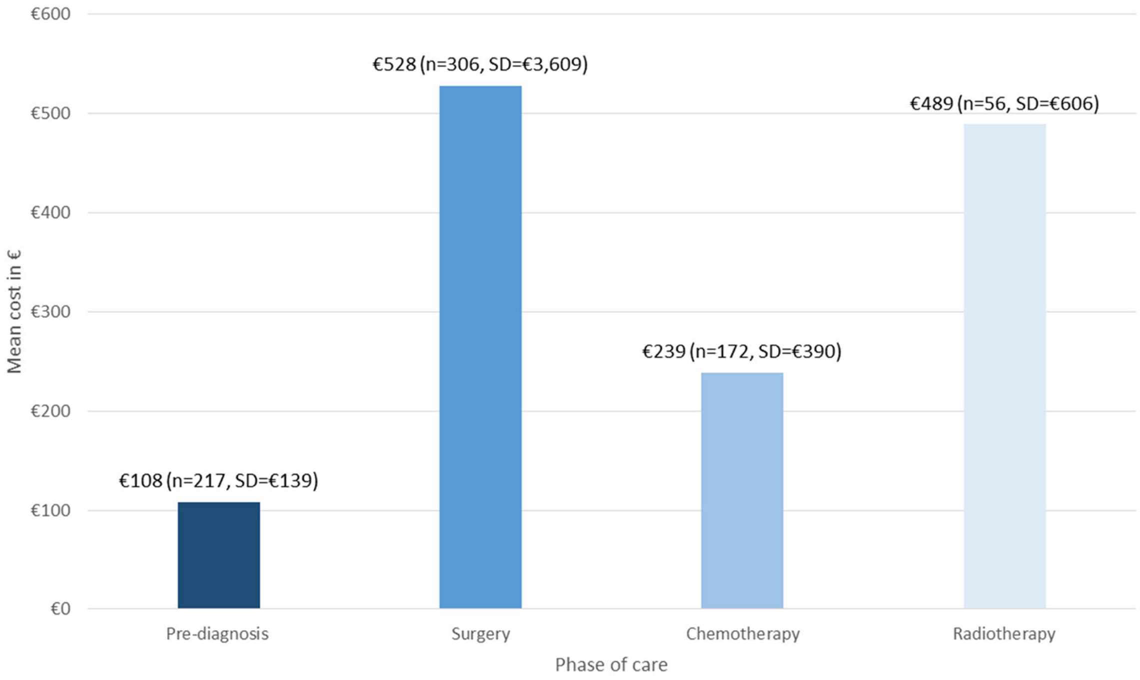

Fig. 1 Mean OOPCs by phase of care in Euro, with number who reported incurring these costs and standard deviations (SD)

to €289.8, $p = 0.022$) as was having rectal cancer (€201.05, 95% CI €62.53–€339.56, $p = 0.005$). In those who were working at diagnosis, 70+ survivors had a lower OOPC (−€25.87, 95%CI −€40.21 to −€11.53, $p < 0.0001$). When the sample was stratified by age, in those <70, stage III disease was associated with significantly higher OOPCs (€260.28, 95% CI €27.62 to €492.93, $p = 0.028$) whilst those with children experienced lower costs (−€420.03, 95%CI −€752.35 to −€87.72, $p = 0.013$). For those aged 70+, being in employment was associated with significantly higher costs (€276.52, 95% CI €67.65–€485.39, $p = 0.010$).

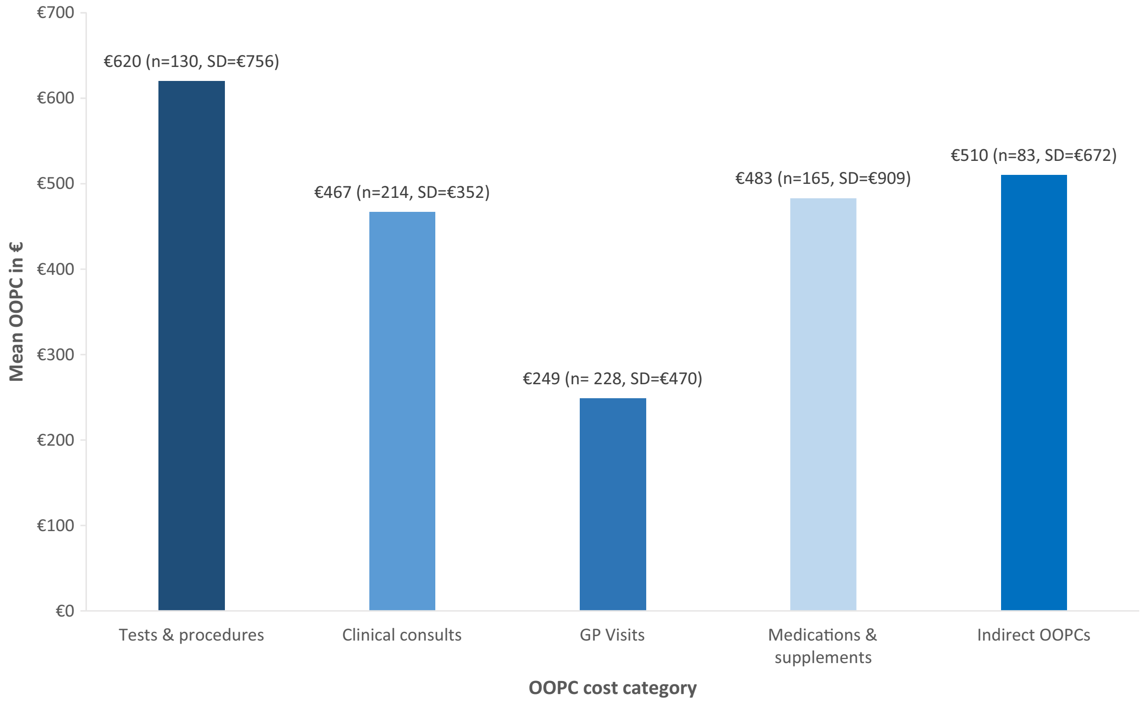

Fig. 2 Mean OOPCs by cost category in Euro, with number who reported incurring these costs

Table 3 Results of robust regression analysis models for socio-demographic and clinical predictors of OOPC (all observations, stratified by age, stratified by employment status): coefficients, 95% confidence intervals and *p* values for significant predictors

Regression model	Coefficient	95% confidence interval		*p* value
All survivors				
Constant	€688.86			
Stage III	€226.61	€89.55	€362.88	0.001
Age (70+)	−€373.91	−€531.12	−€216.69	<0.001
Working[a]	€179.88	€17.86	€341.90	0.030
Stratified by age at diagnosis (age < 70)				
Constant	€1230.98			
Stage III	€260.28	€27.62	€492.93	0.028
Children	−€420.03	−€752.35	−€87.72	0.013
Stratified by age at diagnosis (age 70+)				
Constant	€236.97			
Working at diagnosis	€276.52	€67.65	€485.39	<0.01
Stratified by employment status at diagnosis (working[a])				
Constant	€2538.31			
Age 70+	−€25.87	−€40.21	−€11.23	<0.001
Stratified by employment status at diagnosis (not working[a])				
Constant	€1511.13			
Age 70+	−€16.3	−€23.18	−€9.42	<0.001
Stage III	156.35	22.83	289.87	0.022
Rectal cancer	201.05	62.53	339.56	0.005

[a] Working is defined here as employed OR self-employed

Discussion

Using data collected by a specially developed, context-specific, postal questionnaire, we examined OOPCs incurred by colorectal cancer survivors to determine magnitude and variations by socio-economic, disease and treatment characteristics. Notably, 90% of survivors reported some OOPC and the mean OOPC incurred was €1589. Having stage III at diagnosis and being older were significant drivers of OOPCs, and several other factors—such as disease site, employment status and having children—were important in subgroups.

OOPC burden

The average OOPC for survivors in this study was reasonably modest. The absolute magnitude of the costs, however, does not tell us about an individual's ability to bear them. This ability-to-pay is likely a function of both income and personal circumstances [14, 24]. For survivors of limited means, these costs, therefore, may constitute an onerous financial burden. Moreover, we and others have shown that such costs may be associated with poorer psychological wellbeing [19, 24, 25].

In the USA, Yabroff et al. [14] found the time and travel costs associated with colorectal cancer were approximately $4500 in the first-year post-diagnosis. A Canadian study of patients with colorectal, breast, lung and prostate cancer [12] estimated that monthly OOPCs and travel costs were, on average, CAN$213 (€147) and CAN$372 (€257), respectively. This compares to an average monthly total cost of around €133 in the current study. The costs reported in our study, and the Canadian study, are much lower than the direct medical costs reported by patients in some other health care settings [26]. This illustrates the importance of healthcare provision models in determining the magnitude of the costs borne by patients and survivors. In Ireland, the availability of universal public healthcare, which requires only modest co-payments by patients without a medical card, together with the relatively high levels of PHI, serves to protect the majority of patients/survivors from incurring large OOPCs.

The costs reported in this study were highly variable, however. Nineteen survivors (4% of participants) incurred OOPCs of over €8000 in the first-year post-diagnosis. These individuals mostly required alterations to their home due to cancer. Whilst local authority grants are available, these do not always cover the full cost of alterations, leaving individuals to fund the remainder. If translated to the entire cancer patient/survivor population, this 4% represents many people for whom a cancer diagnosis could entail real hardship or at least the consumption of any savings they might have.

Predictors of OOPC

Our findings suggest that stage at diagnosis is a key determinant of OOPCs. This is probably due to the fact that patients presenting with stage III disease are more likely to receive (neo-) adjuvant chemotherapy. In Ireland, 26% of all incident CRCs are stage III and the number of stage III presentations rose by 2% annually between 1994 and 2004 [27]. This highlights the potential importance of population-based colorectal cancer screening (introduced in Ireland in 2013) from a patient-level financial perspective. Not only does screening potentially represent a long-term saving to health services associated with cancer treatments avoided [28] but also by shifting the stage distribution downwards, it may realise important savings for patients and survivors in terms of OOPCs.

The observation that survivors aged 70+ had lower OOPCs is likely, mainly to be a function of the automatic entitlement to a medical card amongst this group at the time. The association between having children and lower costs in patients <70 was intriguing. It is possible that children are able to subsidise parents' costs to some extent (e.g. children may provide care and services reducing the need to hire taxis, in home help). Other data from Ireland, in which survivors reported being helped financially by family members, support this explanation [24].

The mean OOPC reported by survivors who were working at diagnosis was 43% higher (€1963 versus €1367) than that reported by those who were not working. Forgone wages or earnings were not imputed, so this result was not an artefact of the analysis methods. This is particularly relevant given recent developments in relation to increasing the retirement ages across Europe [29]. In Ireland, by 2028, the retirement age will be 68. This means that more people diagnosed with colorectal cancer in the future will be working, and thus the population-level burden of OOPC will be relatively higher.

Evidence exists that, for cancer and other conditions, those on higher incomes exhibit a greater willingness-to-pay for treatment and incur higher health-related costs than those on lower incomes [30, 31]. In the current study, those in employment may have had a greater ability-to-pay than those not working and therefore incurred higher OOPCs. Evidence also suggests that poorer patients simply cannot afford to use services or make any OOPCs so may self-report very low, or indeed no, health-related spending which is then interpreted as an open choice rather than an inability-to-pay [32]. Several authors suggest that this limitation of self-reported payment data in assessing the true socio-economic impact of cancer for those on lower incomes requires the development and implementation of more standardised and sensitive measurement techniques [31–33] based around broader financial protection profiles [24, 34].

Strengths and limitations

Our study represents one of the few efforts in the literature to document the OOPC for colorectal cancer patients/survivors and how these breakdown by phase of care and type of cost. The costs presented are based on survivors' reports, in contrast to some studies where costs were based on extrapolations from routinely collected data such as Medicare [14]. Furthermore, our participants were sampled from a population-based sampling frame. The response rate of 39% is a limitation and is lower than that in a similar study on breast and prostate cancer survivors in Ireland [35]. This was perhaps due to the questionnaire length and differences in the age and socio-economic distributions of colorectal versus breast and prostate cancer patients. It may also be due to the effects of ongoing treatment on current health status. Whilst the sex and site distribution of respondents were similar to non-respondents, fewer stage IV patients participated possibly due to their poorer prognosis. Whilst every effort was made in the questionnaire to ensure that survivors only reported OOPCs for which they were not reimbursed, it remains possible that some may have reported some costs accruing to other actors, such as PHI providers or relatives/friends. This would mean that OOPCs in this study may be over-estimated. Conversely, as was clear in conversations with patients who called the research team with queries and in our related qualitative research [19], sometimes, survivors did not perceive themselves to have incurred a cancer-related expense even when this was the case. Moreover, other evidence suggest that cancer survivors tend to under-report instances of care [13]; consequently, cost estimates, particularly those relating to the treatment phases, may be underestimated.

Implications for survivors

Our findings indicate that the OOPC burden for colorectal cancer survivors in Ireland is comparatively modest. However, for some, OOPC may be a significant component of disposable income, especially when concentrated around particular episodes of care, such as the surgical inpatient stay or adjuvant treatment requiring daily travel. At present, the supports available to patients or survivors which may alleviate their financial outgoings are limited in nature and often difficult to access [19, 36]. Furthermore, many patients or survivors do not access financial supports and benefits to which they are entitled [37]. More must be done by policy-makers to ensure that patients/survivors can access already-available services and supports. Equally, where services and support are lacking or inadequate (e.g. hospital transportation), the onus should be on service providers to ensure that supports provided better meet individuals' needs.

Since household modifications resulted in large OOPC, local authorities and advocacy groups could usefully collaborate to minimise survivors' exposure to hardship by ensuring that they are supported in making necessary changes to their homes. In terms of the higher costs incurred by survivors who were working at diagnosis, it is now well established that many cancer patients take time off and either do not return to work to return with reduced hours or that survivors have increased risk of unemployment [38]. As the number of working age colorectal cancer survivors increases in the coming years, more needs to be done by both policy-makers and employers to ensure that survivors are facilitated where possible with respect to sick leave and sick pay and supported to return to work post-treatment.

Conclusions

Almost all colorectal cancer survivors report some OOPC, with an average of €1589 OOPC in the year following diagnosis, although some patients incurred much higher costs. Having stage III disease was associated with higher OOPC and older age with lower OOPC, the latter largely due to the financial protections in place for older people in Ireland at the time of the study. These findings may aid policy-makers, service providers and patient advocacy groups to better target supports and advice for colorectal cancer survivors.

CRC, colorectal cancer; NCRI, National Cancer Registry Ireland; OOPC, out-of-pocket cost; PHI, private health insurance

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Compliance with ethical standards Ethical approval was obtained from research ethics committees covering participants' treating hospitals.

Informed consent Informed consent was obtained from all individual participants included in the study.

Conflict of interest The authors declare that they have no conflict of interest.

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