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Original Article

End-of-life care for people with chronic kidney disease: cause of death, place of death and hospital costs

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ABSTRACT

Background. End-of-life care for people with chronic kidney disease (CKD) has been identified as an area of great clinical need internationally. We estimate causes and place of death and cost of hospital care for people with CKD in England in the final 3 years of life.
Methods. Hospital Episode Statistics data were linked to Office for National Statistics mortality data to identify all patients in England aged ≥18 years who died 1 April 2006–31 March 2010, and had a record of hospital care after 1 April 2003 (the study group). The underlying cause and place of death were examined in Office for National Statistics data, for patients without and with CKD (identified by International Classification of Diseases version 10 codes N18, I12 and I13). Costs of hospital admissions and outpatient attendances were estimated using National Health Service Reference Cost data. Associations between CKD and hospital costs, and between place of death and hospital costs in those with CKD, were examined using multivariate regressions.
Results. There were 1 602 105 people in the study group. Of these, 13.2% were recorded as having CKD. The proportion of deaths at home was 10.7% in people with CKD and 17.2% in the age- and gender-matched non-CKD group. Regression analysis suggests that CKD was associated with an increase in hospital costs of £3380 in the last 12 months of life, holding constant place of death, comorbidities and other variables. For the CKD group, home death was associated with a reduction in hospital costs of £2811 in the 12 months before death. The most commonly recorded cause of death in people with CKD was heart disease. CKD was not mentioned on the death certificate in two-thirds of deaths in people with the condition.
Conclusions. People with CKD are less likely to die at home than those without CKD. The condition is associated with increased hospital costs at the end of life regardless of place of death. Home death in CKD is associated with a substantial reduction in hospital costs at the end of life.

Keywords: chronic kidney disease, costs, end of life, health economics

INTRODUCTION

Prevalence rates of chronic kidney disease (CKD) appear to be increasing globally [1, 2], and the condition is associated with high mortality, especially from cardiovascular events [3, 4]. In many countries, there is concern that the quality of end-of-life care for people with CKD is suboptimal. The Kidney Disease: Improving Global Outcomes group has recently identified advanced care planning and end-of-life/supportive care for CKD patients as areas of great clinical need internationally [5].

Most studies of end of life in CKD have focussed on patients on long-term dialysis. In this group, there is international evidence of under-utilization of hospices, relative to other dying patients [6], and of poor communication between patients and doctors regarding palliative care options [7]. These patients experience high rates of hospitalization and use of intensive procedures, relative to patients dying of conditions such as cancer or heart failure [8]. Evidence from North America suggests that most deaths occur in acute hospitals, although a majority of patients would prefer to die at home or in a hospice [6, 7].

Little is known of the care provided at the end of life to the much larger group of people who have CKD but have not been on long-term dialysis, or even of mortality rates at the population level in this group. An earlier study examined age and gender distributions and place of death, in cases where renal disease was mentioned on death certificates [9]. However, CKD is often not mentioned on death certificates, even when the primary cause of death is an event such as heart failure, for which CKD carries increased risk. Our article links mortality data to hospital records to capture a larger cohort of people with CKD. We examine death rates, causes of death and place of death in people who die with CKD in England, and estimate the costs of hospital care at end of life, and the impact of place of death on these costs.

The English National Health Service (NHS) has identified end-of-life care as a key area for improvement. The Department of Health has recognized that 'Some people experience excellent care in hospitals, hospices, care homes and in their own homes. But … many do not. Many people experience unnecessary pain and other symptoms' [10]. There is a commitment to enable more people to die in their own homes, if they wish. Approximately half of all deaths in adults in England occur in hospital, although surveys indicate that most people would prefer to die elsewhere [1, 11, 12].

Lack of knowledge of the cost of current care is a key barrier to the commissioning of high-quality services to enable people to die at home. We hope this article will support future decision making on cost-effective care for these patients.

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MATERIALS AND METHODS

Hospital Episode Statistics (HES) data were linked to Office for National Statistics (ONS) mortality data to identify all patients in England who died aged ≥18 years between 1 April 2006 and 31 March 2010 (the study period), and who had a record of hospital care at any time between 1 April 2003 and the time of death. HES provide details of patient's age, gender, diagnoses, procedures and length of stay for all hospital admissions in England, and of outpatient attendances. ONS mortality data provide details of place of death, underlying cause of death and contributory factors.

People with International Classification of Diseases version 10 (ICD-10) codes N18, I12 or I13 on their death certificate or in HES were identified as having CKD. Patient age at the time of death was calculated from HES data, and patients were divided into eight age groups (18–29, 30–39, 40–49, 50–59, 60–69, 70–79, 80–89 and 90+ years). Children <18 years were excluded as CKD prevalence is very low, and care needs and provision at end of life are likely to be different from those of adults.

Our combined dataset was compared with the full ONS mortality dataset for the study period, to determine the proportion of all deaths included in the combined dataset.

The underlying cause of death, place of death (home or not), comorbidities and hospital resource use were examined for people with CKD and for a comparator non-CKD group of the same gender and age at death. As the comparator group was selected by gender and age at death, comparisons focus only on the distribution of characteristics such as cause of death, and not on the probability of death.

The underlying cause and place of death were taken from ONS mortality data. Comorbidity and resource use were examined in HES data.

Home deaths were identified by an 'H' code in the communal establishment field on the patient's death record. This code indicates that the patient died in his or her own home and that this was not a communal establishment. Nursing homes and residential homes were not included as home deaths, owing to ONS concerns over data quality.

Comorbidities were examined in HES data using ICD-10 codes (see Supplementary data). Hospital activity was examined in HES for 3 years before death for patients with and without CKD, by age group and place of death.

The cost of all hospital admissions and outpatient attendances was estimated using NHS Reference Cost data for 2005–06, by Healthcare Resource Group (HRG) and outpatient specialty [13]. HRGs are groups of healthcare activities that are clinically related and similar in cost. NHS Reference Costs are derived annually by the Department of Health from costs reported by all hospitals in England. Costs were updated to 2014–15 prices, using the Personal and Social Service Research Unit Costs of Health and Social Care [14]. Further details are provided in Supplementary data.

Extended generalized linear model multivariate regression analyses were undertaken, The first regression examined the association between CKD and cost of hospital care at the end of life holding age, gender, place of death (home or not) and comorbidities (diabetes, cancer, chronic obstructive pulmonary disease, heart disease and stroke) constant. The second regression examined the association between place of death and cost of hospital care at the end of life in those with CKD, holding age, gender and comorbidities (as above) constant. In both cases, associations were estimated over the final 3 and 12 months of life.

RESULTS

Prevalence

Between 1 April 2006 and 31 March 2010, there were 1 602 105 deaths in people aged ≥18 years for whom HES records indicated hospital activity after 1 April 2003. Of these, 211 215 occurred in people recorded as having CKD in the HES dataset or on their death certificate.

Comparison of our numbers with the full ONS mortality dataset indicates that our dataset includes 86.4% of all adults who died in England during the study period, and 97.3% of those who had a mention of CKD on their death certificate. For the remainder, no healthcare data were available, as they had no record of hospital care between 1 April 2003 and the time of death. Further details are given in Supplementary data.

In the combined HES/ONS dataset, the mean age of death was 81.0 years in those with CKD, and 77.3 in those without CKD. The prevalence of CKD increased substantially with age at death; prevalence in those who died below the age of 60 years was 6.4% in women and 7.6% in men. Among those who died aged ≥60 years, CKD prevalence was 12.4% in women and 18.0% in men.

Cause of death

In 90.4% of deaths in people with CKD, the underlying cause of death given on the death certificate was non-renal (Table 1). CKD was not mentioned on the death certificate either as the

Table 1 Underlying cause of death on death records of people with CKD, 2006-10

Underlying cause of death	ICD-10	n	% of deaths in people with CKD
Renal causes			
Chronic Kidney Disease	N18	5358	2.5
Other disorders of urinary system	N39	5350	2.5
Malignant neoplasms of urinary organs	C64-C68	4829	2.3
Hypertensive renal disease	I12	2240	1.1
Hypertensive heart and renal disease	I13	790	0.4
Unspecified renal failure	N19	1191	0.6
Acute renal failure	N17	608	0.3
Total renal causes		20366	9.6
Non-renal causes		190849	90.4

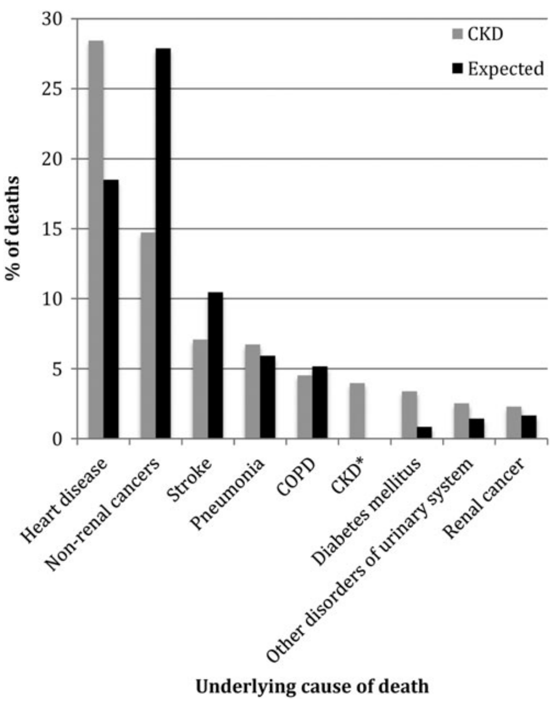

Figure 1 Distribution of underlying causes of death in people with CKD, compared with expected distribution based on deaths in people of the same age band and gender without CKD.
COPD: chronic obstructive pulmonary disease. *ICD-10 codes N18, I12, I13.

underlying cause or a contributory factor in two-thirds of deaths in people with the condition.

The most commonly recorded underlying causes of death in people with CKD were heart disease, cancer, stroke and pneumonia. The proportion of deaths attributed to heart disease (28.4%) was 1.5 times the proportion in people of the same age and gender without CKD (Figure 1). Non-renal cancer accounted for 14.7% of deaths in people with CKD, and 27.9% of deaths in people of the same age and gender without CKD. However, the proportion of deaths attributed to renal cancer (2.3%) was 1.4 times the proportion in people without CKD of the same gender and age at death. Diabetes was given as the underlying cause in four times as many deaths in people with CKD (3.4%) as for people of the same and age and gender without CKD (0.8%). Further details are given in Supplementary data.

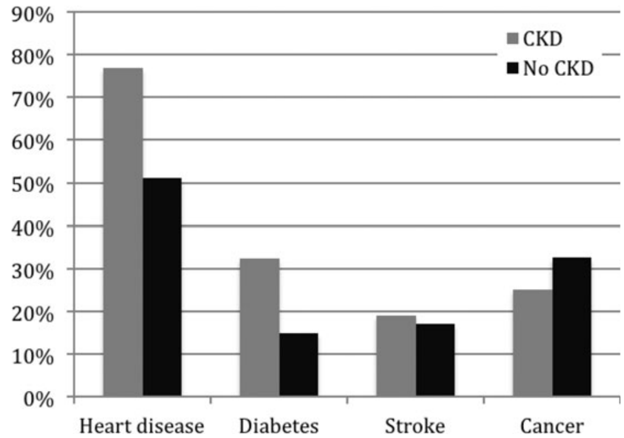

FIGURE 2: Comorbidities in people who died with CKD, and in people of the same age band and gender who died without CKD.

Comorbidities

Of those identified as having CKD in HES, 76.8% also had a diagnosis of heart disease on their HES record, and 32.4% had a diagnosis of diabetes, compared with 51.1 and 14.8%, respectively, in the standardized non-CKD group (Figure 2).

Place of death

The proportion of deaths at home was 10.7% in people with CKD and 17.2% in the standardized non-CKD group. People with CKD were less likely to die at home than those without CKD, in every age category.

Death at home was more common in men than in women in all age groups aged ≥30 years, for those with and without CKD. Overall, 12.5% of men and 8.5% of women with CKD died at home. The age-standardized rates for non-CKD were 19.6% for men and 14.2% for women. Younger age also increased the likelihood of home death; in the CKD group, 16.4% of those aged <70 years and 9.9% of those aged ≥70 years died at home.

Hospital admissions and bed days

The monthly (defined as 30-day) bed-day rate was higher for people with CKD than for the standardized non-CKD group at all stages in the 3 years before death. Over the 3-year period, there were 1.5 times as many bed days in people with CKD as in the standardized non-CKD population.

In both groups, the bed-day rate increased sharply in the months before death. In the CKD group, 12.1% of all bed days in the final 3 years of life occurred in the month before death, and 32.8% of bed days in the 3 months before death. A total of 94.3% of bed days in the last 90 days of life in people with CKD were non-elective (Figure 3).

Of admissions in the last 90 days of life in people with CKD, more than 40% were ascribed to 1 of 10 primary diagnoses (Supplementary data). The most common primary diagnoses were heart failure and pneumonia (each accounting for 8% of all admissions in people with CKD in the last 90 days of life).

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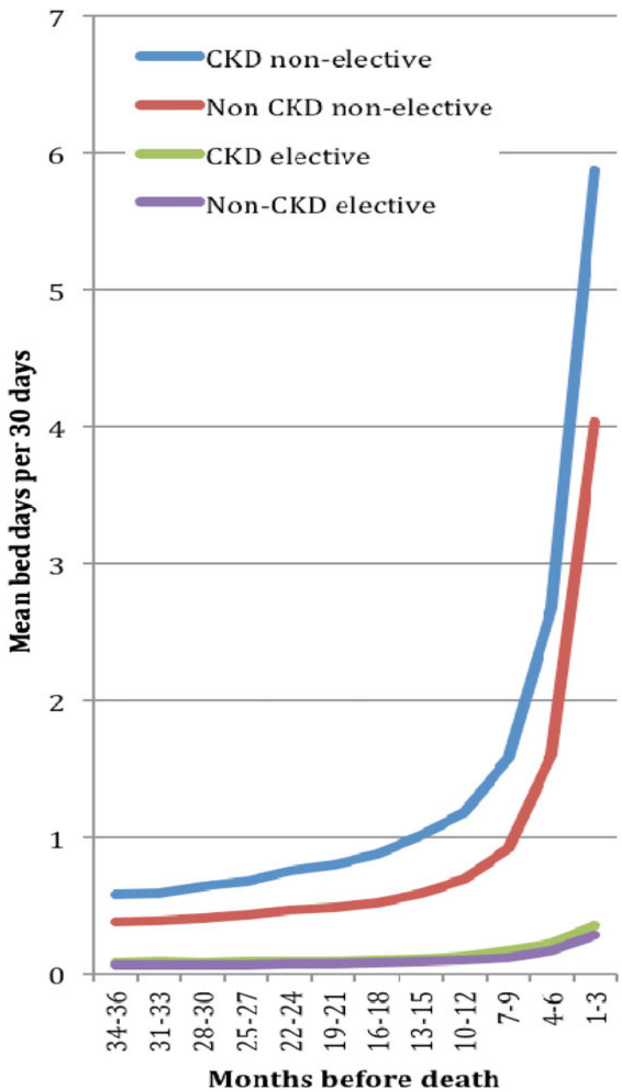

FIGURE 3: Elective and non-elective bed days per 30 days by time to death, CKD, and age- and gender-standardized non-CKD.

Impact of place of death

People with and without CKD who died at home had fewer inpatient bed days than those who died elsewhere in every 30-day period of the final 3 years of life (Figure 4 and Supplementary data). Regardless of place of death, the number of bed days increased month on month in the final year of life, until 30 days before death. In the final 30 days of life, the number of bed days fell sharply for those who died at home, and rose sharply for those who died elsewhere. In the final 30 days of life, people with CKD who did not die at home had 3.2 times as many bed days as those who died at home.

Cost of hospital care

The mean cost of hospital admissions and outpatient care in the 12 months before death was £11 916 for people with CKD and £7832 for standardized non-CKD. For both groups, >50% of final year costs arose in the final 3 months, and around a quarter in the final month. For both CKD and non-CKD patients, hospital costs were lower for those who died at home over 12-, 3- and 1-month perspectives. However,

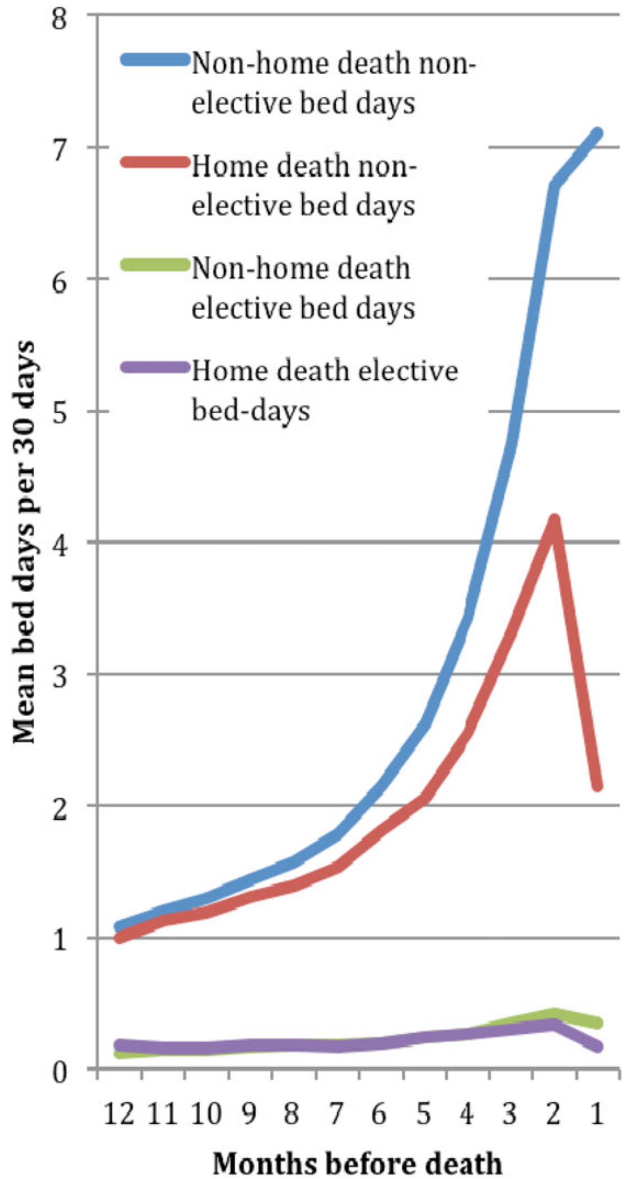

FIGURE 4: Mean bed days per 30 days in people with CKD, by place of death.

the greatest impact of home death on costs was observed in the final 30 days of life (Figure 5). For people with CKD, the mean cost of hospital care in the 12 months before death was £9877 for those who died at home and £12 160 for those who died elsewhere. The mean cost in the final 30 days of life was £1077 for those who died at home and £3206 for those who died elsewhere (see Supplementary data).

Regression analysis suggests that CKD was associated with an increase in hospital costs of £3380 [standard deviation (SD) £113] in the 12 months before death, and £1417 (SD £149) in the 3 months before death, holding constant age, gender, deprivation, place of death and comorbidities (cancer, stroke, heart disease, diabetes and chronic obstructive pulmonary disease).

For the CKD group, home death was associated with a reduction in hospital costs of £2811 (SD £218) in the 12 months before death, and £2924 (SD £105) in the 3 months before

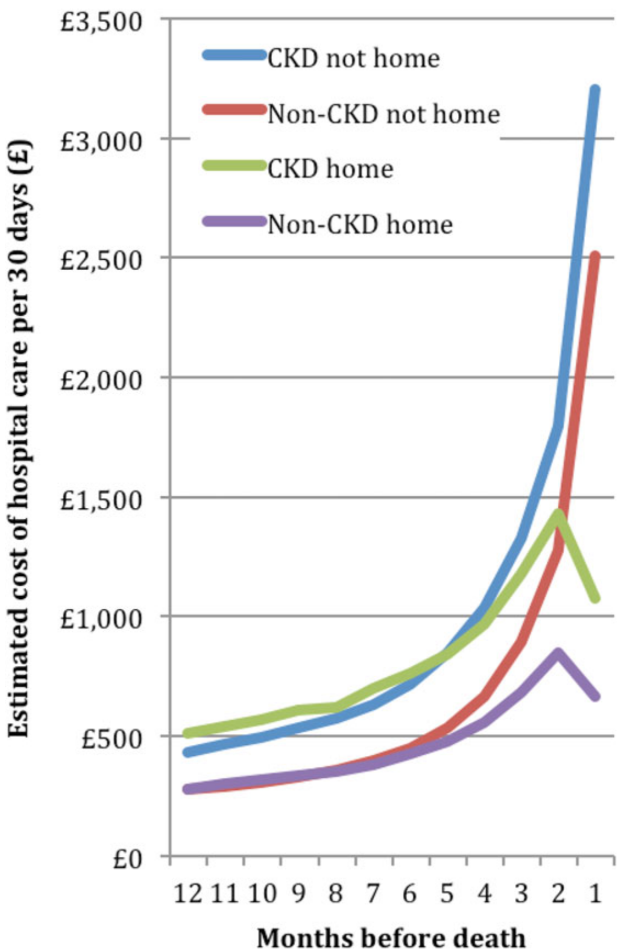

FIGURE 5: Estimated cost of hospital care per 30 days by time to death, CKD, and age- and gender-standardized non-CKD.

death, holding constant age, gender, deprivation and comorbidities (as above).

Sensitivity analysis

We were unable in our dataset discretely to identify patients on renal replacement therapy. While this group represents only ∼2% of the CKD population, the mean cost of care is very much higher than for the rest of the CKD population [15]. Analysis of UK Renal Registry data indicates that there were ∼11 365 deaths in this group during our study period, equivalent to 5.6% of all deaths in those identified as having CKD [16–19]. In sensitivity analysis, we removed from the dataset the 5.6% of patients with the highest hospital costs over the final year of life. The mean cost of hospital admissions and outpatient care in the 12 months before death was £9986 for people with CKD when excluding these high-cost patients (Table 2).

DISCUSSION

We believe that the data presented here provide the most comprehensive analysis to date of hospital care for people with CKD at the end of life, and the impact of place of death on hospital care and costs. We have built on earlier work examining mortality data for those with renal disease mentioned on death certificates [15]. Linkage to HES enabled the identification of three times as many people with CKD, relative to mortality data alone, and examination of patterns of hospital resource use and cost in the years before death.

Table 2. Cost of hospital care by period to death, CKD and non-CKD

	CKD	CKD excluding highest cost patients (5.6%)	Non-CKD standardized	Non-CKD non-standardized
30 days	£2978	£2920	£2183	£2178
3 months	£6048	£5709	£4234	£4264
12 months	£11 916	£9986	£7832	£8025

However, it is important to recognize the limitations of the linked dataset; HES comorbidity data have high specificity but low sensitivity [20]. There is a risk of misclassification bias through under-recording of CKD. Some studies suggest that comorbidities are more likely to be omitted where they are less severe [21]. If this is the case, then our findings may overstate the impact of the disease on length of stay and costs. In our study, the use of several years of data for individual patients, often involving multiple admissions, attenuates but does not eliminate the risk that comorbidities are unidentified. Among those who did have a mention of CKD on their death certificate, HES captured 97.3%, compared with 86.4% of all deaths, perhaps reflecting greater healthcare use in those with CKD and/or increased recording of relatively severe conditions.

In the examination of place of death, we used ONS classifications. Owing to concerns over the accuracy of some data relating to communal establishments, deaths occurring in nursing homes or residential homes were not classified by ONS as home deaths. A disadvantage of this approach is that it does not allow us to distinguish between deaths in hospital and deaths in communal establishments. The quality of ONS data on deaths in communal establishments has improved since the study period. Mortality data for 2014 indicate that, of deaths in England occurring in hospitals or other communal establishments, 63.2% were in hospitals, 7.6% were in hospices and the remainder in establishments such as care homes (https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables). It is not known if the percentage was similar in our period. If, as seems likely, those who die in communal establishments other than hospitals spend less time in hospital at the end of life than those who die in hospital, our study may underestimate the gap in costs between those who die in hospital and those who die at home. Further research is needed on care provided at the end of life to people whose normal place of residence is a communal establishment.

The majority of deaths in people with CKD were ascribed to non-renal causes. The most commonly recorded underlying cause of death in people with CKD was heart disease. However, even where the cause of death was non-renal, CKD added substantially to hospital costs at end of life. Our regression analyses suggest that CKD was associated with an increase in hospital costs of £3380 in the last 12 months of life, holding heart disease status and other comorbidities constant.

Stroke was recorded as the underlying cause in 7.1% of deaths in people with CKD, but, unexpectedly, this was lower than the proportion in people of the same age and gender without CKD (10.5%). This may be due to competing risks or coding practice. Stroke diagnosis on hospital records was more frequent in people with CKD than in those without CKD (Figure 2).

People with CKD were less likely to die at home than those without CKD. They had more hospital bed days per month, and higher hospital costs, than the matched non-CKD group throughout the final 3 years of life. Home death is associated with a substantial reduction in hospital costs at the end of life.

In recent years, the percentage of people dying at home has increased somewhat in England. Recent government figures suggest that in 2011–13, 22.1% of deaths occurred at home [22] (compared with 17.3%, CKD and non-CKD combined, observed here for 2006–10). Meanwhile, population-based studies suggest that ~67% would wish to die at home [23].

One of the obstacles to the commissioning of new services to support people to die at home is ignorance of the cost of current models of care. Our article shows that the mean cost of hospital care in the final 30 days of life is £2129 lower for people with CKD who die at home than for those who die in hospital. For people without CKD, the differential in hospital costs between home and hospital death is £1840. Further research is needed to estimate out-of-hospital costs for these patient groups. Our findings could provide a foundation for such analysis, and support the development of new strategies for cost-effective care at the end of life.

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SUPPLEMENTARY DATA

Supplementary data are available online at http://ndt.oxfordjournals.org.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest. The results presented in this paper have not been published previously in whole or part, except in abstract format.

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