

End of life care for urological cancer patients

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Abstract

Background: Each year around 15,000 men and 2900 women die from a urological cancer. The trajectory at end of life can be long and progressive or punctuated by acute events. Nonetheless those who die from urological cancer share some certain common disease manifestations that necessitate input from secondary care.

Methods: All records of people dying from a urological cancer in 2004–2013 were extracted from Office for National Statistics and National Cancer Registration and Analysis Service databases. Records were linked to hospital episode statistics to analyse patterns of admitted patient care, outpatient attendances and emergency department attendances.

Results: There has been a progressive decline in the proportion of deaths in hospital, from 47% to 35% of deaths. There has been a notable increase in care home deaths, which have risen from 13% to 19% of deaths and overtaken deaths in a hospice. Despite an only modest rise in total deaths from urological cancers (15,573 per year 2004–2006; 16,921 per year 2011–2013) there has been a much larger increase in secondary care activity in the last year of life. The largest change was for outpatient attendances, where the mean number increased from 3.0 to 13.6 per person.

Conclusion: Differences in age at death may account for some of the differences in place of death. Those dying at an older age will be more likely to require care for comorbidities or frailty, and hence be in a care home already. The large increase in outpatient activity could reflect attempts to manage more end of life care without hospital admissions. Yet inpatient activity has increased more quickly than the number of deaths. The increase in outpatient activity may instead be due to developments in treatment for advanced cancer, and prostate cancer in particular, being offered to patients close to the end of life.

Keywords

Prostate cancer, bladder cancer, testis cancer, kidney cancer, penile cancer, urological cancer, end of life, palliative care

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Introduction

Urological cancers encompass a heterogeneous group of malignancies, which differ in incidence, mortality and survival. Each year around 15,000 men and 2900 women die from a urological cancer, representing 6% and 1% of total death, respectively.¹ The trajectory at end of life can be long and progressive as is often the case in those dying of prostate cancer. In contrast, a short illness punctuated by acute events is a more frequent scenario in, for example, bladder cancer. Nonetheless those who die from urological cancer share some certain common disease manifestations

such as urinary tract bleeding, obstructive renal failure, a need for catheterisation and a requirement for pain relief.

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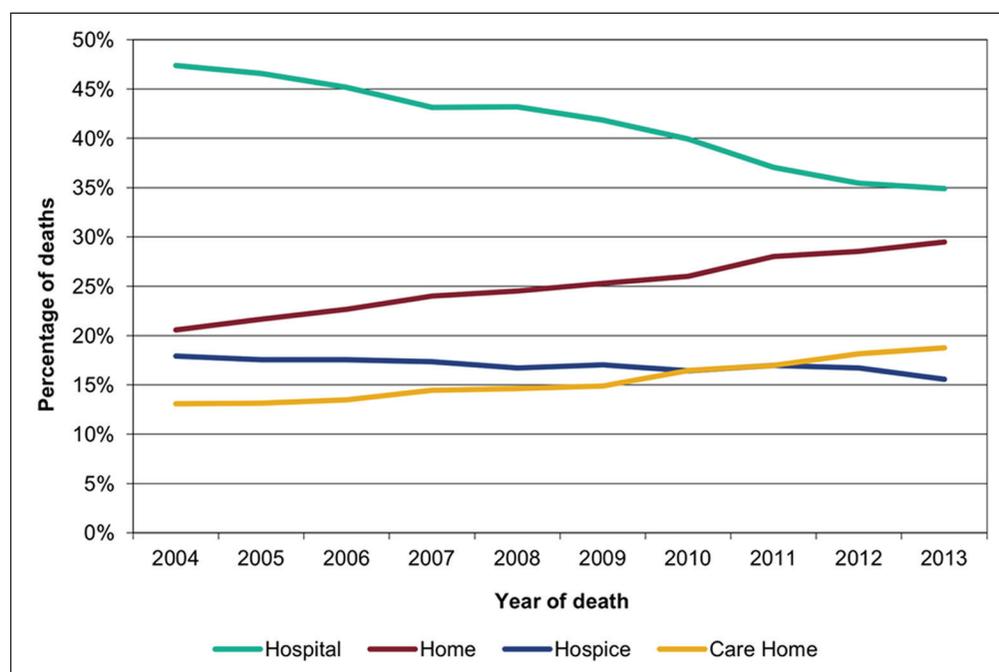


Figure 1. Proportion of urological cancer deaths by place of death, 2004–2013.

Men with advanced prostate cancer are particularly prone to develop skeletal problems due to bone metastases. These complications of cancer at the end of life frequently necessitate input from secondary care.

Although a crude measure, much emphasis has been placed on the place of death as a surrogate marker for quality of care at the end of life. This has arisen from key pieces of work,^{2,3} which have highlighted that the majority of people, when asked in advance, would prefer to die in their own home. A decreasing proportion of deaths in hospital would indicate that systems such as advanced care planning are in place to enable patient wishes to be met, including palliative care arrangements, pain relief and symptom control at home.⁴ We examined trends in national data to see if quality of care in this area appears to be improving.

Methods

Using the Public Health England database of deaths supplied by the Office for National Statistics we extracted all deaths which had a urological cancer as the underlying cause, for the years 2004–2013. The cancer codes used were C60 (penile), C61 (prostate), C62 (testis), C64 (kidney), C65+C66 (upper tract) and C67 (bladder). Data on key demographics were extracted. To analyse the usage of secondary care services we extracted all people from the National Cancer Registration and Analysis Service database who had died from a urological cancer and linked them to hospital episode statistics for admitted patient care, outpatient attendances and emergency department attendances.

Results

Almost all patients die within one of four recorded locations: in hospital, at home, in a care home or in a hospice. In the last decade there has been a progressive decline in the proportion of urological cancer deaths in hospital, from 47% to 35% of deaths (Figure 1). There has been a concurrent increase in home deaths from 21% to 29%. The other notable increase has been in care home deaths, which have gone from 13% to 19% of urological cancer deaths and overtaken deaths in a hospice (Figure 1).

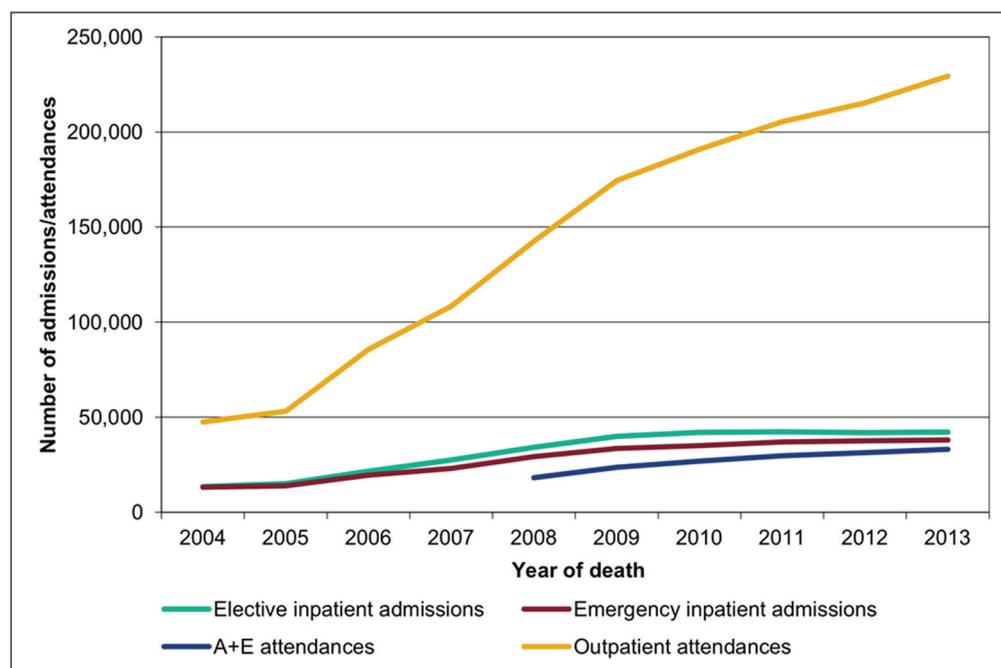
The pattern of place of death is not homogeneous across all the urological cancer groups, although for all groups the hospital is the most common location. The most recent data assessed (2011–2013) show the proportion of hospital deaths was highest for testis cancer (48%), and lowest for upper tract cancers (33%). Home deaths were most frequent for upper tract cancers (31%) and least frequent for bladder cancers (26%).

Median age at death was highest for prostate cancer at 81 years, and lowest for testis cancer at 48 years. As might be expected from the younger age at diagnosis and death, men dying from testis cancer had the lowest use of care homes, with the highest use in those who died from prostate cancer (Table 1).

Death in ‘usual place of residence’ is classified as death at home or at a care home the person has been living in. The proportion of deaths in usual place of residence has increased from 26% in 2004 to 37% in 2013 ($P < 0.001$). The proportion of care home deaths which are classified as death in usual place of residence, that is, the person was living in the

Table 1. Place of death by cause of death, 2004–2013 combined data.

	Care home	Home	Hospice	Hospital	Other places	Total deaths
Penis	14%	21%	23%	41%	1%	849
Prostate	18%	26%	16%	40%	0%	88,151
Testis	5%	26%	14%	52%	3%	564
Kidney	11%	28%	21%	39%	1%	29,592
Upper tract	10%	27%	25%	37%	1%	1530
Bladder	14%	22%	17%	46%	1%	41,509

**Figure 2.** Admissions to hospital and outpatient and emergency department attendances in the last year of life 2004–2013.

care home, has not changed (39% for 2011–2013). Similarly, there has been no change in the proportion of all deaths in usual place of residence that occur in a care home (19% for 2011–2013). The proportion of deaths in a care home which are classed death in usual place of residence showed a small variation (32–38%) when examined by cancer site.

Despite an only modest rise in total deaths from urological cancers (15,573 per year 2004–2006; 16,921 per year 2011–2013) there has been a much larger increase in the number of inpatient admissions in the last year of life (LYOL). Total admissions increased by nearly 200%, from 28,000 to 82,000 per year (Figure 2). The mean number of admissions per person in the LYOL for 2011–2013 was 2.5 elective admissions, 2.2 emergency admissions and 4.8 in total. This equates to a mean length of stay of 3.1 elective days, 22.6 emergency days and 27.6 days total. Attendance at the emergency department has also risen, although data

are only available for 2008 onwards. In that time period the number of attendances rose by 81%, with the mean attendances per person in LYOL increasing from 1.1 to 2.0 attendances. The largest increase in hospital activity has been for attendances at outpatient clinics. The mean number of attendances for those dying in 2013 was nearly five times higher than those dying in 2004, increasing from 3.0 to 13.6 per person.

In 2013 about half of inpatient admissions were for men who died from prostate cancer; although 54% of deaths were from this cause. Around 30% and 20% of admissions were for bladder and kidney cancer, respectively, slightly higher than the 26% and 18% of deaths accounted for by these cancers. Outpatient attendances in 2013 were more closely aligned to cause of death, with 52%, 26% and 19% of attendances for people dying of prostate, bladder and kidney cancer, respectively.

Based on the specialties recorded in the outpatient data, 37% of attendances were for oncology (clinical and medical), 20% for urology and 2% for palliative medicine.

Discussion

Due to the large proportion of urological cancer deaths which are from prostate cancer, it has a strong influence on the overall cancer figures. For example, prostate cancer was the only site which showed a clearly higher proportion of deaths in a care home compared to a hospice, yet the overall figures (Figure 1) would suggest that this was the case for all urological cancers. A clear picture may only emerge if sites are considered separately.

Differences in age at death may account for some of the differences in place of death. Those dying from testicular cancer may well have young families and desire to die in hospital to avoid difficult experiences for their children relating to a home death. Those dying at an older age will be more likely to require care for comorbidities or frailty, and hence be in a care home already. This may have become their usual place of residence, with no home to return to and in that sense some of these people could be considered as dying at 'home'.

The unchanging proportion of death in usual place of residence for care home deaths suggests that for urological cancers there has long been a majority of people dying in a care home where they are not long-term residents. As discussed above, this will be heavily influenced by men dying from prostate cancer who are older, more likely to need care for frailty or comorbidity, and with a more predictable disease trajectory. This means that their cancer is more amenable to management in a care home setting.

Both inpatient and outpatient activity has increased more quickly than numbers of deaths, but the larger increase has been for outpatients. The increase in outpatient activity may be due to developments in treatment for advanced cancer being delivered in an outpatient setting. In particular prostate cancer, which has the greatest influence on the data, has seen a large increase in potential treatment modalities with new drugs such as enzalutamide and abiraterone becoming available. Emerging multimodal therapies may increase both inpatient and outpatient activity.⁵ The well-recognised difficulty in predicting approaching death^{6,7} means that patients even in the last few months of life may be offered such potentially curative therapies.

As the population continues to age and there is a reduction in deaths from more preventable diseases, including ischaemic heart disease and lung cancer, there will be an increased need for end of life care for urological cancers. This is likely to increase demand, particularly in the outpatient setting and for palliative care services. Patient desires may be best met by home or community-based services, such as outpatient clinics visiting local hospitals, palliative care in the community

and hospice at home projects. These may reduce hospital usage and hospital death.⁸ However, the complex needs of those dying from urological cancers mean that this may not be feasible in every case.

Previous work released by the National End of Life Care Intelligence Network found that the highest inpatient costs in the LYOL were for men dying from testicular cancer, at £13,300 per man.⁹ Prostate cancer had the lowest cost per man at £6900, but the highest cost overall due to the frequency of the condition. Other authors have derived much higher costs for end of life prostate cancer care of £14,900 if informal care is included.¹⁰ Therefore the reduction of hospital activity near the end of life may have significant cost savings as well as improving patient experience.

Conclusion

There has been a moderate increase in deaths from urological cancers over the last decade, but a much larger increase in hospital activity, particularly outpatient services. Although broadly in line with the occurrence of death there is slightly more use by those dying from bladder and kidney cancers compared to prostate cancer. Most patients die in hospital, although this is declining with a rise in home and care home deaths. In the future there is likely to be even more pressure on secondary care services from increasing demand for new treatments for advanced disease. Community-based palliative care services may help satisfy patient demand in a more accessible setting.

Data access statement

The aggregated results of data analysis, STATA files and output, and SQL code for data extraction are available from the authors on request.

Individual patient-level data used to generate results are not freely available, but may be applied for through the PHE Office for Data Release.

Conflicting interests

There are no conflicts of interest to declare.

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Ethical approval

Not applicable.

Informed consent

Cancer registration is exempted from patient consent under the NHS Act 2006.

Guarantor

LH.

Contributorship

LH: data extraction and analysis, manuscript preparation (including first draft); SW: literature, manuscript preparation; JV: supervision, manuscript preparation; all authors approved the final version of the manuscript.

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