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# Healthcare use and costs in the last year of life: a national population data linkage study

Katharina Diernberger <sup>1,2</sup>, Xhyljeta Luta <sup>3</sup>, Joanna Bowden,<sup>4</sup> Marie Fallon <sup>5</sup>, Joanne Droney,<sup>6</sup> Elizabeth Lemmon,<sup>1</sup> Ewan Gray,<sup>1</sup> Joachim Marti,<sup>7,8</sup> Peter Hall<sup>1</sup>

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For numbered affiliations see end of article.

## Correspondence to

Dr Peter Hall, Edinburgh Cancer Research Centre, University of Edinburgh, Western General Hospital, Edinburgh, EH8 9YL, UK; [p.s.hall@ed.ac.uk](mailto:p.s.hall@ed.ac.uk)

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## ABSTRACT

**Background** People who are nearing the end of life are high users of healthcare. The cost to providers is high and the value of care is uncertain.

**Objectives** To describe the pattern, trajectory and drivers of secondary care use and cost by people in Scotland in their last year of life.

**Methods** Retrospective whole-population secondary care administrative data linkage study of Scottish decedents of 60 years and over between 2012 and 2017 (N=274 048).

**Results** Secondary care use was high in the last year of life with a sharp rise in inpatient admissions in the last 3 months. The mean cost was £10 000. Cause of death was associated with differing patterns of healthcare use: dying of cancer was preceded by the greatest number of hospital admissions and dementia the least. Greater age was associated with lower admission rates and cost. There was higher resource use in the urban areas. No difference was observed by deprivation.

**Conclusions** Hospitalisation near the end of life was least frequent for older people and those living rurally, although length of stay for both groups, when they were admitted, was longer. Research is required to understand if variation in hospitalisation is due to variation in the quantity or quality of end-of-life care available, varying community support, patient preferences or an inevitable consequence of disease-specific needs.

## BACKGROUND

Improving the availability and quality of palliative and end-of-life care is a global priority set out by WHO in their resolution on palliative care.<sup>1</sup> In 2015, The Scottish Government published The Strategic Framework for Action for Palliative and End of Life Care, with a vision that ‘By 2021, everyone in Scotland who needs palliative care will have access to it.’<sup>2</sup> While ambitious, the vision was said

## Key messages

### What was already known?

- Healthcare costs in the last year of life can be high, and typically increase with proximity to death.
- A range of clinical and demographic factors have been linked to higher healthcare use, including age, gender, the burden of disease and cause of death.

### What are the new findings?

- A whole Scottish population overview of patterns of secondary care use and associated costs in the last year of life.
- Identification of significant variation in secondary healthcare use by age, cause of death, comorbidity burden and rurality.
- Whole population secondary care cost data, which raises questions about the value of different dimensions of care to people in their last year of life.

### What is their significance?

- The findings challenge a prevailing assumption that older people are necessarily higher users of secondary care services.
- The pattern of inpatient and outpatient use towards the end of life varies in a manner that is predictable based on disease and age; raising questions for service commissioners and providers about the extent to which existing services meet needs and preferences of particular groups.
- Further research should seek system explanations for variation in healthcare use to determine if these represent necessary or unwarranted variation that could reflect underlying inequity of provision.

to be achievable through commitments that included commissioning guidance for health and social care partnerships and research to understand current unmet

needs and unwarranted variation in access to care and patient outcomes.

A systematic review of Scotland-based palliative care research published in 2018 revealed a lack of health economic research.<sup>3</sup> This was a timely observation with growing interest in demonstrating the value of healthcare, from the perspectives of people receiving care, and on the part of service commissioners and providers. Realistic Medicine, a landmark report from Scotland's Chief Medical Officer published in 2015, provided clear expectations of a future healthcare system that offered true value and minimised waste; with 'waste' described from the healthcare recipient's perspective, as interventions that do not add value to their care.<sup>4 5</sup>

People who are nearing the end of life are high users of secondary care services, which is referring to healthcare provided in hospitals including accident and emergency and outpatient departments. Around 50% of people in Scotland currently die in hospital.<sup>6–8</sup> Hospitalisation may be odds with the expressed preferences of people living with advanced illness.<sup>9</sup> It may be recommended for some people with complex clinical needs, but may also represent a culture and associated practices of so-called 'overmedicalisation'; whereby hospital-based care and interventions do not offer meaningful benefit to individuals and may even cause harm.<sup>10 11</sup> Clark *et al*<sup>7</sup> studied almost 11 000 hospital inpatients across 25 Scottish hospitals on a single day in March 2010. Almost one-third of inpatients were in their last year of life, with one in 10 dying during their current hospital admission.

A recent paper by Finucane *et al*<sup>12</sup> describes trends in place of death in Scotland between 2004 and 2016. A key finding was the marked reduction in hospital deaths from 58% to 50.1% during the study period and a corresponding increase in deaths in community settings including care homes. Given population projections of rising numbers of deaths and a higher proportion of deaths being in the elderly,<sup>13 14</sup> Finucane *et al* make the case for enhanced community palliative and end of life expertise and provision.

The Community Health Index (CHI) number is a unique identifier allocated to every Scottish resident offers a unique opportunity for robust population-based data linkage.<sup>15</sup> It was previously used by Geue *et al*<sup>16</sup> who used a longitudinal dataset linked to the national inpatient record (Scottish Morbidity Record, SMR01) dataset. The relationship between time-to-death (TTD) and age on healthcare service use and associated costs in 14 860 individuals. Both TTD and age were significant predictors for hospital costs in the last 3 years of life. Furthermore, there was some evidence that socioeconomic status, as measured by the Scottish Index of Multiple Deprivation (SIMD), influenced resource use.

A systematic review examining the intensity of end-of-life care found that the most commonly reported measures

for care intensity are hospitalisations, ICU admissions and chemotherapy use.<sup>17–19</sup>

Understanding the type, intensity of care and variation that people nearing the end of life receive is an important before recommendations can be made to improve access to appropriate palliative care.<sup>20</sup> The present study was conducted in parallel with a study of end-of-life healthcare trajectories and costs for decedents in England during 2010–2017.<sup>21</sup> We describe the rationale for separating the two studies in the Discussion section.

There were three key objectives:

1. To describe secondary healthcare use, trajectory and associated costs over the last year of life for the Scottish population.
2. To describe patterns of healthcare use for disease-specific subpopulations.
3. To investigate associations between demographic characteristics, including age and secondary healthcare access in the last year of life, in order to highlight possible unwarranted variation.

## METHODS

A retrospective population-level data linkage study was undertaken, including all decedents in Scotland in 2012–2017, who were over 60 years of age on their date of death. Secondary healthcare use was examined over the last 12 months of life. Deaths under the age of 60 were not included, in order to maintain sufficient underlying disease prevalence for meaningful study.

### Data sources

Data were obtained from Public Health Scotland via the Scottish Research Data Safe Haven. Linkage was established between the SMR outpatient, inpatient and day case and the National Records of Scotland (NRS) record of deaths using CHI number as the primary key for linkage.<sup>9</sup> SMR01 includes episode-based patient records that relate to all acute inpatient and day cases. To reduce measurement error, the SMR01 data were checked for data entry anomalies such as duplicates, overlapping and nested episodes (see online supplemental table 1). SMR00 relates to all outpatients (new and follow-up) in specialties other than Accident & Emergency and Genito-Urinary Medicine. In addition, we relied on NRS deaths data and the SIMD.

### Inclusion and exclusion criteria

Detailed eligibility criteria are reported in online supplemental figure S1. Major inclusion criteria were:

- ▶ Death registered between 1 January 2012 and 31 December 2017.
- ▶ Age at death  $\geq 60$  years.
- ▶ Healthcare data available for a minimum of 12 months prior to death.

Online supplemental figure S1 describes the data sources and the selection of the study population. The NRS death dataset of participants meeting the eligibility criteria was merged with the outpatient dataset

SMR00 and with the inpatient and day case data SMR01. Inpatient and outpatient resource use was excluded if the patient identifier was missing or if the resource use occurred outside the study period.

#### Patient characteristics

Patient characteristics included gender, age and primary cause of death (one of five ICD-10 categories Cancer, Circulatory, Respiratory, Dementia and other). Comorbidity was estimated using the Charlson Comorbidity Index (CCI).<sup>22</sup> The CCI was based on secondary care coding which entailed a 5-year lookback from the patients first admission, with the limitation that only patients who accessed secondary care during their last year of life had a CCI score. An urban–rural indicator was included, developed by the Rural and Environment Science and Analytical Services Division and the SIMD.<sup>23</sup>

#### Outcome measures

##### Inpatient and day care

Hospital inpatient care in the last year of life was captured as: number of hospital admissions, mean number of bed days per stay and total number of bed days over the 12-month period.

To estimate the cost of inpatient care, the Scottish health service costs (Scottish cost book) was used, mainly R040 (Specialty group costs—Inpatients in all specialties excluding long stays) and R040LS (Specialty group costs—Inpatients in all specialties long stays). Critical care stays are included within mean costs. Day cases were costed using R042 (Specialty group costs—day cases).<sup>24</sup>

##### Outpatient care

Outpatient data included the number and nature of outpatient appointments per patient in the last year of

**Table 1** Study population and resource use (outpatient and inpatient count and SD, overall length of stay (LOS) within a hospital and average in-hospital time per inpatient stay) in the last year of life

Category	N	%	Inpatient count	Outpatient count	LOS	LOS/stay
Sex						
Men	124860	45.6	5.4 (5.1)	3.6 (5.2)	33.2	7.3
Women	149188	54.4	4.9 (4.7)	2.8 (4.4)	34.3	8.1
Age						
60–64	27671	10.1	6.6 (6.6)	5.2 (6.9)	30.5	5.6
65–69	34886	12.7	6.1 (6.0)	4.6 (6.0)	32.1	6.1
70–74	46032	16.8	5.5 (5.4)	3.9 (5.4)	33.0	6.9
75–79	55987	20.4	5.0 (4.6)	3.0 (4.2)	34.8	7.8
80–84	54527	19.9	4.5 (3.8)	2.2 (3.2)	35.6	8.7
85–89	38899	14.2	4.0 (3.2)	1.7 (2.5)	35.0	9.5
90+	16046	5.9	3.6 (3.0)	1.2 (1.8)	33.7	10.0
Main cause of death						
Circulatory	80064	29.2	4.5 (4.1)	2.3 (3.5)	32.7	7.6
Cancer	75236	27.5	6.0 (5.8)	5.4 (6.4)	32.6	7.2
Other	57693	21.1	4.9 (5.0)	2.5 (4.2)	36.2	8.3
Respiratory	38747	14.1	5.2 (4.5)	2.3 (3.3)	35.3	7.4
Dementia	22308	8.1	3.7 (3.1)	1.2 (1.9)	32.7	9.2
SIMD (from most to least deprived)						
First	60562	22.1	5.6 (5.0)	3.3 (4.6)	34.7	7.1
Second	61351	22.4	5.2 (5.0)	3.2 (4.8)	34.1	7.6
Third	58400	21.3	4.9 (4.6)	2.9 (4.6)	32.9	7.9
Fourth	50101	18.3	4.9 (4.7)	3.0 (4.7)	33.1	8.0
Fifth	42982	15.7	5.1 (5.4)	3.3 (5.1)	33.9	8.2
Urban/rural (from urban to rural)						
Large urban areas	90172	32.9	5.6 (5.3)	3.3 (4.4)	37.0	7.7
Other urban areas	97991	35.8	5.1 (4.9)	3.2 (5.2)	32.0	7.3
Accessible small towns	25904	9.5	4.9 (4.5)	3.1 (4.8)	32.8	7.7
Remote small towns	12222	4.5	4.4 (4.7)	2.4 (3.7)	33.9	9.3
Accessible rural	29573	10.8	4.8 (4.7)	3.1 (4.9)	31.8	7.6
Remote rural	18186	6.6	4.4 (4.5)	2.4 (3.7)	31.6	8.6
Total	274048	100.0	5.1 (4.9)	3.1 (4.8)	33.8	7.7

SIMD, Scottish Index of Multiple Deprivation.

**Table 2** Healthcare utilisation in the last year and in the last month of life

Healthcare utilisation	N=274 048	Last 12 months	Last month
Inpatient care	Hospitalisations, no (%)	200 510 (73.16)	80 287 (29.296)
	Hospital admissions, mean (SD)	5.1 (4.9)	0.856 (1.399)
	Hospital duration (days), mean (SD)	33.8 (37.8)	5.14 (6.48)
Day cases	Day cases, no (%)	17 540 (6.3)	1363 (0.497)
Outpatient care	Outpatient visits, no (%)	217 772 (79.465)	92 454 (33.736)
	Outpatient visits, mean (SD)	3.1 (4.8)	0.406 (0.7007)

life. Costs for outpatient appointments were derived from the Scottish health service costs documents R044 (Specialty group costs—consultant outpatients), R045 (Specialty group costs—Nurse-led clinics) and R046 (Specialty group costs—Allied Health Professionals). The costs are based on national average unit costs for each service code.

### Statistical analysis

Descriptive statistics were used to characterise the study population. Means and SD were calculated for services and costs. Generalised linear models (GLM) as recommended by Glick *et al* were used to model costs as they are robust to skewed distributions typical for HC data.<sup>25</sup> Important predictors are age, gender, primary cause of death, SIMD, an urban–rural indicator and comorbidity. In order to estimate the effect of age, primary cause of death and CCI in isolation including the other predictors as covariates in the GLM<sup>26 27</sup> We also assessed potential interactions

between age and gender as well as age and cause of death. Analysis used Stata V.16 (StataCorp).

## RESULTS

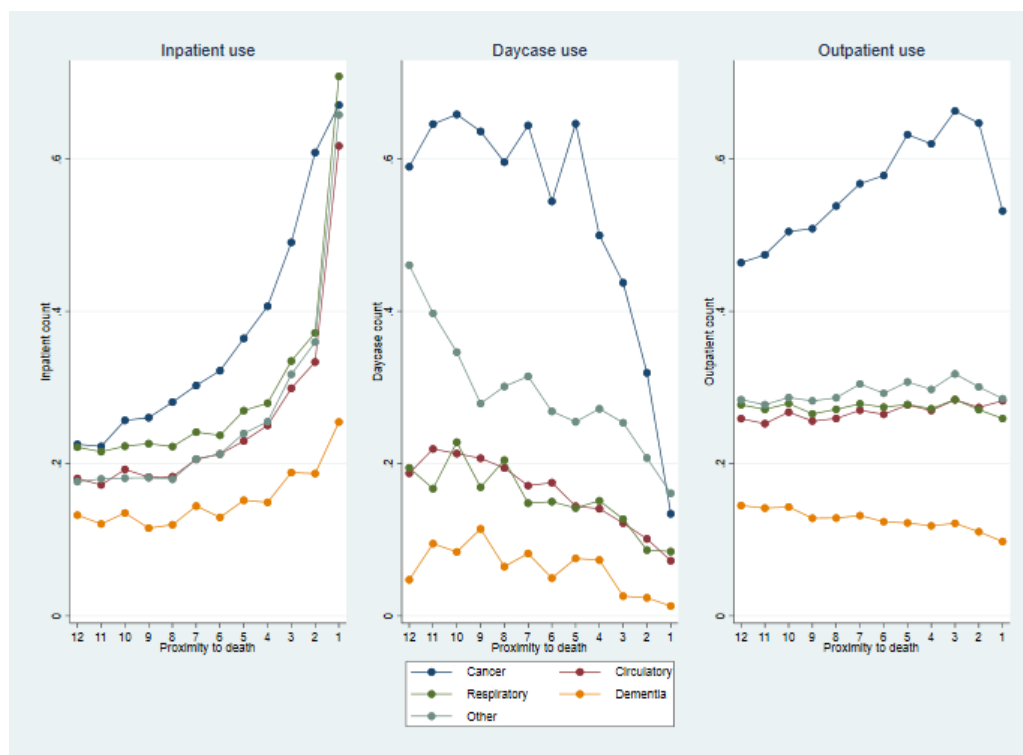
### Patient characteristics

A total of 339 963 people died in Scotland between 1 January 2012 and 31 December 2017, of whom 274 048 met the eligibility criteria.

Sixty per cent of the decedent population were under 80 years old at death and 54% were female (table 1). The most common causes of death were circulatory diseases (29.2%) and cancer (27.5%). Around two-thirds of the study population lived in urban areas, around 20% in accessible small towns or accessible rural areas and 10% in small remote towns and remote areas.

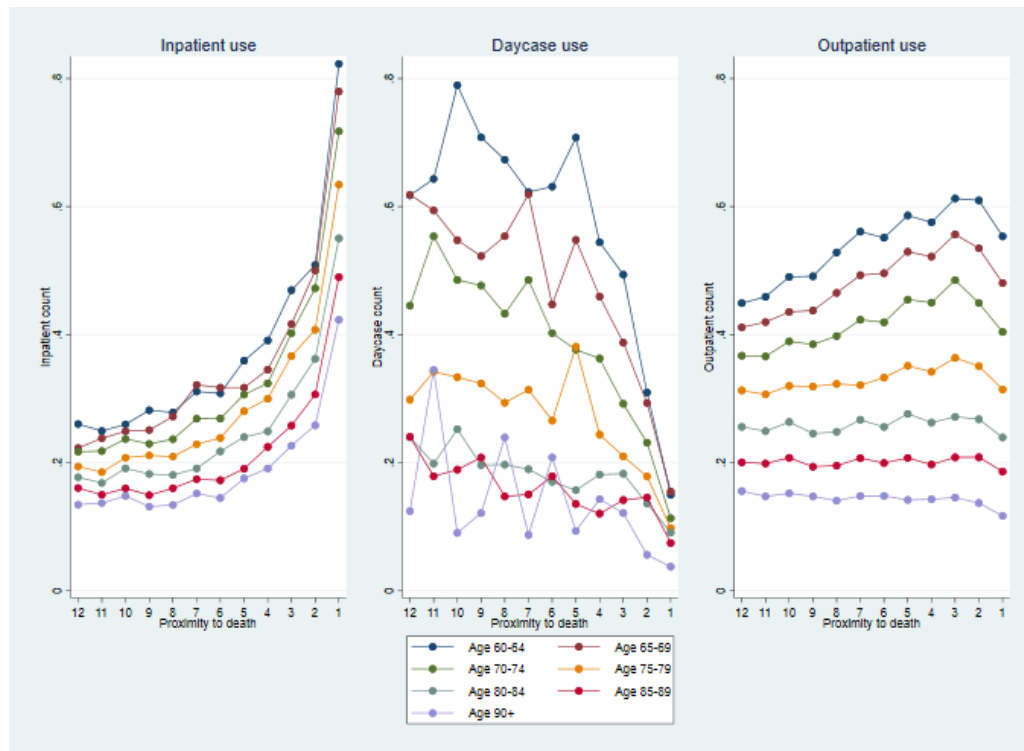
### Inpatient, outpatient and day case use and costs

The mean number of hospital inpatient admissions during the last year of life was 5.1 (SD: 4.9)



**Figure 1** Resource use (secondary care) in the last year of life for inpatient, day case and outpatient use split by main causes of death.





**Figure 2** Resource use in the last year of life for inpatient, day case and outpatient use split by age groups. (The y-axis displays the average number of inpatient, day case and outpatient appointments in the specified month).

and hospital outpatient appointments 3.1 (SD: 4.8) (table 2). The mean total number of hospital bed days in the last year of life was 33.8, with a mean length of stay per admission of 7.7 days. Examining the unadjusted differences, males had a higher number of inpatient and outpatient appointments than females but spent fewer total days in hospital due to a shorter average length of stay. Around three-quarters of study participants were hospitalised at least once in their last year, and 29% in their last month of life. Nearly 80% of the study population had one or more outpatient appointment in their last year, with one-third having an outpatient appointment during their last month of life. The number of day case appointments was comparably small with 6.3% of the population having one or more in their last year and just under 0.5% having a day case appointment in the last month of life.

The mean cost of secondary care was £ 10 134 (95% CI 9921 to 10 337) per person in the last year of life (online supplemental table S3). Proximity to death had the biggest influence on adjusted monthly costs (online supplemental table S4). The main contributor to costs over the final 12 months of life was inpatient hospital stays; peaking during the last 3 months when admissions were most common.

#### Healthcare use by primary cause of death

There were significant differences in patterns of healthcare use by decedents' cause of death (figure 1). Inpatient hospitalisation rates accelerated over the last year of life for all causes of death, and this was

most pronounced in circulatory or respiratory disease. Patients who died from cancer accessed more day care over the last year of life. Frequency of outpatient care remained relatively constant over the last year of life for most groups, except for those who died of cancer were higher users of all three domains of secondary healthcare.

A total of 218 357 decedents had an evaluable CCI score, with missing data reflecting those with no hospital records during the last year of life. Around one-third of this subpopulation had a CCI score of 0, 60% had a score between 1 and 5 and the remaining 5% had a score between 6 and 12 reflecting the highest disease burden (online supplemental table 2). Adding comorbidity as an explanatory variable into a GLM (online supplemental table 3), it can be observed that a higher CCI is associated with higher secondary healthcare costs, but with some variability.

#### Healthcare use and costs by age and demographics

Inpatient hospitalisation increased in frequency in all age categories with proximity to death, with a steep rise in the last 3 months of life (figure 2). The frequency of day case use varied considerably over the last year for all age groups, though younger patients accessed significantly more day case care. Outpatient use was largely constant across the last year for the population groups over 75 years of age, while the younger population had a slight increase until 3 months prior to death, followed by a sharp decrease.

**Table 3** Generalised linear model—unadjusted costs with CIs on the left, adjusted generalised linear model on the right

Age group	Unadjusted costs (£)	95% CI	Adjusted costs (£)	95% CI
60–64	12420.7***	(12262.5 to 12578.9)	12411.4***	(12271, 12551.9)
65–69	11522.1***	(11391.9 to 11652.4)	11894.1***	(11775.6, 12012.5)
70–74	10695.5***	(10590.5 to 10800.4)	11615.5***	(11515.5, 11715.4)
75–79	9525.4***	(9440.4 to 9610.3)	11331.6***	(11240.7, 11422.5)
80–84	8406.5***	(8330.1 to 8482.9)	10970.3***	(10876.9, 11063.7)
85–89	7296.2***	(7216.6 to 7375.7)	10499.6***	(10388.8, 10610.4)
90+	6117.3***	(6009.0 to 6225.5)	10019.3***	(9843.35, 10195.4)
Observations	260636			

Adjusted for gender, main cause of death, SIMD, Urban-rural Indicator, Charlson Comorbidity Index.

95% CI in brackets \* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ .

SIMD, Scottish Index of Multiple Deprivation.

One-year adjusted and unadjusted costs decreased with increasing age (table 3 and figure 2). Unadjusted costs for the youngest group were £12 420.7, which was double the costs for those aged 90 and over. However, after adjusting for gender, primary cause of death, SIMD, RU and comorbidity, costs for the youngest and the oldest begin to converge.

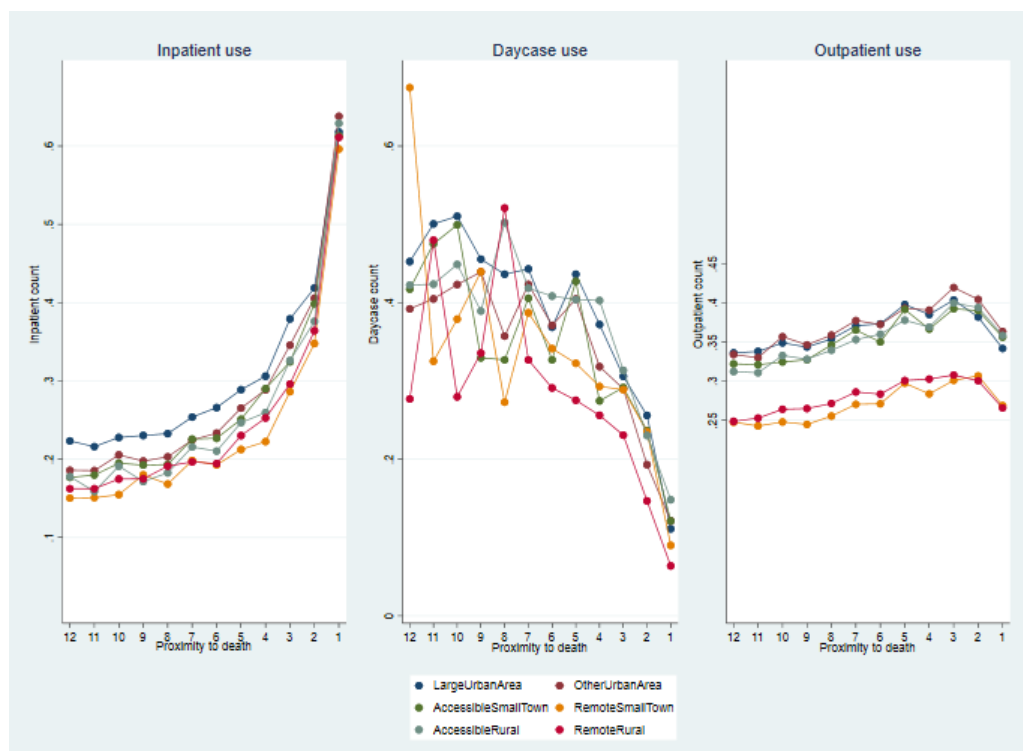
People living in large urban areas had highest use of all types of healthcare (figure 3). Those in remote small towns and remote rural areas used fewest resources, with exceptionally low use of outpatient appointments. No clear trend was observed with deprivation presented in online supplemental table 2.

## DISCUSSION

### Main findings

Inpatient hospitalisation was increasingly common over the last year of life and particularly when close to death. This was consistent across all causes of death, age and rurality groups. On average, people spent more than one of their last 12 months of life in hospital, typically over several admissions. Inpatient costs comprised the greatest proportion of the £10 000 average secondary care cost, at more than £8500 per decedent.

The intensity and pattern of daycase care and outpatient appointments was more mixed, although the use of both fell sharply close to death with considerably smaller costs, at £400 and £650, respectively.



**Figure 3** Resource use in the last year of life for inpatient, day case and outpatient use split by rural–urban indicator.

### Strengths and limitations of the study

The primary strength of our study is that our data covered the entire Scottish population of decedents and captured near-complete secondary care use during their last year of life. Therefore, our resource use estimates are less prone to bias due to non-random selection, as may occur in cohort studies.

The main limitation of our study was the breadth and depth of available data for linkage. We were unable to describe the nature of acute hospital admissions, including reasons for admission and whether the person was admitted to critical care during their inpatient stay. Furthermore, we could not describe the extent to which patients accessed palliative care. These limitations reflect both the lack of usable coded data relating to clinical care episodes, but also, typically, Covid-era restrictions on data access due to human resource reallocation. We must also acknowledge that secondary care represents only one dimension of healthcare. Therefore, data linkage to records reflecting the whole spectrum of health and social care must be a priority for future studies. Our parallel study of decedents in England was able to draw on primary care data, although only for a particular cohort.<sup>21</sup>

### What this study adds

Primary cause of death was clearly associated with differing patterns of healthcare use. The population who died of cancer were consistently the most frequent users of secondary healthcare, with those dying of dementia consistently the least, following a pattern previously described by Murray *et al.*<sup>28</sup> Older decedents used significantly less secondary healthcare during their last year of life, as did those living rurally. These results are in line with the findings of our parallel English study by Luta *et al.*

The extent to which observed patterns of use reflect the needs or preferences of the different populations is unknown. Further research is needed to explore this and to investigate the likelihood of benefit of secondary care interventions close to death. This would allow quantification of the value of care.

Patterns of healthcare use are inevitably influenced by clinical service configuration. For instance, cancer care is predominantly secondary care outpatient led, with individuals typically receiving treatment as day cases. Therefore, it is not surprising that outpatient and day case use was observed to be particularly high in this subpopulation. Services for people with dementia are more likely to be community or social care based and it follows that this population access secondary care less than other groups.

The accessibility of healthcare is important, highlighted by our finding that rural populations access lower levels of secondary healthcare during their last year. We do not know whether rural individuals access more primary care or indeed whether their needs differ from those in more urban areas. The parallel study of decedents in England

showed that lower frequency hospitalisations in the last year of life for people in the South-West region were accompanied by a greater number of primary care contacts. Luta *et al* were not able to comment on causation, but it is possible that more primary care support for people with advanced illness may reduce the need for inpatient hospitalisation.

### CONCLUSION

Improving the quality and appropriateness of care for people in the last phase of life is a national and international priority.<sup>1 2 5</sup> We have described patterns of secondary healthcare use and associated costs for over a quarter of a million Scottish decedents; highlighting that inpatient hospitalisation accounts for a great proportion of costs, and is of uncertain value.

Detailed prospective quantitative and qualitative exploration around the value of admissions, day care and outpatient visits in the last year of life is needed. Apart from insight into the patient experience and appropriateness of care, this could identify gaps in care and inequalities.

We require better insight into the value of the social care system and how community care can be a realistic alternative to hospital-based care.<sup>29</sup> Integrated health and social care in Scotland is a new reality and provides opportunity for whole system learning.<sup>2</sup>

Ultimately, our goal must be to maximise value all round, with people nearing the end of life receiving high value care that is tailored to their needs, but simultaneously offers value to care commissioners and providers.

### Author affiliations

<sup>1</sup>Edinburgh Health Economics Group, University of Edinburgh, Edinburgh, UK

<sup>2</sup>Edinburgh Cancer Research Centre, University of Edinburgh, Edinburgh, UK

<sup>3</sup>Centre for Primary Care and Public Health, University of Lausanne, Lausanne, Switzerland

<sup>4</sup>Palliative Care, NHS Fife, Dunfermline, UK

<sup>5</sup>Palliative Medicine, University of Edinburgh, Edinburgh, UK

<sup>6</sup>Palliative Care, The Royal Marsden NHS Foundation Trust, London, UK

<sup>7</sup>Centre for Primary Care and Public Health (Unisanté), University of Lausanne, Lausanne, Switzerland

<sup>8</sup>Department of Surgery and Cancer, Institute of Global Health Innovation, Imperial College London, London, UK

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#### ORCID iDs

Katharina Diernberger <http://orcid.org/0000-0002-7862-0125>

Xhyljeta Luta <http://orcid.org/0000-0002-5716-4693>

Marie Fallon <http://orcid.org/0000-0001-9214-0091>

#### REFERENCES

- Connor SR, Bermedo MC, eds. *Global atlas of palliative care at the end of life*. Worldwide Palliative Care Alliance, 2014.
- Scottish government: strategic framework for action on palliative and end of life care: 2016–2021, 2015. Available: <http://www.gov.scot/Publications/2015/12/4053/downloads>. In
- Finucane AM, Carduff E, Lugton J, *et al*. Palliative and end-of-life care research in Scotland 2006–2015: a systematic scoping review. *BMC Palliat Care* 2018;17:19.
- Scottish Government. Chief Medical Officer's Annual Report 2014–15. Realistic medicine, 2016. Available: <http://www.gov.scot/Publications/2016/01/3745> [Accessed 2 Apr 2020].
- Scottish Government. Strategic Framework for Action on Palliative and End of Life Care - Supporting Evidence Summary, 2015. Available: <http://www.gov.scot/Resource/0049/00491390> [Accessed 16 Apr 2020].
- Bekelman JE, Halpern SD, Blankart CR, *et al*. Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries. *JAMA* 2016;315:272–83.
- Clark D, Armstrong M, Allan A, *et al*. Imminence of death among hospital inpatients: prevalent cohort study. *Palliat Med* 2014;28:474–9.
- National Records of Scotland. Spreadsheet titled Weekly deaths by location and health board, 2015–2019, 2020. Available: <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/weekly-and-monthly-data-on-births-and-deaths/deaths-involving-coronavirus-covid-19-in-scotland/related-statistics> [Accessed 1 Apr 2020].
- Mills S, Buchanan D, Guthrie B, *et al*. Factors affecting use of unscheduled care for people with advanced cancer: a retrospective cohort study in Scotland. *Br J Gen Pract* 2019;69:e860–8.
- Hughes-Hallet T, Craft A, Davies C. *Palliative care funding review: funding the right care and support for everyone*. London: Department of Health, 2011.
- Earle CC, Neville BA, Landrum MB, *et al*. Trends in the aggressiveness of cancer care near the end of life. *JCO* 2004;22:315–21.
- Finucane AM, Bone AE, Evans CJ, *et al*. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. *BMC Palliat Care* 2019;18:1–11.
- National Records of Scotland. Vital events reference tables 2017. Available: <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statisticsby-theme/vital-events/deaths> [Accessed 15 Aug 2018].
- Office for National Statistics. National population projections: 2016-based projections, methodology, 2016. Available: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/compendium/nationalpopulationprojections/2016basedprojections> [Accessed 13 Aug 2018].
- ISD Scotland. Data dictionary, 2019. Available: <https://www.ndc.scot.nhs.uk/Dictionary-A-Z> [Accessed 2 Dec 2019].
- Geue C, Lorgelly P, Lewsey J, *et al*. Hospital expenditure at the end-of-life: what are the impacts of health status and health risks? *PLoS One* 2015;10:e0119035.
- Luta X, Maessen M, Egger M, *et al*. Measuring intensity of end of life care: a systematic review. *PLoS One* 2015;10:e0123764.
- Pasman HRW, Brandt HE, Deliens L, *et al*. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage* 2009;38:145–56.
- De Roo ML, Leemans K, Claessen SJJ, *et al*. Quality indicators for palliative care: update of a systematic review. *J Pain Symptom Manage* 2013;46:556–72.
- Bardsley M, Georghiou T, Spence R, *et al*. Factors associated with variation in hospital use at the end of life in England. *BMJ Support Palliat Care* 2019;9:167–74.
- Luta X, Diernberger K, Bowden J, *et al*. Healthcare trajectories and costs in the last year of life: a retrospective primary care and hospital analysis. *BMJ Support Palliat Care* 2020. doi:10.1136/bmjspcare-2020-002630. [Epub ahead of print: 02 Dec 2020].
- Sundararajan V, Henderson T, Perry C, *et al*. New ICD-10 version of the Charlson comorbidity index predicted in-hospital mortality. *J Clin Epidemiol* 2004;57:1288–94.
- Scottish Government. Scottish government urban rural classification. defining Scotland by rurality, 2020. Available: <https://www2.gov.scot/Topics/Statistics/About/Methodology/UrbanRuralClassification> [Accessed 16 Jan 2020].
- ISD Scotland. Scottish health service costs. summary guidance. Available: [https://www.isdscotland.org/Health-Topics/Finance/Publications/2019-11-19/Summary\\_Guidance\\_2019.pdf](https://www.isdscotland.org/Health-Topics/Finance/Publications/2019-11-19/Summary_Guidance_2019.pdf) [Accessed 19 Nov 2019].
- Glick HA, Doshi JA, Sonnad SS, *et al*. Economic evaluation in clinical trials. OUP Oxford 2014.
- Hazra NC, Rudisill C, Gulliford MC. Determinants of health care costs in the senior elderly: age, comorbidity, impairment, or proximity to death? *Eur J Health Econ* 2018;19:831–42.
- Moran JL, Solomon PJ, Peisach AR, *et al*. New models for old questions: generalized linear models for cost prediction. *J Eval Clin Pract* 2007;13:381–9.
- Murray SA, Kendall M, Boyd K, *et al*. Illness trajectories and palliative care. *BMJ* 2005;330:1007–11.
- Werblow A, Felder S, Zweifel P. Population ageing and health care expenditure: a school of 'red herrings'? *Health Econ* 2007;16:1109–26.