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Do Disparities in Cancer Care Costs Exist at the End of Life? Evidence from the English National Health Service

### Abstract

In universal healthcare systems such as the English NHS, equality of access is a core principle and healthcare is free at the point of delivery. However little is known about socioeconomic disparities in end-of-life healthcare costs. This study examines disparities in end-of-life costs, and the drivers of these disparities. Evidence from multivariate generalized linear model analyses illustrates that disparities exist for colorectal, breast, and prostate cancer patients. These disparities in costs are independent of comorbidities of the patient. Observed differences are driven largely by the greater use of emergency inpatient care among lower SES patients. Therefore, disparities may be reduced through better management of needs through the use of less expensive, more effective healthcare. More generally, as disparities exist even within a system with free healthcare, non-financial barriers play key roles in socioeconomic disparities in cancer costs and outcomes and further study of these barriers is required.

## Introduction

Cancer presents a substantial burden to societies and healthcare systems. In the English National Health Service (NHS), colorectal, breast, prostate, and lung cancer cost over £1.5 billion annually for hospital care alone.<sup>1</sup> The substantial cost burden of cancer is also observed internationally, with approximately 5% of all healthcare expenditure in the United States and Europe a direct result of cancer.<sup>2-4</sup> A key feature of the cancer cost curve, is that it follows a distinctive U-shape distribution; with costs highest at the end of life.<sup>1,5</sup> However, a dearth of evidence exists on drivers of end-of-life healthcare costs and in particular if socioeconomic disparities are observed. This question is arguably of increased importance in healthcare systems such as the NHS where equality of access is a core principle and healthcare is free at the point of delivery. In this context, socioeconomic disparities may reflect poor management of healthcare needs for lower SES patients and the greater use of less appropriate, and more expensive healthcare, which can affect health outcomes and healthcare costs.

It is well defined that patients with lower socioeconomic status (SES) have higher healthcare costs in general, even in systems with universal access to care such as the NHS.<sup>6-8</sup> In England, despite lower SES individuals having shorter life expectancy, they have higher lifetime hospital costs.<sup>6</sup> While

differences in costs among lower SES individuals may reflect greater need for healthcare overall, difference may also be explained by greater use of low value, less appropriate care. In the United States, there is clear evidence that poorer patients have higher use of low value care, i.e. acute care instead of primary care, or emergency department care, relative to higher SES patients.<sup>9,10</sup> This increased use of less appropriate care among the poor may be driven by insurance coverage and other financial barriers. Yet, even in the NHS where no such financial barriers exist, lower SES individuals have greater rates of emergency care.<sup>6,11</sup> This is of particular concern for cancer, where one in five cancers are diagnosed through emergency presentation in England.<sup>12-14</sup> Patients diagnosed through emergency are much more likely to come from lower SES groups.<sup>15-17</sup> This greatly impacts patients' survival, and the types of care they can receive. In this context, we also examine whether particular forms of healthcare, such as emergency admissions, drive observed disparities in end-of-life costs.

This study examines four important aspects of end-of-life care in cancer patients in England. First, we estimate costs of care in the last six months of life for colorectal, breast, prostate, and lung cancer patients. Second, we examine whether a socioeconomic gradient in end-of-life healthcare costs exist, controlling for a range of important patient-level

characteristics. Third, we establish whether any observed disparities are underpinned by the greater use of emergency admissions, amongst lower SES patients. Finally, as healthcare expenditure in England is concentrated in individuals with multiple comorbidities or complex medical conditions,<sup>18</sup> we examine whether disparities exists within patients with different levels of comorbidities.

#### Data And Methods

Data from a population-based, patient-level database which combines data from the National Cancer Data Repository (NCDR), Hospital Episode Statistics (HES), and the National Schedules of Reference Costs (NSRC), were included in this study. This dataset is similar to SEER-Medicare in the United States. However, while SEER-Medicare includes data on those aged 65 and over only, NCDR-HES-NSRC includes the full population of cancer patients in England. This dataset includes all episodes of care generated by patients between April 2006 and March 2011, before and after their cancer diagnosis.

The NCDR provides information on the characteristics of patients including tumor site (ICD-10), age at diagnosis, date of cancer diagnosis and death. HES collects information on patients' utilization of hospital inpatient and outpatient care. All NHS hospitals are mandated to report the cost of every

service delivered to patients. The NSRC includes information on the cost of all inpatient and outpatient services accessed by NHS patients. This dataset has been used in recent studies to investigate the cost of cancer in England<sup>1,19</sup> and a more detailed explanation of this dataset may be found elsewhere.<sup>1</sup> Previous work has validated the use of HES and NCDR in estimating hospital costs for a cancer population, with costs in HES very similar to those derived from patient medical records.<sup>20</sup>

In this study, we included all individuals aged over 18 with a recorded diagnosis of colorectal cancer (ICD-10 code: C18, C19, C20), breast cancer (females) (C50), prostate cancer (C61), or lung cancer (C34) in the cancer registries of England who died between October 1, 2006 and March 31, 2011. These cancers account for a large proportion of diagnosed cancers and healthcare costs in England and the United States<sup>1,5</sup> and account for almost half of cancer incidence in developed countries.<sup>21-23</sup> We excluded individuals with a previous diagnosis of cancer post-2000, and individuals diagnosed with cancer more than five years prior. We further excluded a small number of patients with improper death certificate registrations in line with previous work.<sup>24</sup> This study sample allowed for hospital utilization and costs to be estimated for all patients for at least six months prior to their death. These costs include the care provided before the diagnosis if the latter occurred less than six months

from death as health utilization, on average, increases prior to diagnosis.<sup>12</sup> The final sample included in our analyses were 66,061 colorectal, 36,698 breast, 39,329 prostate, and 116,749 lung cancer patients.

### **Outcome Measures**

The outcome measure in this study was hospital costs in the last six months of life. We obtained this variable by combining information in HES on patient admissions and HRG costs reported in the NSRC. Inpatient cost data are disaggregated at the level of Healthcare Resource Group (HRG), similar to Diagnosis-Related-Group (DRG), making adjustments for patients' type of admission, length of stay, and access to special services (dialysis, chemotherapy, radiotherapy, and rehabilitation).<sup>1,25,26</sup> To cost outpatient activity, we matched HES outpatient data with NSRC costs using specialty, type of visit, and an indicator for patient appointment attendance. A detailed description of the costing mechanism is provided in the technical appendix.

All hospital activity costs were estimated at fixed 2010 prices to reduce variability from inflation and variation in reporting standards over time. In the results section results are presented in Pound Sterling and in Dollars fixed at  $31^{st}$  December 2010 (f1 = \$1.56).

Costs were modeled using generalized linear models (GLM) with log link and gamma family. GLM estimates account for positively skewed costs in the distribution.<sup>27,28</sup> Not accounting for skewness may results in inaccurate estimates. GLM with log link and gamma family have been used previously to model end-oflife costs among cancer patients.<sup>29</sup>

In the study, analyses were run firstly on overall hospital costs, which includes inpatient (elective and emergency) care and outpatient care. A small number of patients who received no care were included and allocated zero costs. Additionally, analyses were run separately on elective inpatient and emergency inpatient activity using a two-step approach. First, probit models estimated the probability of having any elective or emergency inpatient admission at the end of life. Second, GLM analyses of costs were undertaken those patients who had at least one elective or emergency inpatient admissions respectively. As healthcare expenditure in England is concentrated in individuals with multiple comorbidities or complex medical conditions,<sup>18</sup> we measure difference disparities in costs within patients with different levels of comorbidities.

Differences in the costs of care by SES were calculated by comparing average resource use of patients from different quintiles of the income distribution in England. Similar to other studies,<sup>6,7,30</sup> the income deprivation of patients' Lower

Super Output Area (LSOA) of residence was used as a proxy for individual income, since the latter is not reported in any health database in England.<sup>31</sup> In the analyses, deprivation is aggregated to the level of quintile for ease of computation and to facilitate interpretation of results.

A range of patient characteristics which may impact costs were included in the analyses including age at diagnosis (linear and squared), days from date of diagnosis to death (linear and squared), year of diagnosis, region, weighted Charlson comorbidity index score, and specific site (ICD-10 code) for each cancer. All statistical analyses were undertaken using STATA version 13.<sup>32</sup>

#### Study Results

Unadjusted end-of-life costs differ across SES groups (Exhibit 1). Low SES colorectal, breast, and lung cancer patients have much higher emergency costs than high SES patients (£6,868 (\$10,721) versus £5,399 (\$8,428) for colorectal; £5,868 (\$9,160) versus £4,695 (\$7,329) for breast; £5,677 (\$8,862) versus £4,894 (\$7,640) for lung). However, elective inpatient and outpatient end-of-life costs are similar for low SES and high SES patients.

Exhibit 1 also illustrates that low SES and high SES patients differ considerably across other measures. Low SES colorectal and breast cancer patients, in this sample, survive

for fewer days after diagnosis than high SES patients (478 days versus 513 days for colorectal; 775 days versus 824 days for breast), with smaller differences seen for prostate and lung cancer. Low SES prostate and lung cancer patients are on average one year and 1.6 years younger at diagnosis respectively, than high SES patients. Additionally, lung cancer patients in the sample are on average more deprived areas (26% of sample are Low SES versus 14% high SES), as compared to the others cancers where a more equal distribution of patients is observed across SES groups.

Exhibit 2 illustrates differences in adjusted total end-oflife hospital costs, with results presented as average marginal effects following GLM regressions. Full results tables can be found in the Appendix. Overall, low SES colorectal, breast, and prostate cancer patients had higher end-of-life costs. On average, the lowest SES quintile had £456 (\$712), £526 (\$821), and £564 (\$880) higher costs as compared to the highest SES quintile for colorectal, breast, and prostate cancers respectively. No differences in costs are observed for lung cancer patients which may be a consequence of poor survival across all SES groups.

Average marginal effects from multivariate probit regressions in Exhibit 3 show differences in the probability of having any elective inpatient admission in the last six months of life. The results highlight that for all cancers, higher SES patients have a greater probability of having an elective admission. As compared to the lowest SES quintile, the highest SES quintile had a 7 percentage point higher probability of an elective admission for colorectal and lung cancer, and a 3 and a 5 percentage point higher probability of an elective admission for breast and prostate cancer respectively.

Exhibit 3 also presents differences in adjusted total elective costs for patients who had any elective inpatient admission, with the lowest SES quintile used as the reference category. Results presented reflect average marginal effects following GLM regressions. No differences in elective costs are observed across SES groups for colorectal, breast, and prostate cancer. Costs were slightly higher for high SES patients with lung cancer, with the highest SES quintile having costs £292 (\$456) higher than the lowest SES quintile.

Average marginal effects from multivariate probit regressions in Exhibit 4 show differences in the probability of having any emergency inpatient admission in the last six months of life. The results highlight that for all cancers, lower SES

patients have a greater probability of having an emergency admission. As compared to the lowest SES quintile, the highest SES quintile had a 3 percentage point lower probability of an emergency admission for breast, prostate and lung cancer, and a 6 percentage point lower probability of an emergency admission for colorectal cancer.

Exhibit 4 also presents differences in adjusted total emergency costs for patients who had any emergency inpatient admission, with the lowest SES quintile once more used as the reference category. Results presented reflect average marginal effects following GLM regressions. Large differences in costs are observed across SES groups for all cancers. For colorectal cancer, low SES patients had £693 (\$1,082) higher costs than the highest SES group. Low SES breast cancer patients had £726 (\$1,132) higher costs than the highest SES quintile. The lowest SES quintile prostate cancer patients had £701 (\$1,094) higher costs than the highest SES group. Finally, the lowest SES quintile lung cancer patients had £333 (\$520) higher costs than the highest SES quintile.

Exhibit 5 presents the predicted end-of-life costs of total hospital care (elective and emergency inpatients, and outpatient), following GLM regressions, with results partitioned across SES quintile, and individuals' weighted Charlson

comorbidity index score. To facilitate interpretation of results Weighted Charlson scores were aggregated into three groups; score = 2, score = 3-7, and score = 8+, with higher scores representing sicker patients.

These results show that sicker patients i.e. those which the highest weighted Charlson index scores, have much higher end-of-life costs. Additionally, the results show a socioeconomic gradient exists for colorectal, breast, and prostate cancers regardless of patients weighted Charlson score. The gradient appears to most pronounced for the sickest patients. Using the sickest colorectal cancer patients (score = 8+) as an example, the lowest SES quintile have f1,338 (\$2,089) higher end-of-life costs compared to the highest SES quintile. The gradient for lung cancer is once more noticeably smaller.

Exhibit Al in the Appendix presents the average number of elective and emergency bed days in the final six months of life partitioned by SES group. The number of elective bed days did not differ across SES groups. However, lower SES patients had a noticeably larger number of emergency bed days, and this was seen for every cancer.

A range of sensitivity analyses were also undertaken. Analyses were undertaken, where only those who survived at least one year post-diagnosis were included. A socioeconomic gradient

was observed once more for colorectal and breast cancer. However, smaller socioeconomic gradient was observed for prostate cancer, and no gradient observed for lung cancer. However, only one third of the lung cancer sample survived for one year.

Analyses similar to those presented in Exhibits 3 and 4 were also undertaken for outpatient care. Higher SES patients had a greater number of outpatient visits, and adjusted end-oflife outpatient costs were slightly higher amongst higher SES patients.

# Discussion

While equality of access is a core principle of universal healthcare systems such as the English NHS and healthcare is free at the point of delivery, socioeconomic disparities in endof-life costs still remain. This study highlights that lower SES cancer patients have higher costs of care at the end-of-life. These observed disparities in end-of-life costs remain after controlling for both patient-level characteristics of the patient, and a socioeconomic gradient is observed within patients with different levels of comorbidities.

The results also highlight that much of the observed socioeconomic disparities in end-of-life costs may have been avoided through better management of healthcare needs through

the use of less expensive, more effective elective care rather than emergency care. A substitution effect between elective admissions and emergency care is likely to exist, with lower SES patients substituting emergency care for elective care, more so than the high SES patients. Lower SES patients have a greater probability of having an emergency admission and spend longer on average in hospital, resulting in higher overall end-of-life costs. This is in line with previous studies which found that patients diagnosed with cancer in lower SES areas are more likely to be admitted as an emergency. Additionally in this study, we show that a socioeconomic gradient is observed within patients with different levels of comorbidities.

As the equality and free care at the point of delivery are key components of the NHS, factors other than financial barriers are likely playing key roles in disparities in cancer costs and outcomes. Lower SES patients may have less capability to plan and acquire elective care. Lower SES may have greater difficulty accessing to elective care due to undersupply of health services in their catchment area, or be faced with wait long waiting lists before accessing elective services.<sup>33</sup> They might be less aware of the potential cancer symptoms and available options following a diagnosis. While other cost constraints such as organizational costs, travel costs may also play a role.

A plethora of research has found that disparities in cancer survival and mortality also exist, both in England and internationally. Disparities are a result of many factors, i.e. unhealthier behavior such as smoking amongst poorer individuals<sup>34</sup> and or lower use of screening services.<sup>35-38</sup> However, the results in this study suggest use of more low value, less appropriate healthcare may also play a role. For example, while an early stage diagnosis is more likely in patients diagnosed via screening or through primary care referral (i.e. Two Week Wait referrals), a late stage diagnosis is more likely after an emergency presentation to hospital.<sup>39</sup> Evidence shows that one year survival can be halved in patients diagnosed via an emergency presentation as compared to other  $routes^{12,16,40}$  and one in five cancers are diagnosed after an emergency presentation in England.<sup>12-14</sup> Therefore, further work is warranted on the use of emergency care in lieu of more appropriate care and the potential implications of substituting to high value healthcare has on patient outcomes and healthcare costs.

The findings from this study are also relevant to policymakers in other healthcare systems. Generally, healthcare costs at the end of life constitute a substantial portion of overall costs. For example, a high intensity of care is observed in the last weeks of life in the United States,<sup>41</sup> with approximately 25% of Medicare costs incurred in last year of

life,  $^{42}$  higher than in the England  $^{43}$  and the Netherlands.  $^{44}$  A study of Medicare cancer patients found that 61% were hospitalized, and 10% visited an ED more than once within 30 days of death.<sup>45</sup> Additionally, previous cross-country analyses have shown that end-of-life healthcare costs for cancer patients (aged 65 and over) in England, are approximately half those incurred in Canada and the United States.46 Therefore in those healthcare systems where the burden is highest, understanding whether socioeconomic disparities exists, and whether greater use of less appropriate care occurs, specifically amongst poorer patients, is vital to improve outcomes and reduce costs to the system. Evidence from the United States in particular indicates that low value care, such as emergency departments are increasingly serving as the a key healthcare for poorer or medically underserved patients, such as individuals with Medicaid.<sup>10</sup>

The inclusion of hospital costs only in this study may be seen as limitation. However, this is less of an issue when examining the NHS where the majority of healthcare costs at the end of life in general are incurred in hospital for cancer<sup>43</sup> and non-cancer.<sup>47</sup> But disparities in the use of other forms of care, i.e. primary care and palliative care are still important to understand. A study found cancer patients had on average 11 GP visits in the final three months of life.<sup>47</sup> Additionally, while

the number of people dying in hospital in England has decreased over time, a substantial proportion of people, especially poorer patients, still die in an acute setting.<sup>48</sup> In other healthcare systems, there is evidence that having effective palliative care programmes can reduce healthcare cost. A large cross-country comparisons study argued that effective planning of end-of-life care should evolve to better reflect patients' preferences about place of death irrespective of health system.<sup>46</sup> Earlier palliative care consultation during admission to hospital in the United States is associated with lower hospital costs.<sup>29,49</sup>

# Conclusion

End-of-life healthcare costs in England are higher amongst lower SES patients, even after controlling for patient-level characteristics. The socioeconomic gradient observed is largely due to the greater use of emergency inpatient care amongst lower SES patients, in lieu of more appropriate elective or outpatient care. Additionally, the observed disparities exist within patients grouped by different levels of comorbidities. More generally, as disparities exist even within a system with free healthcare such as the NHS, factors other than financial barriers are likely to play a key role in disparities in cancer costs and outcomes, and require further study.

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	Lowest	Quantile	Quantile	Quantile	Highest
	SES	2	3	4	SES
Colorectal	Qualicite				Qualicite
Number of Patients	11,930	13,348	14,381	14,042	12,360
(% of Total Patients)	(18%)	(20%)	(22%)	(21%)	(19%)
Mean Age at Diagnosis	73.12	74.55	74.47	74.46	73.71
Mean Weighted Charlson	<b>-</b> 44	= 10		E 40	<b>-</b> 44
Index score	5.44	5.40	5.35	5.40	5.44
Mean number of days from	170	100	106	E 0 0	E12
diagnosis to death	470	402	490	500	513
Mean Elective Cost	£3,417	£3,252	£3,442	£3,543	£3,620
Mean Emergency Cost	£6,868	£6,122	£5,816	£5,518	£5,399
Mean Outpatient Cost	£563	£533	£529	£552	£579
Mean Total Cost	£11,138	£10,237	£10,135	£9,958	£9,859
Breast					
Number of Patients	6,728	7,545	7,917	7,795	6,713
(% of Total Patients)	(18%)	(21%)	(22%)	(21%)	(18%)
Mean Age at Diagnosis	70.47	72.20	72.53	72.26	70.67
Mean Weighted Charlson	5 28	5 03	5 06	5 00	5 06
Index score	5.20	5.05	5.00	5.00	5.00
Mean number of days from	775	786	791	804	824
diagnosis to death		/00	7.7 ±	001	021
Mean Elective Cost	£2,490	£2,480	£2,236	£2,480	£2,466
Mean Emergency Cost	£5,868	£5,444	£5,084	£4,859	£4,695
Mean Outpatient Cost	£648	£572	£582	£581	£625
Mean Total Cost	£9,307	£8,855	£8,298	£8,253	£8,131
Prostate					
Number of Patients	6,262	7,698	8,613	8,817	7,939
(% of Total Patients)	(16%)	(20%)	(22%)	(22%)	(20응)
Mean Age at Diagnosis	76.24	77.25	77.69	77.37	77.19
Mean Weighted Charlson	5.58	5.50	5.47	5.42	5.46
Index score					
Mean number of days from	757	751	771	760	775
diagnosis to death					
Mean Elective Cost	£9,637	£8,786	£8,791	£8,388	£8,218
Mean Emergency Cost	£1,836	£1,523	£1,719	£1,753	£1,782
Mean Outpatient Cost	£6,912	£6,330	£6,089	£5,676	£5,560
Lung					1 - 010
Number of Patients	30,089	26,465	23,728	20,549	15,918
(% of Total Patients)	(26%)	(23%)	(20%)	(18%)	(14%)
Mean Age at Diagnosis	71.19	72.13	72.76	72.85	72.80
Mean Weighted Charlson	5.35	5.31	5.28	5.31	5.34
Index score					
Mean number of days from	254	249	250	255	264
diagnosis to death	01 050	0.0.001	00 105	00 105	00 104
Mean Elective Cost	£1,959	±2,081	$t_2, 127$	±2,105	±∠,184
Mean Emergency Cost	£5,677	£5,339	£5,136	£4,937	£4,894
Mean Outpatient Cost	±671	±643	±640	±660	±683
mean Total Cost	±8,547	t8,332	±8,196	£7,986	±8,040

Exhibit 1: Descriptive Statistics



Exhibit 2: Total End-of-Life Costs Across SES Quintiles: Average Marginal Effects (95% Confidence Intervals)

Results following Generalized Linear Models controlling for age (linear and squared), days from diagnosis to death (linear and squared), year of diagnosis, weighted Charlson comorbidity index score, region, sex, and specific cancer site (ICD-10 code)



Exhibit 3: Elective Admission Utilization and Total Elective Admission Costs across SES Quintiles (95% Confidence Intervals)

Results following Generalized Linear Models controlling for age (linear and squared), days from diagnosis to death (linear and squared), year of diagnosis, weighted Charlson comorbidity index score, region, sex, and specific cancer site (ICD-10 code).



Exhibit 4: Emergency Admission Utilization and Total Emergency Admission Costs across SES Groups (95% Confidence Intervals)

Results following Generalized Linear Models controlling for age (linear and squared), days from diagnosis to death (linear and squared), year of diagnosis, weighted Charlson comorbidity index score, region, sex, and specific cancer site (ICD-10 code).