Where do patients with blood cancers die?

NCIN Data Briefing

KEY MESSAGES:

Most people dying of a haematological cancer do so in hospital.

Compared to other cancers, fewer deaths occur at home or in a hospice.

This pattern is seen at all ages.

The proportion of deaths occurring in hospital is falling, but less than seen in other cancers.

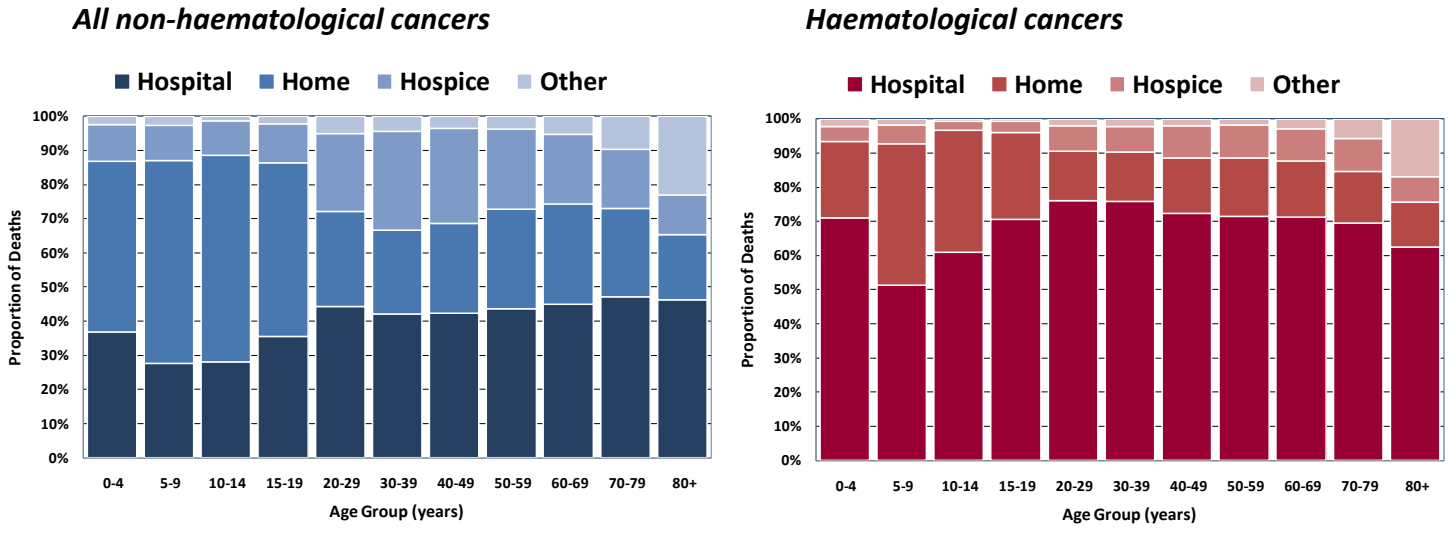
Background

When asked, most people say they would prefer not to die in a hospital – although in fact this is where most people do die. Individuals with cancer are more likely than others to die in a hospice and are generally less likely to die in a hospital. However, this pattern is not seen for all forms of cancer. Individuals dying of haematological malignancies (the blood cancers: leukaemia, lymphoma, myeloma) have previously been reported to have a very different pattern of place of death. We examined the most recent national mortality data to establish the current situation in England and Wales.

Results

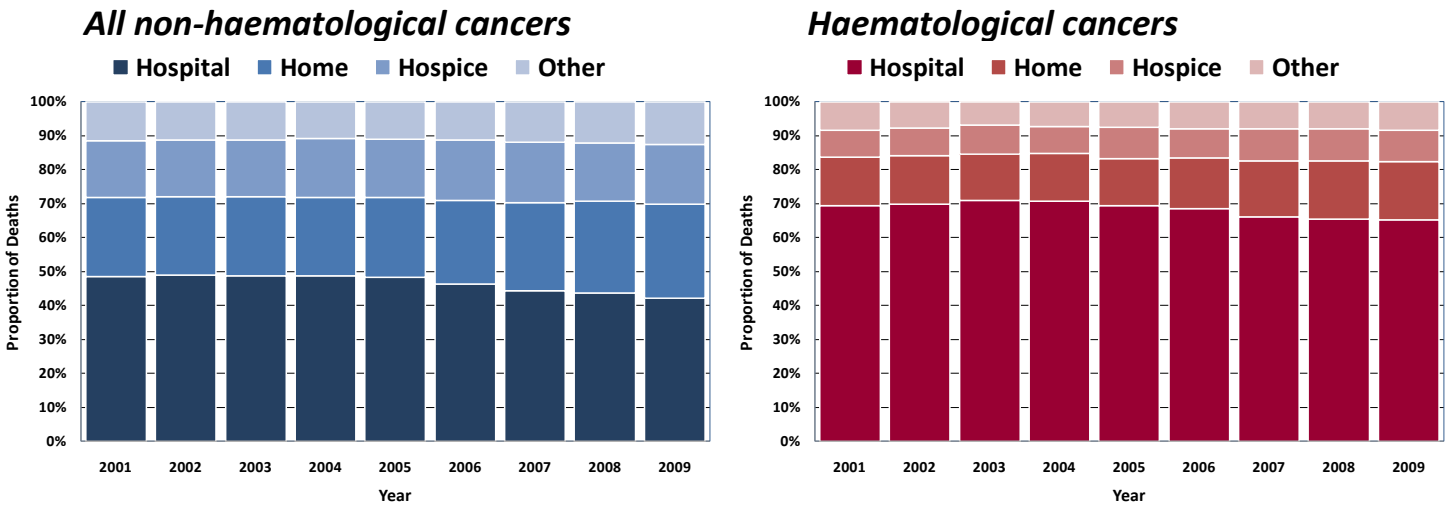
In the nine years from 2001 to 2009 there were 94,962 deaths in England and Wales in which a haematological cancer was identified as the underlying cause of death. Of these, for 64,965 (68%) individuals the death occurred in a hospital; 14,316 (15%) deaths happened at home; 8,277 (9%) deaths were in a hospice; for 7,404 (8%) death occurred in another type of location, chiefly a nursing or care home. When compared to the 1,128,910 deaths caused by other forms of cancer over the same period, people with haematological cancer were far more likely to die in hospital.

Place of Death by age (England and Wales 2001-2009)



The proportions of deaths from non-haematological cancers occurring in different locations were: in-hospital deaths 526,928 (47%), deaths at home 277,619 (25%), deaths in a hospice 194,110 (17%), other location 130,253 (12%). As shown in the figure, the pattern of fewer deaths from haematological cancer happening either at home of in a hospice was seen across all age-groups.

Place of Death by year (England and Wales 2001-2009)



The proportion of deaths due to haematological cancers that occurred in hospital fell slightly between 2001 and 2009, from 69% to 65%, but this change was less than that seen in other forms of cancer where the proportion went from 49% in 2001 to 42% in 2009. Similar patterns in the place of death were seen in all groups of haematological cancer. Patterns in the place of death varied by Cancer Network in England and Wales, with a range of 61% - 79% of deaths occurring in hospital, full details of the patterns by network and disease group are available online at http://www.ncin.org.uk/haematlas/atlas.html

Methods

Analyses were based on national mortality data for England and Wales for death registered in the years 2001-2009 provided by the Office for National Statistics (ONS). The ICD-10 code for the underlying cause of death was used to categorise cancer type: haematological cancers (ICD-10 codes C81-C96) all non-haematological cancer (C00-C80, C97). The place of death was identified and grouped using ONS communal establishment codes.

Commentary

The fact that people with blood cancers are more likely to die in hospital is not peculiar to the UK, it is also seen in the rest of Europe, the USA and Australia. A number of suggestions have been made for this pattern including: the difficulty of establishing if and when a transition from active to palliative care has been made; that disease symptoms and complications of therapy make care out of hospital difficult; that the sustained relationship developed with their haematology team means patients see hospital as their preferred place of death; that links between haematology services and specialist palliative care are under-developed. However, there is currently very little evidence about the importance of these different factors. On its own, simply knowing *where* patients with blood cancer die gives no indication of the *quality* of the care that they receive at the end of life, nor of the preferences of patients or carers, further research is needed to develop a better understanding of these issues.

FIND OUT MORE:

Northern and Yorkshire Cancer Research and Information Service (NYCRIS)
NYCRIS is the lead Cancer Registry for haematological cancers

http://www.nycris.nhs.uk

Other useful resources within the NCIN partnership:

National End of Life Care Intelligence Network – Using intelligence to improve end of life care

http://www.endoflifecare-intelligence.org.uk

The National Cancer Intelligence Network is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research. Sitting within the National Cancer Research Institute (NCRI), the NCIN works closely with cancer services in England, Scotland, Wales and Northern Ireland. In England, the NCIN is part of the National Cancer Programme.