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Fraser, Lorna Katharine, Fleming, Sarah and Parslow, Roger (2018) Changing Place of Death in Children who died after discharge from Paediatric Intensive Care Units:a national, data linkage study. *Palliative Medicine*. pp. 337-346. ISSN: 0269-2163

<https://doi.org/10.1177/0269216317709711>

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Changing place of death in children who died after discharge from paediatric intensive care units: A national, data linkage study

Palliative Medicine

1–10

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DOI: 10.1177/0269216317709711

journals.sagepub.com/home/pmj



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Abstract

Background: Although child mortality is decreasing, more than half of all deaths in childhood occur in children with a life-limiting condition whose death may be expected.

Aim: To assess trends in place of death and identify characteristics of children who died in the community after discharge from paediatric intensive care unit.

Design: National data linkage study.

Setting/participants: All children resident in England and Wales when admitted to a paediatric intensive care unit in the United Kingdom (1 January 2004 and 31 December 2014) were identified in the Paediatric Intensive Care Audit Network dataset. Linkage to death certificate data was available up to the end of 2014. Place of death was categorised as hospital (hospital or paediatric intensive care unit) or community (hospice, home or other) for multivariable logistic modelling.

Results: The cohort consisted of 110,328 individuals. In all, 7709 deaths occurred after first discharge from paediatric intensive care unit. Among children dying, the percentage in-hospital at the time of death decreased from 83.8% in 2004 to 68.1% in 2014; 852 (0.8%) of children were discharged to palliative care. Children discharged to palliative care were eight times more likely to die in the community than children who died and had not been discharged to palliative care (odds ratio=8.06 (95% confidence interval=6.50–10.01)).

Conclusions: The proportion of children dying in hospital is decreasing, but a large proportion of children dying after discharge from paediatric intensive care unit continue to die in hospital. The involvement of palliative care at the point of discharge has the potential to offer choice around place of care and death for these children and families.

Keywords

Paediatric intensive care unit, palliative care, place of death, hospice, child

What is already known about the topic?

- Child mortality is decreasing, but more than half of all deaths in childhood are for children with a life-limiting condition whose death may be expected.

What this paper adds?

- Although the proportion of children dying in the community after discharge from paediatric intensive care unit (PICU) has increased over time, most children continue to die in hospital or PICU.
- Children who died after the involvement of palliative care were eight times more likely to die in the community rather than hospital than children who died and were not discharged to palliative care.

Implications for policy, practice or theory

- Further provision of hospital-based specialist paediatric palliative care teams should be a priority to enable further integration of specialist palliative care services with other specialities, particularly Paediatric Critical Care.

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Introduction

Child mortality has decreased in high-income countries including the United Kingdom over the last 30 years,¹ but reductions in the United Kingdom have been less marked than similar countries.² Mortality rates in paediatric intensive care units (PICUs) have also decreased over time,³ but some children do continue to die both in PICU⁴ and after discharge. It is estimated that more than 50% of deaths in children and young people in the United Kingdom are related to life-limiting conditions; therefore, their deaths may be expected⁵ and since the World Health Organization (WHO) definition of children's palliative states that 'It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease',⁶ you may expect that discussions regarding choice of place of care/death may have occurred in this population.

The notion that an out-of-hospital death is better than an in-hospital death as a universally valued goal is becoming contentious in both children^{7,8} and adults,⁹ as the evidence on patient and families' preference⁷ and importance of place of death is mixed. However, admissions to PICU are known to be stressful,¹⁰ and it has been known for some time that parents and siblings of children who died in hospital show more psychological symptoms¹¹ and poorer adjustment¹² than if their child or sibling had died at home. In particular, fathers showed higher levels of stress, depression and anxiety if their child had died in hospital compared to home.¹³ It should also be noted that within the National Health Service (NHS) in England, the proportion of people dying in hospital is currently used as a measure of quality.¹⁴ However, facilitating choice of place of care can only occur where resources are made available.^{15,16}

In the United States, an increasing number of children with complex chronic conditions died at home rather than in hospital when comparing 1989–1993 to 1999–2003, but still more than 80% of these deaths occurred in the hospital.¹⁷

A previous descriptive study in the United Kingdom showed a difference in place of death in those discharged from PICU to palliative care and those not discharged to palliative care; but other clinical and demographic factors were not accounted for and no assessment of trends over time could be undertaken.¹⁸ A large multicentre study from the United States has showed that children with complex chronic conditions had longer lengths of stay in PICU and higher mortality than other children, but mortality data after discharge from PICU were not available.¹⁹

This study aimed to assess the trends in place of death for children who died after discharge from PICU and the clinical and demographic factors which were associated with death in the community rather than hospital.

Materials and methods

Dataset

Paediatric Intensive Care Audit Network data. All children admitted to a PICU in the United Kingdom between 1 January 2004 and 31 December 2014 were identified in the Paediatric Intensive Care Audit Network (PICANet) dataset.²⁰ Only children who were resident in England and Wales were included in the cohort for analyses, as only their deaths would be recorded on the Office for National Statistics (ONS) death records. Linkage to the ONS death certificate dataset was undertaken by the Health and Social Care Information Centre, using their standard algorithm which uses NHS number, date of birth, sex and postcode. These data were available with a censor date of 1 November 2015, but due to the delays that can occur in registering deaths, only data up to the end of 2014 were included in these analyses.

Clinical variables. Clinical diagnoses for each admission were coded using Clinical Terms 3 (The Read Codes) which were aggregated into 12 primary diagnostic groups.²¹

The Paediatric Index of Mortality (version 2; PIM2) is used within UK PICUs to assess severity of illness at the point of admission and therefore the risk of mortality in PICU. It is based on physiological measurements in the first hour of admission, specific interventions and diagnoses.²² PIM2 used in this study was recalibrated coefficients calculated using admission data submitted to PICANet for the years 2011–2013.³ PIM2 was categorised into five categories of risk <1%, 1%–<5%, 5%–<15%, 15%–<30% and 30%+.

The number of PICU admissions was categorised as single admission, two admissions, three admissions and four or more admissions.

PICANet defined discharge for palliative care as 'withdrawal of care at the current level if it is deemed that the admission can no longer benefit'. This variable identifies when a child was discharged from a PICU to a palliative care area.²¹ In this study, an individual patient was assigned as discharged for palliative care if they had been discharged for palliative care after any PICU admission.

Death data were obtained from the ONS death certificate system.²³ Date of death and place of death data were used in these analyses. Place of death was categorised into PICU, hospital (excluding PICU), home, hospice or other based on the recorded address of death.

Demographic variables. Age at admission to PICU was categorised as <1 year, 1–4 years, 5–10 years, 11–15 years and ≥16 years. Sex was included in the analysis only where it was non-ambiguous (male or female). An Index of Multiple Deprivation (2010; IMD)²⁴ category was assigned to each individual based upon their Lower Super Output Area (LSOA) of residence. An LSOA is a census

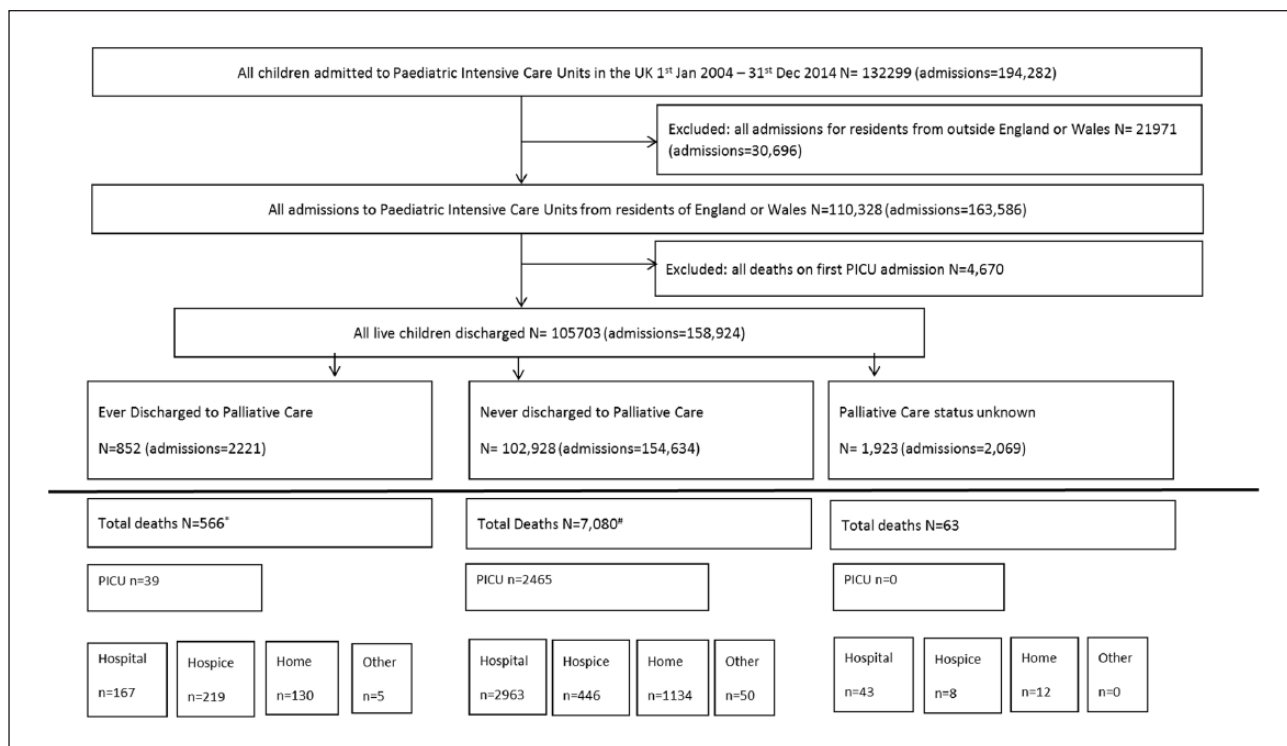


Figure 1. Study flowchart.

geographical area built up of Output Areas. There are 34,753 LSOAs (2011 Census) in England with a population of 1000–3000 per LSOA.²⁵ These data were split into five categories for analyses with category 1 being the least deprived.

The ethnicity variable in PICANet is incomplete therefore South Asian ethnicity, the commonest ethnic minority group in England,²⁶ was determined using two South Asian names analysis programs. These programs, Nam Pehchan^{27,28} and the South Asian Names and Group Recognition Algorithm,²⁹ classified individual children as South Asian (Pakistani, Indian or Bangladeshi) or not. The results from these programs were corrected manually for known misclassification errors.³⁰

Statistical analyses. Descriptive statistics were undertaken overall and by palliative care discharge status. Differences between groups were assessed by chi-squared or *t*-test.

Random effects logistic regression was undertaken to account for inter PICU variation in the outcome. A binary place of death variable was the dependent variable: community (home, hospice or other) or hospital (PICU and Hospital). Apart from the palliative care variable, all data in the model pertained to the last PICU admission prior to death for each individual. Variables were included in the model in a forced entry method with variables retained if $p < 0.05$ or they improved the model fit assessed using the Bayesian information criterion (BIC).

All analyses were carried out using STATA version 13, and all tests of statistical significance were at $p \leq 0.05$.

Ethical approval. Collection of personally identifiable data has been approved by the Patient Information Advisory Group (now the NHS Health Research Authority Confidentiality Advisory Group; see <http://www.hra.nhs.uk/documents/2015/12/piag-register-8.xls>), and ethics approval was granted by the Trent Medical Research Ethics Committee (ref. 05/MRE04/17 +5).

Results

The cohort consisted of 110,328 individuals with 163,586 PICU admissions (Figure 1). A total of 4670 deaths occurred in PICU on first admission and were not included in the analyses. In all, 7709 deaths occurred after discharge from PICU and form the cohort for this study (Table 1). Of the individuals, 37.4% ($n = 2885$) had a single PICU admission, 30.2% ($n = 2327$) had two PICU admissions, 13.8% ($n = 1060$) had three PICU admissions and 18.6% ($n = 1437$) had more than four PICU admissions.

The numbers of children dying each year after discharge from PICU varied between 640 and 782, apart from the first year (2004) which had a lower number of deaths due to left censoring of the dataset.

Of the children admitted to PICU, 852 (0.8%) were discharged for palliative care, of which 566 (7.3% of all

Table 1. Descriptive statistics of children resident in England and Wales who died after PICU discharge (2004–2014).

Variables	Total deaths excluding first PICU ^a		Palliative		Never	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
	7709		566		7080	
Gender						
Male	4225	54.8	311	54.9	3877	54.8
Female	3480	45.1	253	44.7	3201	45.2
Missing	4	<0.1	2	0.4	2	<0.1
Age category						
<1 year	3320	43.1	237	41.9	3061	43.2
1–4 years	1868	24.2	137	23.7	1711	24.2
5–10 years	1063	13.8	80	14.1	979	13.8
11–15 years	1087	14.1	88	15.5	985	13.9
16+	371	4.8	24	4.2	344	4.9
Diagnostic group ^b						
Neurological	957	12.4	115	20.3	833	11.8
Cardiac	1821	23.6	73	12.9	1735	24.5
Respiratory	2092	27.1	207	36.6	1869	26.4
Oncology	794	10.3	52	9.2	728	10.3
Infection	452	5.9	37	6.5	412	5.8
Musculoskeletal	200	2.6	9	1.6	191	2.7
Gastrointestinal	473	6.1	18	3.2	452	6.4
Other	366	4.7	14	2.5	351	5.0
Blood and lymph	86	1.1	<5	<0.9	81	1.1
Trauma	40	0.5	<5	<0.9	39	0.6
Endocrine/metabolic	322	4.2	32	5.7	290	4.1
Multisystem	16	0.2	<5	<0.9	13	0.2
Body wall and cavities	90	1.2	<5	<0.9	86	1.2
Risk of mortality (PIM2) ^b						
<1%	1233	16.0	23	4.1	1191	16.8
1–<5%	3415	44.3	254	44.9	3130	44.2
5–<15%	1996	25.9	195	34.5	1792	25.3
15–<30%	618	8.0	61	10.8	556	7.9
30%+	447	5.8	33	5.8	411	5.8
South Asian						
No	6427	83.4	475	83.9	5894	83.2
Yes	1282	16.6	91	16.1	1186	16.8
Length of stay (days)						
Mean	8.7		12.1		8.5	
SD	19.2		40.9		16.4	
Median	3.4		6.2		3.1	
IQR	1.0–9.4		2.1–13.9		1.0–9.1	
Missing	2		0		2	
Year of death						
2004	437	5.7	39	6.9	394	5.6
2005	639	8.3	61	10.8	577	8.1
2006	696	9.0	39	6.9	655	9.3
2007	742	9.6	46	8.1	692	9.8
2008	729	9.5	21	3.7	702	9.9
2009	761	9.9	57	10.1	699	9.9
2010	782	10.1	56	9.9	718	10.1
2011	718	9.3	47	8.3	656	9.3
2012	775	10.1	66	11.7	698	9.9
2013	728	9.4	66	11.7	659	9.3
2014	702	9.1	68	12.0	630	8.9

Table 1. (Continued)

Variables	Total deaths excluding first PICU ^a		Palliative		Never	
Place of death^b						
Hospital	3173	41.2	167	29.5	2963	41.9
Hospice	673	8.7	219	38.7	446	6.3
Home	1276	16.6	130	23.0	1134	16.0
Other	55	0.7	5	0.9	50	0.7
PICU	2504	32.5	39	6.9	2465	34.8
Not known	28	0.4	6	1.1	22	0.3
No. of PICU admissions^b						
One admission	2885	37.4	263	46.5	2569	36.3
Two admissions	2327	30.2	123	21.7	2197	31.0
Three admissions	1060	13.8	69	12.2	990	14.0
Four and more admissions	1437	18.6	111	19.6	1324	18.7
Deprivation (IMD 2010) score						
Category 1 (least deprived)	927	12.0	66	11.7	861	12.2
Category 2	955	12.4	72	12.7	883	12.5
Category 3	1253	16.3	100	17.7	1153	16.3
Category 4	1696	22.0	118	20.8	1578	22.3
Category 5 (most deprived)	2499	32.4	185	32.3	2314	32.7
Missing	379	4.9	25	4.4	291	4.1

IMD2010: Index of Multiple Deprivation 2010; PICU: paediatric intensive care unit; PIM2: Paediatric Index of Mortality (version 2); SD: standard deviation; IQR: interquartile range.

^aPalliative care status was missing for 63 individuals who had died; therefore, palliative and never columns do not total 7709.

^bChi² results: $p < 0.001$ between palliative and non-palliative groups.

deaths) had died at the censor point. Therefore, only 7.4% of children who died had been referred for palliative care.

There were some statistically significant differences in clinical characteristics between those who died after being discharged for palliative care and those who died and who had not been discharged for palliative care (Table 1), but no significant differences in gender, age, ethnicity or deprivation scores.

A higher percentage of those in the palliative care group had a primary neurological (20.3% vs 11.8%) or respiratory (36.6% vs 26.4%) diagnoses, and a lower percentage had a cardiac diagnosis (12.9% vs 24.5%; $\chi^2=113.4$, $p < 0.001$).

The length of stay in PICU was higher in those from the palliative care group (median length of stay 6.2 days vs 3.1 days). Those children from the palliative care group were less likely to have more than one PICU admission (53.5% vs 63.7%, $\chi^2=31.1$, $p < 0.001$). A smaller percentage of the palliative care group had a <1% chance of mortality within PICU on their last PICU admission (4.1% vs 16.0%; $\chi^2=76.4$, $p < 0.001$).

Place of death differed significantly between the two groups with a higher percentage of those in the palliative care group dying at home (23% vs 16.0%) or hospice (38.7% vs 6.3%) and a lower percentage dying in a

hospital ward (29.5% vs 41.9%) or PICU (6.9% vs 34.8%) ($\chi^2=797.2$, $p < 0.001$).

Place of death

Overall, 41.2% of the deaths occurred in hospital, 32.5% in PICU, 16.6% at home, 8.7% in hospice and 0.7% elsewhere. Deaths in hospital decreased from 43.5% in 2004 to 38.2% in 2014. Death in PICU decreased from 40.3% to 29.9%, while deaths in hospice rose from 3.9% to 11.1% and deaths at home rose from 12.4% to 20.1% (Figure 2) during the same time period.

Modelling

Table 2 shows the results of the random effects logistic modelling with community death (home, hospice or other) compared to hospital setting (hospital including PICU) as the outcome variable. All age groups were significantly more likely to die in the community rather than the hospital setting compared to the under 1 year age group. Children with neurological (odds ratio (OR)=1.71 (95% confidence interval (CI)=1.41–2.08)) or oncology diagnoses (OR=3.30 (95% CI=2.65–4.09)) were significantly more likely to die in the community than those with respiratory diagnoses. Conversely, children with cardiac

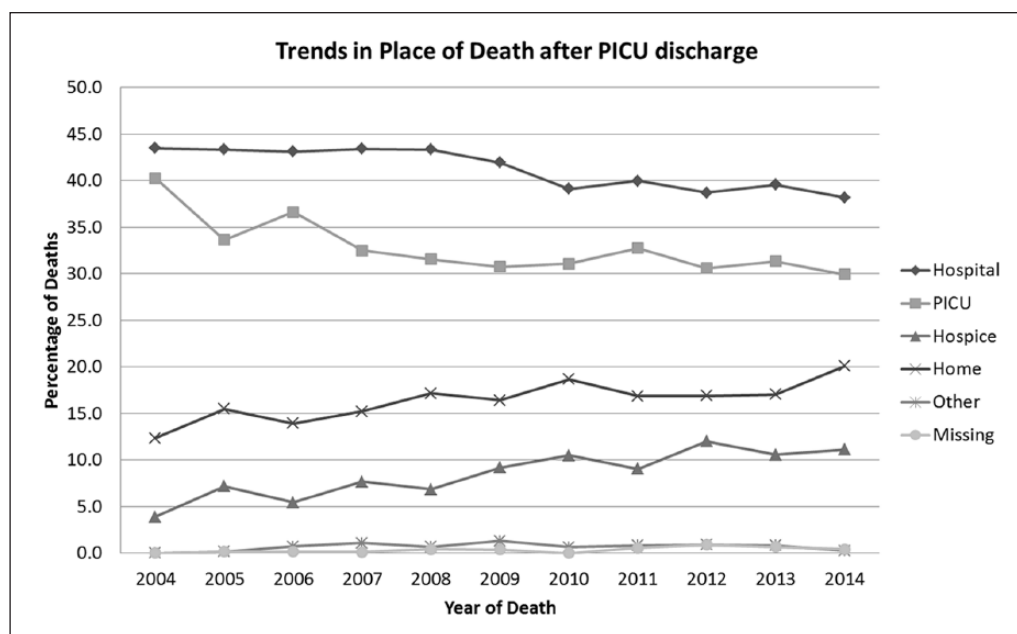


Figure 2. Trends in place of death.

Table 2. Random effects logistic regression with community death as dependent variable of children resident in England and Wales who died after PICU discharge (2004–2014).

Variables	Odds ratio	p value	95% CI	
Age category				
<1 year	REF			
1–4 years	1.83	<0.001	1.54	2.17
5–10 years	2.46	<0.001	2.02	2.99
11–15 years	2.47	<0.001	2.04	2.96
16+	1.77	<0.001	1.34	2.34
Sex				
Male	REF			
Female	0.90	0.09	0.79	1.02
Diagnostic group				
Respiratory	REF			
Neurological	1.71	<0.001	1.41	2.08
Cardiac	0.49	<0.001	0.39	0.61
Oncology	3.30	<0.001	2.65	4.09
Infection	0.98	0.90	0.74	1.31
Musculoskeletal	0.57	0.01	0.38	0.84
Gastrointestinal	0.77	0.07	0.58	1.02
Other	1.30	0.09	0.98	1.73
Blood and lymph	1.06	0.95	0.60	1.88
Trauma	0.46	0.09	0.19	1.13
Endocrine/metabolic	1.28	0.12	0.94	1.75
Multisystem	3.48	0.05	1.02	11.9
Body wall and cavities	0.66	0.25	0.33	1.34
Risk of mortality (PIM2)				
<1%	REF			
1–<5%	0.69	<0.001	0.58	0.82
5–<15%	0.44	<0.001	0.36	0.54
15–<30%	0.40	<0.001	0.30	0.54
30%+	0.24	<0.001	0.16	0.35

Table 2. (Continued)

Variables	Odds ratio	p value	95% CI	
Ever discharged to palliative care				
No	REF			
Yes	8.06	<0.001	6.50	10.01
Length of PICU stay (days)	0.99	0.03	0.99	1.00
Number of PICU admissions				
One admission	REF			
Two admissions	0.41	<0.001	0.35	0.48
Three admissions	0.41	<0.001	0.34	0.51
Four and more admissions	0.34	<0.001	0.28	0.41
South Asian ethnicity				
No	REF			
Yes	0.48	<0.001	0.39	0.58
Deprivation category (IMD2010)	0.99	<0.001	0.99	0.99
Category 1 (least deprived)	REF			
Category 2	0.87	0.22	0.69	1.09
Category 3	0.81	0.06	0.65	1.01
Category 4	0.80	0.04	0.65	0.99
Category 5 (most deprived)	0.63	<0.001	0.51	0.77
Year of death	1.06	<0.001	1.04	1.08

IMD2010: Index of Multiple Deprivation 2010; PICU: paediatric intensive care unit; PIM2: Paediatric Index of Mortality (version 2); CI: confidence interval. $n=7303$, Wald $\chi^2=1227$, $p<0.001$, $\rho=0.022$, $\sigma=0.27$.

(OR=0.49 (95% CI=0.39–0.61)) or musculoskeletal diagnoses (OR=0.57 (95% CI=0.38–0.84)) were significantly less likely to die in the community than those with respiratory diagnoses.

Children with a higher risk of mortality, calculated by the PIM2 score, were all significantly less likely to die in a community setting compared to those with the lower risk of mortality. Those with more than one PICU admission were also significantly less likely to die in the community than those who only had one PICU admission. Children discharged for palliative care were eight times more likely to die in the community (OR=8.06 (95% CI=6.50–10.01)).

Children from a South Asian background were significantly less likely to die outside the hospital than non-South Asian children (OR=0.48 (95% CI=0.39–0.58)). Children living in the two most deprived categories were significantly less likely to die outside the hospital than children living in the least deprived areas (category 4 OR=0.80 (95% CI=0.65–0.99) and category 5 (most deprived) OR=0.63 (95% CI=0.51–0.77)).

There was a significant trend over time of dying in the community with an increase of 6% per year (OR=1.06 (95% CI=1.04–1.08)). Interaction terms between palliative care status, length of stay, diagnostic group and number of PICU admissions were not retained within the model as they were not significant and did not improve the model fit.

The result of the sensitivity analyses excluding the deprivation variable in the random effects logistic model

shows that the interpretation of the main variables of interest remains the same (data not shown).

Discussion

The proportion of children dying in hospital and PICU has decreased over the period of this study in England and Wales, but 68.1% of children who died after PICU admission still died in hospital in 2014. Discharge for palliative care had the largest effect on whether a child died in the community setting rather than hospital after a PICU admission, with children referred for palliative care having eight times the odds of dying in the community compared to children who had not been discharged for palliative care.

Children older than 1 year of age were more likely than the under 1 year age group to die in the community. The prevalence of life-limiting conditions in children is by far the highest in the under 1 year age group,³¹ and admission rates to PICU are also higher in the under 1 year age group. Overall mortality² and within PICU mortality are also significantly higher in the under 1 year age group;³ therefore, they should be seen as a priority group for input from specialist palliative care services. Although choice of place of death should be available for neonates and infants, given the relatively well-developed palliative care services and established guidelines in the United Kingdom, it may not be offered.³²

The underlying diagnoses had an effect on whether the child died in the community or hospital setting. Different diagnostic groups may have different disease trajectories

and more reliance on services currently provided by hospitals, for example, cardiac and respiratory conditions. Children with an oncology diagnoses were 3.5 times more likely than children with respiratory diagnoses to die in the community. Children's cancer services are configured differently than other children's health services in the United Kingdom, and they are usually well provided with community care specialist nursing teams, which can be critical to enabling a death outside of the hospital setting. A recent paper has shown that consistently, since 1993, 40% of children who died from cancer in England died at home, but the children with haematological malignancies were more likely to die in hospital.³³ More specialist resources may be required to care these children at home compared to other dying children, and their disease trajectories are often more unpredictable, but choice should still be facilitated where possible.

While it should not be assumed that all children and families, if given a choice, would choose for a child to die at home,⁷ if true choice was available then we should see a higher percentage of children dying in the community than was found in this study. More than 60% of these children who died had more than one PICU admission, and although not all of these deaths would have been expected, many would be, therefore opportunities for involving palliative care in the care of these children and families may have been missed. There are some examples in England of integration of palliative care and PICU services but there are also hospitals in England where hospital-based specialist paediatric palliative care services do not exist.³⁴ Previous research with paediatric intensive care specialists has shown that there are mixed opinions on the role and usefulness of paediatric palliative care teams.³⁵

Inequity in the place of death has been shown in this study with children from the most deprived areas in England and Wales being less likely than those in the least deprived areas to die in a non-hospital setting. A previous study from PICANet data showed that deprivation was not significantly associated with whether or not a child was discharged for palliative care;³⁶ therefore, these inequities may also exist within place of death even when palliative care services are involved.

Children with a South Asian background were less likely to die outside the hospital setting than non-South Asian children. These differences in place of death by ethnic group are similar to a study from the United States which showed that Black and Hispanic children were 50% less likely to die at home than the White population.¹⁷ Previous work using the PICANet dataset showed that they were no less likely to be referred to palliative care but they were more likely to receive this care in hospital rather than in the community.³⁶ This is a complex issue, and flexibility of services to provide culturally competent care is key and some children's hospices have well-established reputations at engaging the South Asian community.³⁷

It is important to note that high-quality palliative care should be available in all settings, so if a child and family wish to die in hospital, or an alternative setting is not possible, that they should still be offered access to specialist paediatric palliative care services.

Strengths/limitations

These analyses were undertaken on a national, mandatory dataset with full population coverage over an 11-year period. This dataset was enhanced to provide mortality data after discharge by linkage to official death record statistics. Place of death was derived from recorded address in these data, and in this study, in only 0.4% of cases was this unable to be assigned. Address of death is validated via postcodes.³⁸ There are known delays to recording deaths of children particularly if coroners require to be notified. A total of 199 children who died in PICU (7.9% PICU deaths) did not have a matched ONS record. The majority of these were children who had died in the years 2012–2014. The analyses have been rerun only including children up to 2011 with no difference in the results.

The PICANet data are estimated as 99.9% complete, and the data are validated online including validation of the NHS number which is vital for linkage with other datasets.³

The definition of discharge for palliative care used within the PICANet dataset is quite restrictive: 'withdrawal of care at the current level if it is deemed that the admission can no longer benefit'.²¹ As paediatric palliative care services care for children throughout their illness, not just at the end of life, some children may have been receiving palliative care but not recorded on the PICANet dataset. This narrow definition may also influence the decisions of PICU clinicians regarding referral to palliative care.

There were missing data on palliative care status for a small number of the children who had died (0.8%). Importantly, we had no objective information available on the relationship between individual PICU units and the availability of palliative care services in their catchment areas and no information on situations in which palliative care was discussed and a referral was not made.

The ONS death certificate data cover children who died in England and Wales. Therefore, if a child had moved to another country and subsequently died, we would not have their information. However, we expect those to be a very small number of children.

Conclusion

Over the last 11 years, the proportion of children dying in hospital in England is decreasing, but a large proportion of children dying after discharge from PICU continue to die in hospital. A very small percentage of these children who died had been referred to specialist palliative care.

Involvement of palliative care before the point of discharge has the potential to offer choice around place of care and death for these children and families. Further provision of hospital-based specialist paediatric palliative care teams should be a priority to enable further integration of specialist palliative care services with other specialties, particularly Paediatric Critical Care.

Acknowledgements

The PICANet Audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit Programme (NCA). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP holds the contract to manage and develop the NCA Programme, comprising more than 30 clinical audits that cover care provided to people with a wide range of medical, surgical and mental health conditions. The PICANet Audit is funded by NHS England, the Welsh Government, NHS Lothian/National Service Division NHS Scotland, the Royal Belfast Hospital for Sick Children, The National Office of Clinical Audit (NOCA), Republic of Ireland and HCA Healthcare.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: This paper is an independent research arising from a Postdoctoral Fellowship supported by the National Institute for Health Research. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health. This study was funded by Research Trainees Coordinating Centre (Grant/Award Number: PDF-2013-06-001).

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