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Rising National Prevalence of Life-Limiting Conditions in Children in England

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KEY WORDS
life-limiting conditions, palliative care, HES, ethnicity, deprivation

ABBREVIATIONS
CI—confidence interval
GOR—government office region
HES—Hospital Episodes Statistics
ICD-10—*International Classification of Diseases, 10th Revision*
LAD—local authority district
LLC—life-limiting condition
NHS—National Health Service

Ms Fraser jointly conceived the study with Dr Parslow and was responsible for the initial study design, data analyses, writing the first paper draft and subsequent redrafts; Mr Miller was involved in the development of the ICD-10 coding framework; Dr Hain provided the "Hain dictionary" and was involved in the ICD-10 framework; Dr Norman provided the population data and was involved in the geographical interpretation of the data; Dr Aldridge was involved in the clinical interpretation of the data; Dr McKinney was involved in the data interpretation and redrafting of the final manuscript; and Dr Parslow jointly conceived the study with Ms Fraser and was involved in the data interpretation and redrafting of the final manuscript.

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WHAT'S KNOWN ON THIS SUBJECT: For children and young people with life-limiting conditions, palliative care services should be available, but few national or local data are available to estimate the burden of these conditions.

WHAT THIS STUDY ADDS: The prevalence of life-limiting conditions in children and young people in England was double the previously reported estimates, at 32 per 10 000 population. This identifies a need for specialist pediatric palliative care services.

abstract

BACKGROUND: Life-limiting conditions (LLCs) describe diseases with no reasonable hope of cure that will ultimately be fatal. For children with these diseases, palliative care services should be available but few data are available to estimate the burden of these conditions.

METHODS: Children (0–19 years) with LLCs were identified within an English Hospital Episode Statistics dataset (2000/2001–2009/2010) by applying a customized coding framework of the *International Classification of Diseases, 10th Revision*, disease codes. Prevalence per 10 000 population (0–19 years) was calculated by age, diagnostic group, ethnicity, deprivation, and region for each year.

RESULTS: The Hospital Episode Statistics extract contained 175 286 individuals with 1 or more LLCs of which congenital anomalies were the most common (31%). Prevalence increased over 10 years from 25 to 32 per 10 000 population. Prevalence in the South Asian (48 per 10 000); black (42 per 10 000); and Chinese, mixed, and "other" (31 per 10 000) populations were statistically significantly higher compared with the white population (27 per 10 000). Prevalence shows an inverse J-shaped relationship with 5 categories of deprivation, with the highest prevalence in the most deprived areas and the lowest in the second least deprived.

CONCLUSIONS: In 2010, the prevalence of LLCs in children in England was double the previously reported estimates and had increased annually in all areas over the past decade. This clearly identifies an escalating need for specialist pediatric palliative care services. When planning services for these increasing needs, the excess prevalence in ethnic minority groups, especially in deprived areas, needs to be considered. *Pediatrics* 2012;129:e923–e929

Life-limiting conditions (LLCs) in children have been defined as conditions for which there is no reasonable hope of cure and from which children will die. Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer.[1] LLCs include life-threatening conditions in this article.

Pediatric palliative care is a clearly different specialty from adult palliative care. The World Health Organization's definition of palliative care for children includes the statement, "It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease."[2] Children tend to be cared for over extended time periods, longer than 20 years in some instances,[3] whereas adult services generally focus on end-of-life care, which can be measured in days or weeks.[4]

In 2007, an independent review of children's palliative care services in England[5] highlighted the lack of available data on the number of children and young people who received or who would benefit from palliative care services.

Previous estimates of the prevalence of LLCs in children in England rose from 10 per 10 000 in 1997,[6] to 12 per 10 000 in 2003,[7] with the most recent estimate of 16 per 10 000 in 2007 (aged 0–19 years).[8] This recent estimate was based on death certificate data, which has limitations with respect to data quality and, as children live longer with their conditions, these figures are likely to be underestimates; anecdotally, clinicians working in pediatric palliative care consider that the currently available data underrepresents the burden of disease. There is no current national database of children with LLCs that can provide more accurate figures.

This study used routinely collected data to estimate the prevalence of LLCs in children and to assess trends over time by using an empirically derived diagnostic coding framework.

METHODS

The National Health Service (NHS) Hospital Episodes Statistics (HES) dataset contains clinical and demographic information about individuals' inpatient consultant episodes. Diagnoses are coded by using the *International Classification of Diseases, 10th Revision* (*ICD-10*), disease classification.[9] To identify children with an LLC, a coding framework of ICD-10 disease codes was developed.

Definition of Life-Limiting Conditions

An a priori list of ICD-10 codes that constituted the conditions of interest was produced before accessing the HES dataset. Two independent sources of information were used: the Hain Dictionary version 1.0 of ICD-10 codes for children seen by palliative care providers (developed by R.H., see Supplemental Information) and a list of diagnoses for children accepted for care at Martin House Children's Hospice from 1987 to 2010. A 4-digit ICD-10 code was assigned to 92% of diagnoses on the Martin House list; the 8% not coded were children without clear diagnoses (eg, "degenerative neurologic disease with no firm diagnosis").

Combining both sets of codes produced a provisional list of 801 ICD-10 codes for further scrutiny (84% of codes appeared on both lists).

All of these ICD-10 codes were individually subjected to the following 2 questions:

1. Are most children with this diagnosis life-limited/life-threatened?
2. Are most subdiagnoses within the ICD-10 code life-limiting/life-threatening?

A list of ICD-10 codes that fulfilled these criteria was compiled and completed by adding all malignant oncology ICD-10 codes (the data source was hospital admissions, so this would not include children "cured" of cancer).

The final ICD-10 coding framework consisted of 777 4-digit ICD-10 codes. Malignant oncology codes accounted for 445 (57%) codes, with congenital malformations and chromosomal abnormalities having 87 (11%) codes (available as Supplemental Table 3).

For statistical analysis, diagnoses were categorized into 11 groups based on the main ICD-10 chapters: neurology, hematology, oncology, metabolic, respiratory, circulatory, gastrointestinal, genitourinary, perinatal, congenital, and "other." No attempt was made to prioritize multiple diagnoses for individuals; therefore, individuals may have more than 1 life-limiting diagnosis.

Patient Data

An extract of inpatient HES[10] was obtained from the NHS information center for the 10-financial year time period 2000/2001 until 2009/2010. The selection captured all episodes for all patients ever coded, with 1 of the defined ICD-10 codes and/or the ICD-10 code for palliative care (used to capture children with no firm diagnosis). The extract excluded patients older than 19 years at the start of an episode and those whose country of residence was outside England.

The start age recorded at the first hospital episode in each year was used to assign the age category for each individual. Age was categorized into 5 groups: younger than 1 year, 1 to 5 years, 6 to 10 years, 11 to 15 years, and 16 to 19 years.

The data for each hospital episode included a code for gender and ethnicity. Gender was coded as male, female, or not known. Individuals with more than 1 recorded gender were assigned the most commonly recorded gender. Ethnicity within HES should be self-reported

by the patient. Individuals with more than 1 ethnicity were assigned the most commonly reported ethnicity, unless the most common ethnicity was "not known."[11] This ensured that the same code for an individual's ethnicity was assigned to all episodes (ie, if coded white in 2001/2002 data and 2002/2003 but not known in 2003/2004, he or she would be counted as white in all years). The 16 census ethnic groups[12] were merged into 4 super-groups to avoid very small numbers in some groups: white (white: British; white: Irish; white: other white), South Asian (Asian or Asian British: Indian; Asian or Asian British: Pakistani; Asian or Asian British: Bangladeshi; Asian or Asian British: other Asian), black (black or black British: black Caribbean; black or black British: black African; black or black British: other black), Chinese and other ethnic groups (mixed: white and black Caribbean; mixed: white and black African; mixed: white and Asian; mixed: other mixed; Chinese and other ethnic group). More than 50% of the other ethnic group population in the 2001 census had been born in the Far East.[13]

Each individual was assigned a local authority district (LAD) and government office region (GOR) of residence based on their lower super-output area of residence. These assignments were done per year and if an individual moved a LAD within that year, the first LAD reported that year was used. This allowed the individual to be assigned a new LAD over the time period but not within a year.

An index of multiple deprivation 2007[14] score was assigned to each individual based on their LAD. The index of multiple deprivation 2007 is an area-based score that combines many housing, social, and economic indicators to indicate the level of deprivation in each area. These scores were split into 5 equal categories based on the scores for the whole of England (20% of the local authorities in each category; category 1 is the most deprived and category 5 is the least deprived). Population data by ethnicity were unavailable for smaller geographical areas, so lower super-output area deprivation score could not be used in analyses investigating the joint effects of deprivation and ethnicity.

Population Data

Populations at risk were midyear estimates by age, gender, and ethnic group for local authorities in England obtained from http://ethpop.org/. This source has been used in preference to the subnational estimates produced by the Office of National Statistics, because the cohort component population estimation model[15] incorporates more detailed demographic information by ethnic group in relation to newborns, mortality, and, most importantly, both subnational migration and international migration. Indeed, the Office of National Statistics has recently warned about the quality of their estimates.[16]

Analyses

Prevalence and 95% confidence intervals (CIs) per 10 000 population (aged 0–19 years) were calculated overall, for each year, for each ethnic group per year, for each geographical unit per year, and for the age groups per year and the diagnostic groups per year.

All data manipulation was undertaken in Microsoft SQL server 2008; statistical analyses were undertaken in Stata version 11 (Stata Corp, College Station, TX).

RESULTS

There were more than 1.7 million finished consultant episodes for 175 286 individuals who were included in the final dataset.

Prevalence

Table 1 shows the crude number of patients and prevalence per 10 000 population overall and by age group. Overall prevalence has increased from 25 per 10 000 (2000/2001) to 32 per 10 000 population (0–19 years) in the most recent year (2009/2010).

The prevalence was highest in the ≤1 age group and decreased through the age bands. The increase in prevalence over time was seen in all of the age groups but was most marked in 16- to 19-year-olds, where there was a 44.8% increase in prevalence over the 10 years, with a 37.9% increase in the 11- to 15-year-olds, 31.9% in the 6- to 10-year-olds, 17.1% in the 1- to 5-year-olds, and 7.7% in those younger than 1 year.

The prevalence in the male population was significantly higher than in the female population in all years, with the following figures for 2009/2010: male, 35.2, 95% CI 34.7–35.7; female, 29.2, 95% CI 28.8–29.6. This difference was constant across age groups and diagnostic groups (data not shown).

Diagnoses

There were 216 119 life-limiting diagnoses in the 175 286 individuals. Each year between 21.7% and 29.9% of children had >1 life-limiting diagnosis. All results in this subsection are by diagnoses, not by individual.

The distribution of life-limiting diagnoses was as follows: congenital anomalies (30.7%), oncology (13.7%), neurologic (12.0%), hematology (9.8%), respiratory (8.8%), genitourinary (6.2%), perinatal (7.7%), metabolic (3.8%), circulatory (3.8%), gastrointestinal (2.4%), and the "other" group (1.1%).

The trends in prevalence by year are shown in Fig 1. The highest prevalence was of congenital anomalies, with the lowest prevalence in circulatory and gastrointestinal diagnoses. All diagnostic categories showed consistent increases in prevalence with the exception of oncology diagnoses and the "other" group.

TABLE 1 Number and Prevalence (per 10 000 Population) of Children Aged 0 to 19 Years With LLCs by Year and Age Group in England, 2000–2010

Year	No. of Patients	Prevalence per 10 000 Population											
		Total	95% CI	Age ≤1 y	95% CI	Age 1–5 y	95% CI	Age 6–10 y	95% CI	Age 11–15 y	95% CI	Age 16–19 y	95% CI
2000/2001	30 643	24.9	24.6–25.1	116.7	113.9–119.5	29.1	28.5–29.7	18.8	18.3–19.3	17.4	17.0–17.9	16.3	15.7–16.8
2001/2002	29 443	23.8	23.6–24.1	105.9	103.3–108.6	28.0	27.4–28.6	18.1	17.6–18.6	17.0	16.6–17.4	16.2	15.7–16.7
2002/2003	30 503	24.7	24.4–25.0	104.2	101.6–106.8	29.5	28.9–30.2	19.1	18.6–19.5	18.0	17.5–18.4	16.5	16.0–17.0
2003/2004	31 280	25.3	25.1–25.6	104.1	101.5–106.6	29.9	29.2–30.5	19.6	19.1–20.1	18.5	18.0–18.9	17.5	17.0–18.0
2004/2005	31 639	25.6	25.4–25.9	102.1	99.6–104.6	29.9	29.3–30.5	20.1	19.6–20.6	18.4	18.0–18.9	17.9	17.3–18.4
2005/2006	34 066	27.6	27.3–27.9	106.7	104.2–109.2	31.1	30.4–31.7	21.8	21.3–22.4	20.4	19.9–20.9	19.5	18.9–20.0
2006/2007	36 013	29.1	28.8–29.4	123.4	120.8–126.1	31.4	30.8–32.0	22.3	21.7–22.8	21.0	20.5–21.5	19.7	19.2–20.3
2007/2008	37 447	30.2	29.8–30.5	113.5	111.0–116.0	32.9	32.3–33.6	23.5	22.9–24.1	22.4	21.9–22.9	21.1	20.6–21.7
2008/2009	37 601	30.3	30.0–30.6	117.5	114.9–120.1	32.4	31.8–33.0	23.6	23.0–24.1	22.5	22.0–23.1	22.0	21.4–22.6
2009/2010	40 042	32.2	31.9–32.6	125.7	123.1–128.4	34.1	33.5–34.7	24.8	24.2–25.4	24.0	23.4–24.5	23.6	23.0–24.2

Ethnicity

Overall, 25% of patients had their ethnicity coded as not known. The proportion of unknowns decreased over time from 33% in 2000/2001 to 11% in 2008/2009 and 9% in 2009/2010. Data from the 2 most recent years were selected for analysis and no assessment of time trends was undertaken (Table 2).

The highest prevalence was in the South Asian (47.6 per 10 000, 95% CI 46.8–48.4), black (41.5 per 10 000, 95% CI 39.5–43.5), and Chinese and other (30.7 per 10 000, 95% CI 29.4–32.0) populations. These 3 ethnic categories had significantly higher prevalence than the white population (27.0 per 10 000, 95% CI 26.7–27.3).

Deprivation

The prevalence per 10 000 population in each deprivation category over time shows an inverse J-shaped relationship with deprivation, with the highest prevalence in the most deprived category and the lowest in category 4 (second least deprived). All categories are significantly different from each other ($\chi^2 = 29.2$, $P < .001$)

Deprivation by Ethnic Group

Figure 2A and B shows the prevalence and the 95% CIs by deprivation category by ethnic group for 2009/2010. Similar results were seen for the previous year. A J-shaped association with deprivation is seen in all 4 ethnic groups. In the second-most affluent areas (category 4), a significantly lower prevalence was seen for the white population compared with all other categories ($\chi^2 = 27.2$, $P < .001$) and for the black population compared with the 3 most deprived categories ($\chi^2 = 27.2$, $P < .001$). In the South Asian population, prevalence in the most deprived category was significantly higher than the prevalence in all the other categories, with category 4 having the lowest prevalence ($\chi^2 = 123.2$, $P < .001$).

The Chinese, mixed, and "other" groups were also analyzed separately. Although prevalence was higher in the "other" group, no significant differences were observed between the deprivation categories for the Chinese or mixed or "other" groups, where small numbers gave wide overlapping CIs.

Figure 2B shows the same data grouped by deprivation category to allow easier comparison among the ethnic groups. The South Asian prevalence is significantly higher than the white population in all deprivation categories apart from category 4.

Geographical Variation

There is some significant geographical variation in prevalence at GOR level with the North East, North West, West Midlands, and London having higher prevalence than the South West, Yorkshire, and Humber and the East Midlands (2009/2010). The prevalence rose uniformly in all GORs over the 10-year period.

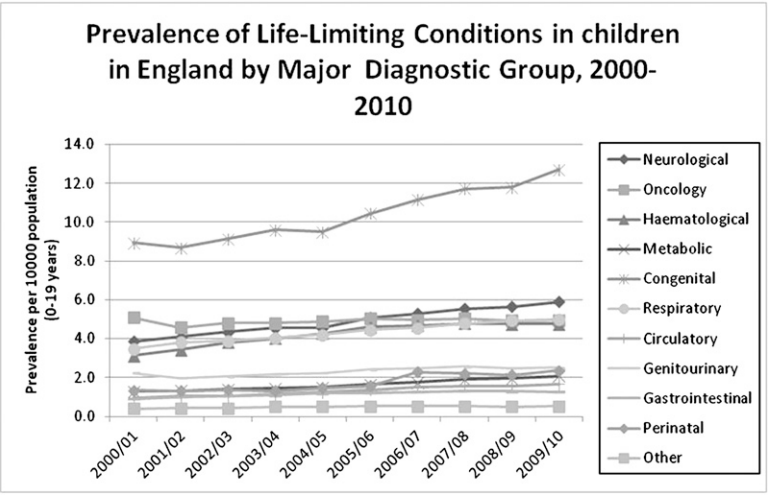

FIGURE 1
Prevalence of LLCs in children in England by major diagnostic group, 2000–2010.

TABLE 2 Prevalence (per 10 000 Population) of Children with LLCs in England Aged 0–19 Years by Ethnic Group (2008/2009, 2009/2010)

Ethnic Group	No. of Patients (col %)	Prevalence 2008/2009	95% CIs	No. of Patients (col %)	Prevalence 2009/2010	95% CIs
White	25 875 (68.8)	24.8	24.5–24.8	28 065 (70.1)	27.0	26.7–27.3
Black	1529 (4.1)	37.5	35.6–39.4	1714 (4.3)	41.5	39.5–43.5
South Asian	3987 (10.6)	43.0	41.7–44.3	4520 (11.3)	47.6	46.8–48.4
Chinese and other	1920 (5.1)	30.2	28.9–31.6	2093 (5.2)	30.7	29.4–32.0
Missing	4290 (11.4)			3650 (9.1)		

col %, percentage of total individuals in each ethnic category.

DISCUSSION

We estimate that more than 40 000 children (0–19 years) in England in 2009/2010 were living with an LLC. The prevalence of 32 per 10 000 population (0–19 years) in 2009/2010 is double the previous prevalence estimates of 16 per 10 000 (n = 23 500)[8] in England. We consider our estimates robust, as they are derived from a large routine NHS dataset by using a standard set of codes to define LLCs. In future, the coding schema can be applied to other international datasets for comparative research.

Prevalence was shown to have increased steadily over the past 10 years across all areas of England. Differential increases in prevalence were seen by age group. The most prominent increase in prevalence over 10 years (44.8%) occurred in 16- to 19-year-olds and this suggests increasing survival times, rather than rising incidence might be driving the increasing burden of these conditions. The rising numbers of children seen within the HES dataset is unlikely to be explained by an increasing likelihood of hospital referral for such serious conditions. Changes in clinical practice over the study period, particularly with respect to interventions, may have led to more hospital admissions for each individual but not whether an individual was ever admitted to hospital. The quality of HES data may also have improved over time, particularly with respect to more accurate and complete *ICD* disease coding; however, the number of diagnoses recorded for individual patient admissions did not show any temporal change, arguing against improved data quality being responsible for the large increase in prevalence.

The higher prevalence in the male population is constant across all age groups and time, and is consistent with our previous regional studies.[17,18]

Congenital anomalies were the largest diagnostic group, although oncology codes dominate the coding schema, and the rising prevalence contrasted with some other diagnostic groups whose prevalence was stable. This is consistent with a previous analysis of death certificate data[8] in England, which showed the most common cause of death requiring palliative care in this age group was congenital malformations. This is also reflected in referrals to pediatric palliative care. A Canadian study[19] found that neurologic diagnoses (24%) formed the largest group of referrals to a pediatric palliative care program, followed by congenital anomalies (21%), and in a recent North American cohort study of hospital-based pediatric palliative care programs,[20] the largest diagnostic group was congenital conditions (40.8%), followed by neuromuscular disorders (39.2%).

The higher prevalence in the ethnic minority groups (South Asian, black, and Chinese and "other" ethnic groups) compared with the white population is an important finding, which also has implications for service provision. This reflects previous research, which showed that more South Asian patients were referred to a regional children's hospice than was expected.[3,17]

The J-shaped relationship with deprivation shown in this study is different from the relationship with deprivation seen in a previous regional study looking at referrals to pediatric palliative care services where higher numbers of cases from areas of higher deprivation were seen and lower numbers in less deprived areas.[17]

In an effort to disentangle the potentially joint effects of living in a deprived area and originating from an ethnic minority, a limited analysis was conducted, although it was constrained by the availability of ethnic-specific population data and the completeness of the ethnic coding within HES. The differences by ethnicity in the different deprivation categories indicate that deprivation does not wholly account for the difference in prevalence seen in the ethnic groups. Assigning deprivation categories at the local authority level is not ideal, as it may smooth out differences seen when analyzing at smaller geographical areas, but this analysis was limited by available ethnic-specific population data.

The highest requirement of children with LLCs for palliative care occurs in the first year of life and decreases during childhood, in contrast to adult palliative care. In pediatrics, this distribution is not unexpected, but our findings provide evidence of increasing prevalence in all age groups. The notable increase in the 16- to 19-year age group specifically highlights the need for adequate transition and young adult services. Many children's hospices in the United Kingdom will care for young people until their early 20s but only a handful can retain patients after this age.[21] Adult hospices in England generally provide end-of-life care, and

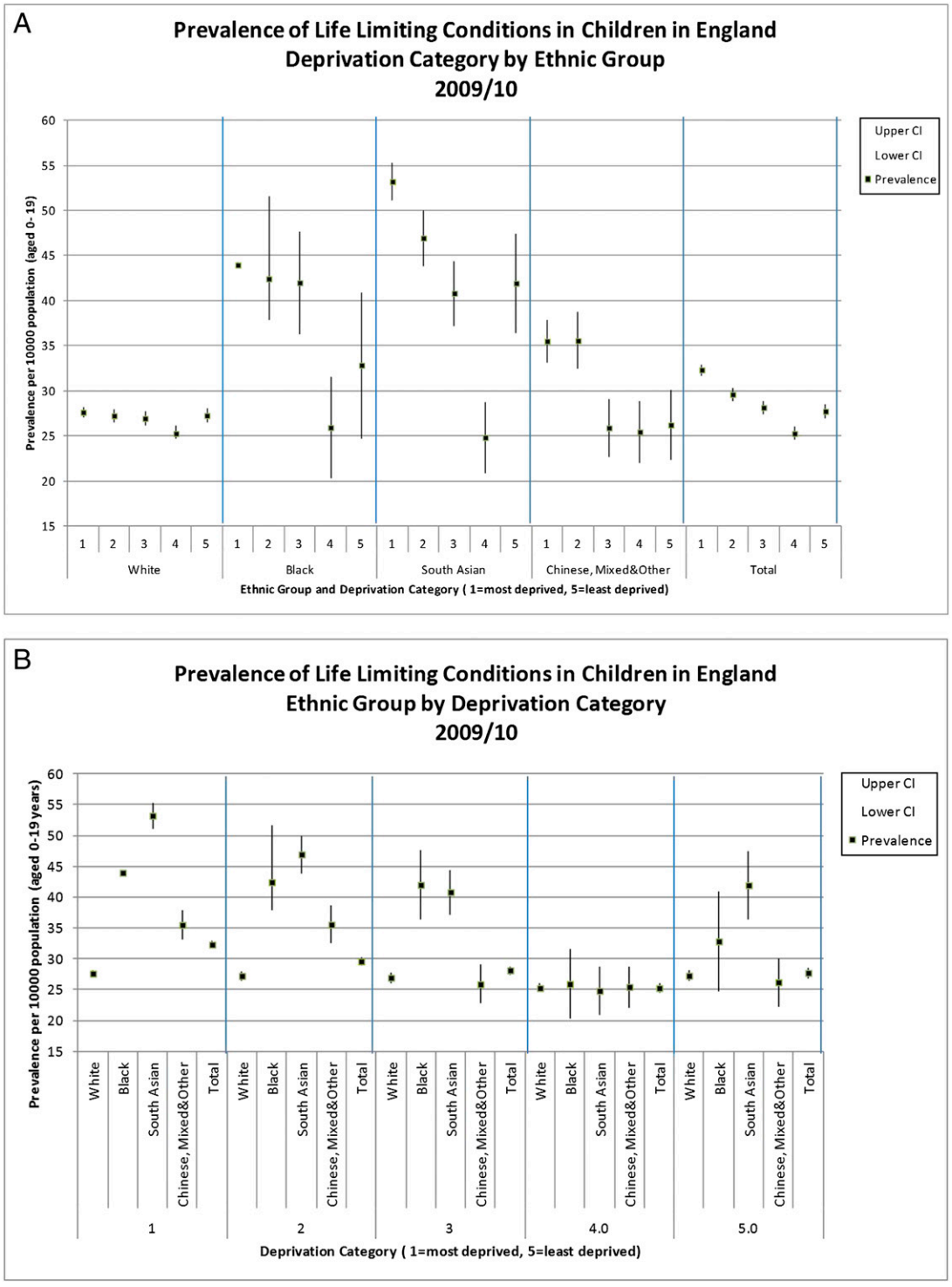

FIGURE 2

A, Prevalence of LLCs in children in England: deprivation category by ethnic group 2009/2010. B, Prevalence of LLCs in children in England: ethnic group by deprivation category 2009/2010.

transition to an adult hospice for longer-term care is rarely an option for young adults leaving children's hospice services.

One new finding from this study was the significant geographical variation in prevalence at the level of GOR, with the highest prevalence in the North East, North West, West Midlands, and London, and the lowest prevalence in the South West, Yorkshire and Humber, and the East Midlands. This contrasts with

previous work showing considerable geographical variation by the Strategic Health Authority (SHA) in death rates per population for conditions deemed to have required pediatric palliative care services, with the North East having the lowest death rates along with the Southern SHAs. They found that London, Yorkshire and Humber, and the West Midlands had the highest rates.[8]

Strengths

This was an analysis of an extremely large routinely collected national dataset that used a carefully constructed ICD-10 coding dictionary to identify cases of children with LLC.

Limitations

The prevalence estimates are dependent on the correct identification of individuals with LLC. Some children may not have had an inpatient hospital admission during the study period. In this case, we would have underestimated prevalence. In an effort to compensate for possible underascertainment, we obtained outpatient HES data to capture outpatient visits; however, the data were of insufficient quality for analysis, particularly with respect to the diagnostic coding.[22]

The levels of completeness observed for diagnoses were not seen for ethnicity. The large proportion of individuals with ethnicity "not known" precluded the assessment of time trends.

CONCLUSIONS

The prevalence of LLCs in children in England is double previously reported estimates and is increasing. Our findings demonstrate an increasing need for services for children and their families, particularly those from ethnic minority backgrounds and especially in more deprived areas. This will increase the burden for specialist pediatric palliative care providers and young adult services.

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