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. Using data on 66,061 colorectal, 36,698 breast, 39,329 prostate, and 116,749 lung cancer patients from the National Cancer Data Repository, Hospital Episode Statistics, and the National Schedules of Reference Costs, evidence from generalized linear models illustrates that disparities exist. 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. 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.[1] A substantial cost burden is observed internationally, with ~5% of all healthcare expenditure in the United States and Europe a direct result of cancer.[2–4] A feature of the cancer cost curve is its distinctive U-shape distribution; with costs highest at the end of life.[1,5] 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, and patients have access to similar quality of care according to their needs rather than their willingness to pay. 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 costs.

It is well defined that patients with lower socioeconomic status (SES) have higher healthcare costs in general, including in universal healthcare systems such as the NHS.[6–8] In England, despite lower SES individuals having shorter life expectancy,

they have higher lifetime hospital costs.[6] 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 (ED) care, relative to higher SES patients.[9,10] This increased use of less appropriate care among the poor may be driven by insurance coverage and other financial barriers. Yet, in the NHS where no such financial barriers exist, lower SES individuals have greater rates of emergency care.[6,11] This is of particular concern for cancer, where one in five cancers are diagnosed through emergency presentation in England[12–14] and diagnoses through emergency much higher among lower SES groups.[15–17] This greatly impacts patients' survival, and the types of care they can receive.

This study examines three 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.

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. While SEER-Medicare includes data on those aged 65 and over only, this dataset includes all 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 including date and method of admission and discharge, clinical information on diagnoses and care provided (details on the most common types of care are provided in the Appendix) and geographical information with can be merged with other data sources. 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[1,18] and a more detailed explanation of this dataset may be found elsewhere.[1] 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.[19]

In this study, we included all individuals aged 18 and over with a recorded diagnosis of colorectal cancer (ICD-10 codes: C18, C19, C20), breast cancer (females) (C50), prostate cancer (C61), or lung cancer (C34) who died between October 1, 2006 and March 31, 2011. These four cancers account for a large proportion of diagnosed cancers and healthcare costs in England and the United States[1,5] and equate to almost half of cancer incidence in developed countries.[20–22] We include patients having a first cancer diagnosis between 2006 and 2010 to correspond to the HES data available, and group patients according to the first cancer diagnosis, though patients can have a recurrence or a secondary cancer after the first diagnosis and enter end of life care. We excluded a small number of patients with improper death certificate registrations in line with previous work.[23] 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.[12] The final sample included 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 costs reported in the NSRC. Inpatient cost data are disaggregated at the level of Healthcare Resource Group (HRG), similar to Diagnosis-Related-Group (DRGs), making adjustments for patients' type of admission, length of stay, and access to special services.[1,24,25] To cost outpatient activity NSRC costs at the level of specialty, type of visit, and patient appointment attendance were used. A detailed description of the costing mechanism can be found in previous work.[1] All hospital activity costs were estimated at fixed 2010 prices to reduce variability from inflation and variation in reporting standards over time.[26]

Costs were modeled using generalized linear models (GLM) with log link and gamma family. GLM estimates account for

positively skewed costs in the distribution[27,28] and in line with previous analyses on end-of-life costs.[29] Not accounting for skewness may results in inaccurate estimates.

In the study, analyses were run firstly on overall hospital costs, which includes elective and emergency inpatient, and outpatient care. Elective inpatient care corresponds to a pre-planned/booked admission to hospital. An emergency admission is not pre-planned and in these data emergency admissions include admissions directly from an ED, an emergency request from a General Practitioner, or an emergency transfer from another hospital. 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 end-of-life elective or emergency inpatient admission. Second, GLM analyses of costs were undertaken on those patients who had at least one elective or emergency inpatient admission respectively.

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,[6,7,30] 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.[31] LSOA are homogeneous small areas with a population of 1,500 units and designed to improve the reporting of small area statistics in England. Patients were grouped into different SES quintiles by using the income domain of the 2010 Index of Multiple Deprivation (IMD), which measures the proportion of residents in a LSOA relying on mean-tested income benefits.[32] 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), year of diagnosis, region, and weighted Charlson comorbidity index score. The specific site of the tumor for each cancer is also controlled for in all models using ICD-10 4-digit codes, providing a greater on the etiology and severity of the tumor. Finally, days from diagnosis to death, in linear and quadratic form, was included in all models. All statistical analyses were undertaken using STATA version 13.[33]

Limitations

There are a number of limitations in this study. Important individual-level data such as marital status, household-level income, and specific cause of death are not available. Staging

information for tumors was incomplete for colorectal and breast cancer, and not available for prostate and lung cancer. However, days from diagnosis to death is used a proxy for staging in all analyses. Little information on type of care provided in an outpatient visits exist. Furthermore, the data does not cover non-acute forms of care such as primary or palliative care. However the majority of end-of-life healthcare costs are incurred in hospital for cancer.[34,35] While high costs of informal care have been observed across healthcare systems,[36,37] no information on informal care costs were available for this study. The income deprivation of patients' small area of residence may be subject to ecological fallacy.

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. Elective inpatient and outpatient end-of-life costs show little disparity. Low SES colorectal and breast cancer patients, in this sample, survive for fewer days after

diagnosis than high SES patients. Low SES prostate and lung cancer patients are on average one year and 1.6 years younger at diagnosis respectively, than high SES patients. Lung cancer patients are on average more deprived.

Exhibit 2 illustrates differences in adjusted total end-of-life hospital costs, with results presented as average marginal effects following GLM regressions.[38] The lowest SES quintile had £456 ($712), £526 ($821), and £564 ($880) higher costs on average compared to the highest SES quintile for colorectal, breast, and prostate cancers respectively. The lack of differences for lung cancer patients is a consequence of poor survival across all groups.

Average marginal effects from multivariate probit regressions in Exhibit 3 show the differences in the probability of having any elective or emergency inpatient admission in the last six months of life. Low SES patients had a lower probability of having an elective admission, and a higher probability of having an emergency admission. Compared to the highest SES quintile, the lowest SES quintile had a 7 percentage point higher probability of an elective admission for colorectal and lung cancer. The lowest SES quintile had a 3 percentage point higher probability of an emergency admission for breast, prostate and lung cancer, and a 6 percentage point higher probability of an emergency admission for colorectal cancer.

Average marginal effects following GLM regressions for adjusted total elective and emergency costs (for patients who had any elective or emergency admissions respectively) are shown in Exhibit 4. For elective admissions no differences in costs across SES groups for colorectal, breast, and prostate cancer is seen. Costs were slightly higher for high SES patients with lung cancer. However, for emergency admissions, large differences in costs are observed across SES groups. The Lowest SES quintile had £693 ($1,082), £726 ($1,132), £701 ($1,094), and £333 ($520) higher costs than the highest SES group for colorectal, breast, prostate, and lung cancers respectively.

A number of other analyses were conducted.[38] Exhibit A1 shows that in the final six months of life, the number of elective bed days did not differ across SES groups, though lower SES patients had a larger number of emergency bed days. Analyses show higher SES patients had a greater number of outpatient visits, and adjusted end-of-life outpatient costs were slightly higher amongst higher SES patients. Exhibit A2 shows patients a socioeconomic gradient exists for colorectal, breast, and prostate cancers regardless of patients weighted Charlson score. Exhibit A3 show that even in the last month of life, a socioeconomic gradient is observed for type of care used.

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, this study finds evidence that socioeconomic disparities in end-of-life costs still remain. We find that end-of-life hospital costs for cancer patients are substantial, and lower SES patients have noticeably higher cost. This study finds that disparities in costs are due to a greater use of emergency care. Disparities in costs remain after controlling for patient-level characteristics.

The study highlighta 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 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. Similar disparities were observed in the last month of life. The greater use of emergency care is in line with previous studies which found lower SES patients had a higher probability of diagnoses through emergency presentation.[15]

As equality and free care at the point of delivery are key components of the NHS, the factors generating the observed disparities differ to those in market-based healthcare systems.

In this context, factors other than financial barriers play key roles. Similar quality of care is accessible to all patients regardless of their ability to pay in England, treatment available to patients is dependent upon meeting cost-effectiveness criteria, and financial incentives at the hospital- and doctor-level are at most minimal. Therefore, any disparities in cancer costs are likely explained by failures to more effectively manage the care of the patient, resulting in the use of less efficient care, particularly by lower SES patients. Difficulties accessing elective care may be due to undersupply of health services in more deprived areas and patients may face longer waiting times.[39] Organizational costs, travel costs, and informal care costs may also play a role.

A plethora of research has found that disparities in cancer survival and mortality exist in England and internationally. Disparities are a result of many factors including unhealthier behaviors such as smoking[40] and or lower use of screening.[41–44] 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.[45] These disparities are often placed within the wider social determinants of health literature.[46,47] Evidence shows that one year survival can be halved in patients diagnosed via an

emergency presentation as compared to other routes[12,16,48] and one in five cancers are diagnosed after an emergency presentation in England.[12–14] Therefore, further work is warranted on the key drivers of emergency care rather than primary and/or elective and the potential implications of substituting to non-emergency healthcare has on patient outcomes and healthcare costs.

The findings from this study are relevant to policymakers in other healthcare systems more generally. Healthcare costs at the end of life constitute a substantial portion of overall costs with Approximately 25% of Medicare costs incurred in the last year of life,[49] and a slightly lower proportion in England[35] and the Netherlands.[50] This intensive use of care at the end of life is found for cancer patients in England in this study. Similar intensive use of care is also seen amongst Medicare cancer patients, with 61% being hospitalized, and 10% visiting an ED more than once within 30 days of death.[51] Previous analyses have shown that end-of-life healthcare costs for cancer patients (aged 65 and over) in England are only half those in Canada and the United States.[52] This may reflect other types of care continuum in place, or a greater pecuniary incentive to provide to provide intensive care. However, similar use of emergency care amongst the poor is seen, with evidence from the United States showing EDs are increasingly serving as key healthcare for poorer or medically underserved patients, such as

individuals with Medicaid.[10] Additionally, other studies have shown emergency cancer surgery rates, often used as a proxy for quality of care, are higher amongst the uninsured or Medicaid patients[53] and amongst lower SES patients in England[54] resulting in increased hospital use and costs in both systems. While the lack of, or inadequate, insurance acts as a barrier to receiving of appropriate healthcare in the United States,[55] this cannot account for disparities in the NHS. Therefore disparities in costs manifest in different ways (though use off less appropriate care underpins disparities in all cases) and may be interpreted differently across healthcare system.

An increasingly key element in the cancer care pathway, which may also reduce hospital costs at the end-of-life, such as ED care,[56] is the use of more appropriate palliative care. The number of people dying in hospital in England has decreased over time, though a substantial proportion of people, especially poorer patients, still die in an acute setting.[57] The proportion of cancer patients dying in hospital in England (42%) is twice that observed in the US,[52] though lower than other countries, including Canada, where over half of patients die within an acute setting. [52] Having effective palliative care programs can reduce healthcare costs. Earlier palliative care consultation during admission to hospital in the United States is associated with lower hospital costs.[29,58] Additionally, effective end-of-

life care planning should reflect patients' preferences regarding place of death[59] irrespective of the healthcare system.[52] However, as other have discussed, it would not be wise to simply shift the burden of costs to informal carers.[60] Evidence from England highlighting that already, caregivers for end-of-life cancer patients spend approximately 10 hours daily providing care,[61] and people in lower SES often feel that they have less sufficient support to care for someone dying at home.[62]

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. 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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Exhibit List

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Caption: [Descriptive Statistics]
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Sources/notes: SOURCE [Authors' Analysis.]
• EXHIBIT 3 (figure)
Caption: [Elective and Emergency Admission Utilization across SES Quintiles (95% Confidence Intervals)]
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• EXHIBIT 4 (figure)
Caption: [Total Elective and Emergency Admission Costs across SES Groups (95% Confidence Intervals)]
Sources/notes: SOURCE [Authors' Analysis.]

Exhibit 1: Descriptive Statistics

	Lowest SES Quantile	Quantile 2	Quantile 3	Quantile 4	Highest SES Quantile
Colorectal					
Number of Patients	11,930	13,348	14,381	14,042	12,360
Mean Age at Diagnosis	73.12	74.55	74.47	74.46	73.71
Mean Weighted Charlson Index score	5.44	5.40	5.35	5.40	5.44
Mean number of days from diagnosis to death	478	482	496	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
Mean Age at Diagnosis	70.47	72.20	72.53	72.26	70.67
Mean Weighted Charlson Index score	5.28	5.03	5.06	5.00	5.06
Mean number of days from diagnosis to death	775	786	791	804	824
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
Mean Age at Diagnosis	76.24	77.25	77.69	77.37	77.19
Mean Weighted Charlson Index score	5.58	5.50	5.47	5.42	5.46
Mean number of days from diagnosis to death	757	751	771	760	775
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					
Number of Patients	30,089	26,465	23,728	20,549	15,918
Mean Age at Diagnosis	71.19	72.13	72.76	72.85	72.80
Mean Weighted Charlson Index score	5.35	5.31	5.28	5.31	5.34
Mean number of days from diagnosis to death	254	249	250	255	264
Mean Elective Cost	£1,959	£2,081	£2,127	£2,105	£2,184
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**	**£8,332**	**£8,196**	**£7,986**	**£8,040**