Children and young people who die from cancer: epidemiology and place of death in England (1995-9)

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BMJ 2003;327:478–9

Survival from cancer among children and young adults has improved, but a need remains to care for the one in four who cannot yet be cured.[1–3] One component of quality care is to provide it in the place of choice,[3] usually home; we analysed factors affecting place of death.

Participants, methods, and results

We derived data from death registrations for all cancer deaths (international classification of diseases, 9th revision, codes 140-239) in England and Wales, for 1995-9, for ages 0-24. Age, sex, social class, country of place of birth, geographical location, underlying cause of death, and place of death were available directly. Further potential explanatory variables were a classification of local authority type (rural, urban, inner London, etc) from the Office for National Statistics and deprivation indices for 2000, from the Department of Environment, Transport, and the Regions, at parliamentary ward level (treated as continuous variables, higher scores indicated greater deprivation). We defined two further variables: diagnosis (main primary tumour) and whether or not the cancer was a solid tumour.

Response variables indicated whether death took place at home or in hospital, or in a hospice or palliative care unit. We analysed age groups 0-15 (children and adolescents) and 16-24 (young adults) separately. Social class, recategorised on a scale (I-VI, table) and treated as a continuous variable, was based on parents for age range 0-15 years. We used binary logistic regression models in our exploratory analysis to examine associations between place of death and potential explanatory variables. We used multiple logistic regression models to determine the joint effect of variables identified as significant or borderline ($P = 0.05$-0.1) during exploratory analysis. Odds ratios with 95% confidence intervals are presented.

During 1995-9 a total of 3197 deaths from cancer in young people aged 0-24 were registered in England. Of the small number of deaths in hospices, 23 (42.6%) among children and adolescents and 34 (24%) among young adults were from brain cancer (table).

Descriptive statistics for cancer deaths registered in England and Wales in 1995-9, for children and adolescents (age range 0-15) and young adults (age range 16-24). Values are numbers (percentages) unless otherwise indicated

Age range	Children and adolescents (n=1725)	Young adults (n=1472)	Total (n=3197)
Sex:			
Male	978 (56.7)	854 (58.0)	1832
Female	747 (43.3)	618 (42.0)	1365
Age group (years):			
<1	91 (5.3)		91
1-5	579 (33.6)		579
6-10	530 (30.7)		530
11-15	525 (30.4)		525
16-20		712 (48.4)	712
21-24		760 (51.6)	760
Social class*:			
Professional (I) or managerial and technical (II)	675 (39.1)	129 (8.8)	804
Skilled, manual (IIIa) or non-manual (IIIb)	609 (35.3)	288 (19.6)	897
Partly skilled (IV) or unskilled (V)	277 (16.1)	154 (10.5)	431
Unemployed (VI)	161 (9.3)	886 (60.2)	1047
Missing	3 (0.2)	15 (1.0)	18
Diagnosis (ICD-9 codes):			
Brain cancer (191)	405 (23.5)	176 (12.0)	581
Acute lymphoid leukaemia (204)	347 (20.1)	213 (14.5)	560
Acute myeloid leukaemia (205)	180 (10.4)	166 (11.3)	346
Bone and articular cartilage (170)	84 (4.9)	169 (11.5)	253
Endocrine glands other than thyroid (194)	188 (10.9)	20 (1.4)	208
Connective and other soft tissue (171)	96 (5.6)	90 (6.1)	186
Hodgkin's disease (201)	4 (0.2)	70 (4.8)	74
Kidney and other urinary cancer (189)	58 (3.4)	10 (0.7)	68
Melanoma (172)	5 (0.3)	51 (3.5)	56
Female genital organs (179-184)	6 (0.3)	52 (3.5)	58
Testis (186)	2 (0.1)	36 (2.4)	38
Other	350 (20.3)	419 (28.5)	769
Place of death:			
General hospital or multifunction site	747 (43.3)	849 (57.7)	1596
Home	901 (52.2)	448 (30.4)	1349
Hospice	54 (3.1)	139 (9.4)	193
Other	23 (1.3)	36 (2.4)	59

*Based on parents for 0-15 year olds.

A multivariate model for home death, for children and adolescents, indicated that death at home rather than in hospital was less likely for those at the bottom of the social scale (odds ratio 0.93, 95% confidence interval 0.87 to 0.99)—home deaths were 65% in social class I, 49% in V, 44% in VI), with leukaemia or lymphoma rather than solid tumours (0.46, 0.37 to 0.58) less likely in inner London (0.54, 0.32 to 0.92—for example, 62% "prosperous" England, 58% rural, 37% inner London) and in areas with high rates of child poverty (0.99, 0.99 to 1.00), all $P<0.05$. This was consistent with associations found in univariate analysis. The only potential explanatory variable that was significantly associated with dying in a hospice was a diagnosis of brain cancer (2.52, 1.45 to 4.38, $P=0.001$).

Among young adults multivariate analysis found that home death was less likely with increasing age (0.91, 0.80 to 0.95), less likely for young women (0.73, 0.56 to 0.94), patients with leukaemia or lymphoma rather than solid tumours (0.22, 0.97 to 0.30), and where access to local services (school, shops, general practitioner) was good (1.25, 1.05 to 1.49), all $P<0.05$.

Comment

Home is an important place of death; 52% of children and adolescents, and 30% of young adults died at home. This is higher than for the United States (20%)[4] and for adults (26%).[5] Primary care and community services are therefore critical, although individual services encounter patients rarely. Lower social class, living in inner London, or living in an area of high childhood poverty reduced the likelihood of home death. Although relatively few children died in hospices, brain tumours accounted for around half of these. These findings are relevant to service planning and need investigation in prospective research.

We thank the Office for National Statistics for its helpful collaboration, making available these datasets, and guiding us in their interpretation.

Contributors: IJH conceived the idea for the study, was responsible for day to day management, analysis plan, literature review, and interpretation; MT was responsible for liaison with the Office for National Statistics, data checking, recoding, merger of datasets, and data analysis. Both contributed to the writing of the manuscript and act as co-guarantors for the paper.

Funding: King's College London and the Interdisciplinary Research Group on Palliative and Person Centred Care funded MT to undertake the analysis.

Competing interests: None declared.

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(Accepted 5 August 2003)

Two memorable physicians

I have had the good fortune to work for and with physicians whose grasp and practice of medicine set them comfortably beyond their competent fellows. But against my two most memorable physicians, even peers are challenged in insight, analysis, and diagnosis. I worked for the first, Norman Swift Plummer, as his house physician at Charing Cross Hospital, and for the latter, Malcolm Davenport Milne, as senior registrar at Westminster Hospital.

Plummer (1907-78) was in the top echelon of London teaching hospital physicians of his day. He was a tall, slim, grave, well dressed man, a public school product. His modest self confidence, diagnostic acumen, kindness, and advice led to the months I spent as his house physician being my most rewarding period in general medicine and left me with happy memories of my good fortune. "Plummer was the ideal physician to successions of senior registrars … many considered him to be the finest physician they had known."[1] A sentiment I appreciate, and a post I wish I had held.

Milne (1915-91) was an outstanding clinical scientist (FRS 1978). From a grammar school boy, he grew into a short, fat man not given to self advancement. He was gruff on ward rounds and shy in social matters, but not when discussing medicine or giving one of his invariably entertaining lectures in his flat Mancunian accent. The speed and depth of his thinking and his replies to questions were impressive. It was a pleasure to observe, and at times uncomfortable to suffer from, his ability to ask simple questions that dissected unthinking statements. Ward rounds were excellent: he knew everything and missed nothing. It was always instructive to accompany him to see patients referred to him by other physicians. Difficult cases made simple. Many unwell doctors consulted him—a "physician's physician."

I first heard of Milne when I was a house physician at Hammersmith Hospital, where he was invariably referred to as distinguished—an endorsement not frequently used in that establishment. I recall a small group of my fellows at Hammersmith wincing at the intellectual strength of Milne ripping through the traps they had set him for the Wednesday morning clinicopathological conference. His first degree was in chemistry, which he applied to human metabolism. In the 1950s and '60s journals were peppered with his contributions. One piece with which Milne was pleased was his clarification of the tyramine monoamine-oxidase inhibitor interaction (the "cheese reaction").[2] His substantial reputation would have been enhanced further if he could have had the then undescribed aldosterone assayed from a hypokalaemic, alkalotic, hypertensive woman. He postulated its presence but had no method to detect an excess of a sodium retaining hormone. The following year the same patient consulted a Dr Conn.

Using himself and staff for experimental purposes was part of Milne's practice. On my first day on his unit, I was recruited to save my dejecta for three weeks and later learnt the art of stool blending. Unfortunately, a rival unit published before our assays were completed. Milne did not replicate others' findings. Homogenates and aliquots were discarded. Instead, we drank amino acid slurries.[3]

These two doctors were different in many ways. Their similarities lay in the quality of their medicine. Plummer taught me to enjoy medicine; Milne to ask obvious questions. I remain grateful for their influence.

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