End-of-life care for people with urological cancer

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- Number of people with urological cancers and where they die
- Role of the urology/continence nurses in end-of-life care
- How services can be designed to meet needs

Authors

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Abstract


The National End of Life Care Intelligence Network has produced its first report looking at differences in where people with urological cancers die – at home, in hospital, hospices or nursing homes – depending on the type of cancer they have and other factors such as age, sex and socioeconomic status. This article summarises the key findings of the report and their implications for urology nursing practice.

Some 16,000 people die each year from urological cancers in England – including 8,600 (55%) from prostate cancer and 4,100 (26%) from bladder cancer. Urological cancers also include penile, prostate, testicular, kidney, renal pelvis and ureter, and bladder cancers.

Deaths from urological cancers in England

A 2001–10 report describes how, in addition to the 16,000 urological cancer deaths each year, a further 5,000 deaths have a urological cancer as a contributory cause (National End of Life Care Intelligence Network, 2012).

In this report, prostate cancer was mentioned in 5% of all deaths in England in 2001–10, but this increased to 7% for those who died aged over 85 years. During the same period, bladder cancer was mentioned on the death certificate for 2% of male deaths and 1% of female deaths. The report also identifies that more men die from urological cancers than women (66% and 31% respectively), and that most of all urological-cancer deaths (62%) occur in people aged 65–84 years. Testicular cancer, however, shows a different age pattern with 79% of deaths occurring in men aged under 65.

Place of death

The majority of people dying from urological cancers do so in hospital (46%), rather than in their own homes (23%). However, the proportion of those deaths in hospital is lower than the current average for hospital deaths from all causes (51%). Closer inspection of these figures shows there is variation in place of death by urological cancer type – people with testicular cancer are the most likely to die in hospital (57% of testicular cancer deaths), while those with kidney cancer are the most likely to die at home (only 26% of kidney cancer deaths occur in hospital).

Hospital admissions and costs

The amount of time spent in hospital and the cost of inpatient care in the last year of life varies between the urological cancer types. Emergency hospital admissions tend to be longer and more costly than planned admissions and, in the three largest groups (prostate, bladder and kidney cancers), emergency admissions are more common than those that are planned.

The highest inpatient costs in the last year of life are for testicular cancers – at £13,304 per person – while prostate cancer has the lowest cost at £6,931 per person. A key recommendation of the NELCIN’s (2012) report is for healthcare providers to consider developing services that help to avoid

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● This article has been double-blind peer reviewed

5 key points

1 16,000 people die each year from urological cancers

2 The majority of people dying from urological cancers do so in hospital

3 Emergency admissions for urological cancers in the last year of life are more common than planned admissions

4 End-of-life care for patients dying of, and with, urological cancers is challenging due to variations in presentation, prognosis, complications and treatment

5 A collaborative approach to caring for these patients is essential, with the urology/continence nurse playing a key role in the overall end-of-life care team
emergency admissions in the last year of life, which are often distressing and costly.

End-of-life care for patients dying of, and with, urological cancers is challenging due to variations in presentation, prognosis, complications and treatment. The report recommends that effective management of the multiple health issues or complications experienced by these patients may enable more to die at home, if desired.

S状ing nursing practice
Although the report is aimed at helping commissioners to identify end-of-life care needs for people with urological cancers so they can plan services effectively, the findings could also help to inform nursing practice and service development.

The data shows that some people die with, rather than from, a urological cancer. Many have a range of other conditions; a collaborative approach to caring for these patients is essential, and the urology/continence nurse is a key part of the overall end-of-life care team.

Patients with prostate cancer, for example, may be dying from cardiovascular or respiratory problems but need specialist urology/continence nursing support around catheterisation. Combining a range of specialist nursing skills helps ensure they are cared for holistically so their final days are as comfortable and dignified as possible.

Giving patients options
The NELCIN (2012) report data indicated that more men than women with urological cancers die at home – usually because their wife/partner and family members care for them. There is an opportunity for hospital-based urology/continence specialist nurses to work with colleagues in community services to support these patients and their families. This could be by providing training and mentoring to community nurses, or by offering an outreach service to visit patients at home, in hospices or in care homes so symptom management or practical procedures such as changing a catheter can be carried out at home.

Patients with testicular cancer are the most likely to die in hospital, and the age profile is very different from that of other urological cancers. Almost 80% of deaths are among men under 65, and inpatient costs are also highest among this group. This could be linked to the fact that patients are younger and may be receiving aggressive treatment regimens with a high risk of side-effects, which may lead to longer inpatient stays.

Urology nurses may be part of the active treatment team but could also help these men by providing palliative care and practical support so they can leave hospital and spend as much time with their families as possible. It is a very different approach to that of caring for older patients with urological cancer, who may wish to remain in hospital because they do not have a support network to care for them at home.

Reducing emergency admissions
The team that compiled the report is doing a further piece of work on hospital admissions for patients with urological cancer. The aim is to understand why people are admitted, the length of stay and whether or not it was an emergency. This will feed into service development or redesign, again with the goal of enabling people to be cared for and end their life in the place of their choice, which is often not hospital.

Urology/continence nurses caring for people at the end of life can identify local opportunities to improve care or redesign care pathways. For example, a patient near the end of life who needs a catheter replaced may have to spend a few precious days in hospital, when this could be dealt with in the community (Young and Conway, 2011). Nurses can influence how care is provided, to help reduce repeated or emergency admissions and ensure, as far as possible, a patient’s wishes are met.

Planning for end-of-life care
Giving patients choices about their care at the end of life requires good teamwork and excellent communication. Palliative care nurses and other specialists are part of the team, but urology nurses can also play a key role in the process. For example, incorporating an end-of-life care element into nurse-led clinics for patients with prostate or renal cancer can help open up conversations about what patients and their families wish to happen at the end of life. It is a chance to discuss options and begin the process of advance care planning. This lets patients make their wishes about care and treatment clear, and take steps to make a will, plan their funeral and make provisions for children or other dependants.

Coordination among all professionals involved in caring for those who are dying, is vital; this includes social care and voluntary sector colleagues. An Electronic Palliative Care Coordination System (EPaCCS) records patients’ wishes about what should happen if they are admitted to hospital, whether they want to receive resuscitation and their preferred place to die. Nurses can gain access to an EPaCCS; some are authorised to add information to it.

Of course, care does not end when a patient dies. Nurses build up a good relationship with the family and carers, and can help them access bereavement support and other help they may need to cope with losing their loved one.

Conclusion
End-of-life care needs to be considered and discussed as part of the overall care for people living with a urological cancer. Everyone should have access to high-quality care at the end of their lives, and services should be tailored to the needs of local populations so more people are able to die in the place of their choice.

References

“Look after your emotional and mental health”
Jenny Kay p30