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Place of death and hospital care for children who died of cancer in England, 1999–2006

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ABSTRACT

Aim: To describe patterns of hospital care and to evaluate factors influencing place of death for children who died after a diagnosis of cancer in England during 1999–2006.

Materials and methods: Registrations of children on the National Registry of Childhood Tumours (NRCT) who were diagnosed with cancer and died during 1999–2006 in England were linked to the Hospital Episode Statistics (HES) and to death certificates. Multivariable logistic modelling was used to assess factors that influence dying at home or in hospital.

Results: 1864 (96%) of children with cancer registrations were linked to HES records. The validation of hospital as a place of death and ethnicity between data sources was good, although anomalies within HES data exist. Similar proportions of children are dying at home (45%) and in hospital (47%), and the percentage dying in a hospice or care home increased from 2% to 10%. Of the children who died in hospital, 74% were admitted as emergencies or as a transfer from another hospital. Greater proportions of children diagnosed with a leukaemia or lymphoma, those dying within six months of diagnosis, Asian and Black children, those from a deprived background, and those not treated in a CCLG centre died in a hospital.

Conclusions: Patterns of hospital care varied considerably by type of cancer, death within six months of diagnosis, ethnicity and deprivation. Further research is required to elucidate explanations for these patterns and to evaluate methods to increase the proportion of children dying at home who wish to do so.

1. Introduction

Cancer remains an important cause of death among children, despite striking improvements in survival and cure.[1,2] Palliative medicine has developed considerably over the last 20 years, and an increasing number of hospices for children have been opened.[3,4] Palliative care services for children are acknowledged to vary in availability and quality across England.[5] The Department of Health has recommended a 'total approach to palliative care for children and young people and their families, which embraces physical, emotional, social and spiritual elements'.[6] The majority of young children with cancer would choose to die at home, rather than in a hospital, when circumstances allow.[7]

This study seeks to describe patterns of hospital care from the time of diagnosis to death, and to evaluate the factors affecting place of death for children who were diagnosed with cancer in England and who died during 1999–2006.

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2. Materials and methods

A combination of cancer registry, Hospital Episode Statistics (HES) and death certificate data have been used for this study of children (<15 years) who were diagnosed with cancer and who died under the age of 20 years in England during 1999–2006.

The National Registry of Childhood Tumours (NRCT) based at the Childhood Cancer Research Group (CCRG) is a population-based registry of malignant neoplasms and benign brain tumours diagnosed at ages 0–14 years since 1962. CCRG has received information on an estimated 97% of all cases of childhood cancer since 1971. The Children's Cancer and Leukaemia Group (CCLG, formerly the UK Children's Cancer Study Group) have notified CCRG of all children registered and treated by its members since 1977. CCLG notifications are now received for 93% of all the children included in the NRCT. Details of all children who survive for at least three years after diagnosis are sent to the NHS Central Registers (NHSCR) in Southport and Edinburgh. These individuals are 'flagged' and the NRCT is notified if and when NHSCR receives a death certificate relating to these individuals. Less than 2% of cases have been lost to follow-up since 1981.

NRCT data have been linked to HES data for children with cancer by NHS number, sex, date of birth and postcode. Each time a patient sees a doctor in a hospital, whether as an inpatient or a day case, a record or 'episode' is created and added to the HES database. The record contains patient details, diagnosis, treatment and lengths of hospital stay. Outpatient data are only available from 2003 and are not included here. Radiotherapy data has not been collected in HES.

Place of death obtained from death certificates was categorised as home, hospital or hospice/care home and evaluated by age at diagnosis and death, sex, type of cancer, ethnicity, deprivation, treatment at a CCLG centre and clinical trial status. The few children who died of other causes such as road traffic accidents or other medical conditions were excluded from the study ($n = 13$). The third edition of the International Classification of Childhood Cancer[8] was used to classify type of cancer, with germ cell tumours of the central nervous system (CNS) being included with brain and spinal tumours. If a child was diagnosed with a subsequent primary tumour, their death was ascribed to the last malignancy. Place of death recorded as hospital on a death certificate was validated using HES data. Ethnicity as recorded on HES was validated between records submitted to HES from different NHS Trusts and between records from CCLG centres. Ethnicity as recorded on CCLG records was used when no other data was available. Deprivation was assigned using the income domain of the Index of Multiple Deprivation linked to the super output area of a patient's postcode at death.[9]

Multivariable logistic modelling was used to compare dying at home with dying in hospital by potential explanatory factors, with those who died in a hospice or a care home being excluded from analysis. Chi-squared tests were used to evaluate trends and patterns. The data were analysed using STATA version 11.1.[10]

3. Ethics

The CCRG is a member of the UK Association of Cancer Registries, which permits the holding and processing of individual data on children diagnosed with cancer. This is currently sanctioned by Section 251 of the Health and Social Care Act (2008) without individual consent. Ethical approval for epidemiological research using NRCT data has also been approved by the Oxford NHS Research Ethics committee (Ref: 07/Q1606/54).

4. Results

Of 10,548 children who were diagnosed with cancer during 1999–2006 1947 also died during the same period. It was possible to link HES records to cancer registrations for 1864 (96%) of these children. About 134 (14%) children who died in hospital did not have their death recorded in a HES episode, and looking at available records for two large specialist centres ($n = 15$), it seemed that about half died in intensive care units. 14 (1%) children who were recorded in HES as dying in hospital, had death certificates recording home or hospice as place of death. Ethnicity from different sources was validated and agreement reached for 84% of children. Ethnicity as recorded by CCLG was used for 12% of children when this was the only data source. The record of ethnicity by CCLG was found to be 99% accurate when compared with HES.

Of the children who had linked HES episodes, 47% died in hospital and 45% at home (Table 1). Similar proportions of boys and girls died at home, hospital and in a hospice and a similar proportion of patients who participated in a clinical trial died at home or in hospital. A decreasing proportion of children died in hospital by increasing age at death, which is attributable to many older children diagnosed with brain or spinal tumours dying at home or in a hospice. Death in hospital was more likely for children diagnosed with leukaemias and lymphomas than children diagnosed with solid tumours. 70% of Asian and Black children died in hospital, compared to 42% of white children. Increasing deprivation was associated with an increasing likelihood of a child dying in hospital. Useful additional information on the reasons for 47% of children dying in hospital was not available within death certificates or HES data, as the original malignancy was most often reported as cause.

The proportion of children dying in a hospice increased significantly by year of diagnosis from 2% to 10% during 1999–2006. Of the 150 children who died in a hospice 57% were diagnosed with a brain or spinal tumour, 11% with a bone tumour and only 9% with a leukaemia; 79% were white and no pattern was evident by deprivation. 31 different hospices were a place of death for these children, with four each being the place of death for more than 10 of the children studied.

Within 6 months of diagnosis, 543 children died, of whom 70% died in hospital, 54% were under five years of age at death and the majority were not included in a trial (69%). Many of these children had been diagnosed with a brain or spinal tumour (43%) and with a leukaemia (23%). In those surviving

Table 1 – Characteristics of children who died after a diagnosis of cancer who have a hospital record in England, 1999–2006.

	Place of death						Total %	
	Died at home %		Died in hospital %		Died in hospice/care home %			
Total linked to HES records	847	45	867	47	150	8	1864	100
Sex								
Male	471	46	467	46	82	8	1020	55
Female	376	45	400	47	68	8	844	45
Age at diagnosis								
<1 year	90	42	110	51	15	7	215	12
1–4 years	268	44	295	48	47	8	610	33
5–9 years	230	48	202	42	52	11	484	26
10–14 years	259	47	260	47	36	6	555	30
Age at death								
<1 year	30	28	65	61	11	10	106	6
1–4 years	217	40	286	53	34	6	537	29
5–9 years	267	50	216	40	56	10	539	29
10–14 years	237	47	232	46	34	7	503	27
15–19 years	96	54	68	38	15	8	179	10
Type of cancer								
Brain and spinal tumours	311	49	243	38	86	13	640	34
All leukaemias	129	28	313	69	14	3	456	24
ALL	76	29	179	68	8	3	236	13
AML	42	30	94	67	4	3	140	8
Soft tissue sarcomas	102	57	66	37	12	7	180	10
Sympathetic nervous system tumours	104	59	65	37	6	3	175	9
Bone tumours	80	59	39	29	16	12	135	7
Lymphomas	34	30	76	68	2	2	112	6
Renal tumours	40	56	25	35	6	9	71	4
Hepatic tumours	21	55	12	32	5	13	38	2
Epithelial tumours	21	57	13	35	3	8	37	2
Germ cell and gonadal tumours	3	23	10	77	0	0	13	1
Other and unspecified malignant neoplasm	2	29	5	71	0	0	7	0
Died within six months of diagnosis	131	24	381	70	31	6	543	29
Ethnicity								
White	737	50	625	42	126	9	1488	80
South Asian	49	30	110	66	7	4	166	9
Black	11	17	48	76	4	6	63	3
Other	30	41	34	47	9	12	73	4
Unknown/missing	20	27	50	68	4	5	74	4
Index of multiple deprivation income domain quintile								
Affluent	245	51	197	41	38	8	480	26
2	123	49	105	42	24	10	252	14
3	158	50	134	42	27	8	319	17
4	159	44	178	49	27	7	364	20
Deprived	162	36	253	56	34	8	449	24
Registered at a CCLG centre								
Yes	830	47	804	45	147	8	1781	96
No	17	20	63	76	3	4	83	4
Clinical trial status								
Yes	404	47	414	48	50	6	868	47
No	443	44	453	45	100	10	996	53

longer than six months, the majority were included in a clinical trial (53%) and died at home (54%).

Among the few children (*n* = 83) who were not seen at a CCLG centre 76% died in hospital and only 37% of these children were white. Many of these children were diagnosed with a brain or spinal tumour (42%), were aged over 10 years at diagnosis (34%) and died within six months of diagnosis (60%).

At the univariate level, age at death, type of cancer, dying within six months of diagnosis, ethnicity, socio-economic status and whether treated at a CCLG centre were all significantly associated with dying at home or hospital ($P < 0.001$) (Table 2). In the multivariable analysis, all of these factors continued to have a significant association with place of death, except age at death, which was no longer important

Table 2 – Univariate and multivariable analysis of place of death (home vs hospital) of childhood cancer patients who were diagnosed and died during 1999–2006, in England.

	Univariate analysis			Multivariable analysis			
	Odds ratio	95% CI		Odds ratio	95% CI		P value
Sex							
Male	1.00						
Female	0.93	0.77	1.13				
Age at diagnosis							
<1 year	1.00						
1–4 years	1.11	0.80	1.54				
5–9 years	1.39	0.99	1.95				
10–14 years	1.22	0.88	1.69				
Age at death							
<1 year	1.00						
1–4 years	1.64	1.03	2.62				
5–9 years	2.68	1.68	4.28				
10–14 years	2.21	1.38	3.54				
15–19 years	3.06	1.80	5.21				
Type of cancer							
Leukaemia	1.00			1.00			
Lymphomas	1.09	0.69	1.71	1.45	0.89	2.36	0.139
Brain and spinal tumours	3.11	2.38	4.05	4.23	3.16	5.66	<0.001
Other solid tumours	3.85	2.96	5.01	3.96	3.00	5.24	<0.001
Died within six months of diagnosis							
Yes	1.00			1.00			
No	4.28	3.41	5.39	4.48	3.48	5.77	<0.001
Ethnicity							
White	1.00			1.00			
South Asian	0.35	0.24	0.52	0.45	0.29	0.69	<0.001
Black	0.22	0.11	0.44	0.20	0.10	0.43	<0.001
Other	0.71	0.42	1.21	0.82	0.45	1.47	0.503
Unknown/missing	0.48	0.36	0.65	0.81	0.58	1.13	0.219
Index of multiple deprivation income domain quintile							
Affluent	1.00			1.00			
2	0.94	0.68	1.30	0.99	0.69	1.42	0.952
3	0.95	0.70	1.28	0.93	0.67	1.30	0.679
4	0.72	0.54	0.95	0.84	0.61	1.15	0.281
Deprived	0.52	0.39	0.68	0.60	0.44	0.82	0.001
Registered at a CCLG centre							
Yes	1.00			1.00			
No	0.26	0.15	0.45	0.36	0.20	0.66	0.001
Clinical trial status							
Yes	1.00						
No	1.00	0.83	1.21				

when dying within six months of diagnosis was included in the model. More children from ethnic minorities were classified as deprived, but both these variables still had an independent association with dying in hospital.

Short duration of survival (deaths between 3 and 18 months from diagnosis) was a significant factor associated with dying in hospital rather than at home in the multivariable analyses, regardless of the cut point used (data not shown). The odds of dying in hospital decreased from 6.83 for deaths within 3 months to 2.05 for deaths within 18 months. The impact of death within six months has been presented because almost all patients would be receiving treatment during this period after diagnosis.

The average time between diagnosis and death for all children studied was 481 days, of which about a fifth were spent in hospital. The average number of hospital episodes and bed days from diagnosis to death varied by type of cancer and place of death (Table 3). Children with leukaemia had longer time between diagnosis and death and more bed days in hospital than children with brain and spinal tumours or other solid tumours. Children with AML on average had more bed days (>150 days) than other children, regardless of place of death.

Children who died in hospital had more bed days, particularly in the six months prior to death. Unsurprisingly, their last hospital episode was much longer than the last hospital

Table 3 – Hospital admissions by place of death for children who were diagnosed and died of cancer, England 1999–2006.

	Place of death					
	Died at home		Died in hospital		Died in a hospice/care home	
Average number of hospital episodes from diagnosis to death						
All cancers	39		30		37	
All leukaemias	58		39		54	
ALL	69		45		64	
AML	41		28		50	
Lymphomas	52		22		20	
Brain and spinal tumours	23		19		26	
Other solid tumours	45		32		51	
Average time between diagnosis and death (days)						
All cancers	571		377		581	
All leukaemias	640		457		673	
ALL	740		507		697	
AML	486		390		758	
Lymphomas	570		296		206	
Brain and spinal tumours	476		303		452	
Other solid tumours	646		374		801	
Average bed days spent in hospital from diagnosis to death						
All cancers	105		111		98	
All leukaemias	185		133		172	
ALL	182		116		105	
AML	193		153		294	
Lymphomas	137		97		107	
Brain and spinal tumours	58		78		75	
Other solid tumours	113		120		117	
Average bed days in hospital in the 6 months prior to death						
All cancers	32		55		31	
All leukaemias	81		64		62	
ALL	87		58		42	
AML	74		72		62	
Lymphomas	60		63		60	
Brain and spinal tumours	18		44		31	
Other solid tumours	25		54		20	
Average duration of last hospital admission (days)						
All cancers	5		20		9	
All leukaemias	9		22		26	
ALL	8		19		16	
AML	10		23		20	
Lymphomas	5		23		28	
Brain and spinal tumours	5		18		9	
Other solid tumours	3		17		3	
Average time to death following last discharge (days)						
All cancers	51		N/A		46	
All leukaemias	15		N/A		26	
ALL	14		N/A		41	
AML	19		N/A		4	
Lymphomas	14		N/A		5	
Brain and spinal tumours	74		N/A		47	
Other solid tumours	47		N/A		52	
Type of last hospital admission						
Elective	415	49	218	25	63	42
Emergency	386	46	505	58	78	52
Transfer between hospitals	40	5	138	16	9	6
Other	0	0	4	<1	0	0
Unknown	6	1	2	<1	0	0

episode for children who died at home. After their last hospital admission, on average, children who died in a hospice lived another 46 days and children who died at home lived another 51 days. Of the children who died in hospital, 58% were admitted as emergencies and 16% were transferred between hospitals for their last admission. For about half of the children who died in a hospice or at home, their last hospital admission was an emergency.

5. Discussion

The vast majority of children who were diagnosed and died from cancer during 1999–2006 in England have had their cancer registration linked to hospital records. The anomaly of some deaths in hospital not being registered within HES data illustrates that caution is required when interpreting findings, especially given that the purpose of collecting HES data is for funding rather than research. We have made the assumption that we were able to link all hospital records for each patient, although partial matches were visually inspected to improve the quality of linkage. It was possible to validate ethnicity for most patients, providing some reassurance of the quality of hospital data available. Ethnicity as recorded by CCLG centres is even more complete and of higher quality than HES.

A limitation of the study was that it only included children who were diagnosed and who died during 1999–2006, which has resulted in an over-representation of short-term survivors. A maximum survival time of just less than eight years was possible. Death certificates were not available for 2007–2008, but we estimate an additional 340 children died in these two years who had been diagnosed during 1999–2006. A second limitation of the study is that we do not have data on the proportion of patients with whom palliative care and place of death was discussed, whether preferences were stated or the reasons for death in hospital.

Among children dying from cancer during 1995–1999 in England and Wales, and during 2004–2008 in Scotland, only 3% died in a hospice.[11,12] During 1999–2006 in England a child dying in a hospice was still rare, although the proportion increased from 2% to 10%. An explanation for this may be that whilst the number of hospices has increased, the services they offer may be directed towards offering respite and bereavement care rather than residential palliative care. Similar proportions of teenagers and younger children died in a hospice, demonstrating that this option is available to young people of all ages.

Of the children who die in hospital, 74% were admitted as emergencies or as a transfer from another hospital, which may relate to care being shared between hospitals, absence of an intensive care unit at a hospital or if a family no longer has the resources for a child to die at home.

Similar findings with the study of children dying of cancer in England and Wales during 1995–1999 and in Yorkshire during 1990–2005 were that children who were diagnosed with a leukaemia or a lymphoma were more likely to die in hospital and the majority of children dying in a hospice had been diagnosed with a brain or spinal tumour.[11,13] Children with a leukaemia or a lymphoma may often die whilst still receiving curative treatment or being treated for a relapse, and therefore, it is unsurprising that hospitals provide more care for them.[14] These children often undergo bone marrow transplantation, which in itself is associated with a high mortality rate. Also, a hospice requires adequate facilities and staff with appropriate skills to be able to provide transfusions. In contrast, children who have a brain or spinal tumour are likely to be identified as requiring palliative care sooner than children with other malignancies, and it is relatively easy for their neurological symptoms to be managed in a hospice or at home.

Death within six months of diagnosis was an important factor associated with more deaths in hospital. A possible explanation for this is that these children had acute conditions, and little time was available to access specialist palliative care services or to consider place of death, whilst curative treatment was being attempted. Over 90% of these children were treated in CCLG centres, and a lower proportion of these children being involved in clinical trials probably relates to trials not running for their diagnoses.

The pattern of place of death with registration or not at a CCLG centre may be explained by health professionals at CCLG centres being more likely to have the systems and a team approach to facilitating death at home between patient, family, outreach nursing teams and GPs.[15]

That a substantial proportion of children from ethnic minorities or deprived backgrounds are dying in hospital rather than at home or in a hospice is likely to be a complex issue. Possible explanations for fewer deaths at home include the level of understanding and acceptance of the concept of palliative care amongst family members from ethnic minorities may be low,[16] that ethnicity and financial status affects access to a range of services, and a belief may exist amongst health professionals and/or patient's families that they may not be able to cope with a child dying at home.

Explanations can be given for the association between place of death and type of cancer, dying within six months of diagnosis and treatment at a CCLG centre. Potential exists for more children with leukaemias and lymphomas to die at home or in a hospice. Further research is required to understand why more children with Asian or Black ethnicity or from a deprived area die in hospital. Also, more detailed investigations will be conducted into the use of hospital services for children with each type of cancer, in particular comparing children who survive with those who die within five years of diagnosis. Overall, the gold standard of care would be for health-care teams to offer children and their families comprehensive options on place of death and the ability to alter decisions as circumstances change.

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Conflict of interest statement

None declared.

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