Incidence of Cerebral Palsy in Yorkshire by ethnicity and area deprivation

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Objective. This short report investigates variations in the incidence of cerebral palsy in children by broad ethnic group and area deprivation

Design. An observational study of the incidence of cerebral palsy in children registered on the Yorkshire Cerebral Palsy Register during 1984-1999. Denominators for rates were derived from live birth counts with estimates by South Asian and non-South Asian ethnicities. Linkages to area deprivation were achieved using postcode of residence.

Results. 11.1% of the 1,462 registered cases were of South Asian ethnic origin. The overall rate of cerebral palsy was 2.4 per 1,000 live births. This rate was 2.2 per 1,000 live births in the non-South Asian population but significantly higher at 4.3 per 1,000 live births in the South Asian population. A higher proportion of cases in both ethnic groups live in areas of high deprivation.

Conclusion. There is a significantly higher incidence rate of cerebral palsy in the South Asian population in Yorkshire. Now that ethnicity coding is improving this work can be updated using Hospital Episode Statistics (HES) which is important given ongoing population growth in the South Asian ethnic group.

Keywords: Cerebral palsy; South Asian ethnicity; Ethnicity & health; Deprivation & health

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1. Background

Cerebral Palsy (CP) is a group of disorders of movement and posture which occur as a result of a non-progressive brain disorder (Rosenbaum *et al.* 2005) and is one of the commonest causes for motor disability in childhood (Rankin *et al.* 2010). The incidence of cerebral palsy from UK based registers is around 2 per 1,000 live births although this increases with lower birth weights (Surman *et al.* 2009). There is some evidence which shows that higher rates of CP are seen with increasing socioeconomic deprivation (Dolk *et al.* 2010) and a previous small study using data from 1985 to 1987 found a higher rate of CP in the South Asian population in Bradford (Sinha *et al.* 1997). This short report aims to describe the incidence of CP in Yorkshire by ethnicity and area deprivation using a population based dataset.

2. Methods

The Yorkshire Cerebral Palsy Register (YCPR) collected data from 1984-1999. During this period paediatricians within the former Yorkshire Health Authority were requested to notify all cases of cerebral palsy by completing a registration card and were actively contacted to improve registration. The data collected included date of birth, postcode of residence, health authority district, description of CP, birth weight, gestation and multiple birth. The description of cerebral palsy was recorded on the register in one of twelve categories. For analyses, these twelve categories were collapsed into six: unilateral; bilateral; ataxic / athetoid / hypotonic; mixed; not specified; and unknown). Details of 1,462 children were present on the YCPR. Birthweight, gestation and multiple birth variables were collected for less than 1% of the children so these variables were excluded from the analyses.

Prior to anonymisation of the records, ethnicity (South Asian or not) was classified using two South Asian name-recognition software packages; SANGRA (Nanchahal *et al.* 2001) and Nam Pehchan (BHA / CBMDC, 2002). Children were classified as South Asian if both programmes identified them as so. Manual checking for obvious errors was undertaken. This methodology does not allow for more detailed South Asian ethnicity (Indian, Pakistani or Bangladeshi) to be reliably assigned. Quintiles of Townsend

deprivation scores from the 1991 Census (Norman 2010) were assigned to each child based on the postcode of their residence at registration.

Population figures by ethnic group for the year 1991 and a time-series of live birth counts were calculated for each of the 16 health authorities that were in existence from 1991-1999. This calculation involved using ward level estimates of mid-year 1991 and 2001 ethnic group populations by age and sex (Norman *et al.* 2008; Sabater and Simpson 2009) and estimating births for each calendar year by ethnic group using a back-projection from 2001 with ethnic-specific fertility rates (Norman *et al.* 2010). The estimated birth counts were constrained to be consistent with annual birth registration numbers from the vital statistics. The populations and live births were converted from the ward geography to the health authority boundary definitions (Norman *et al.* 2003). The live birth estimates were used as the denominator for the incidence rate calculations.

Between group differences were assessed using the chi-squared test. All statistical analyses were performed using STATA version 10.

3. Results

3.1 Overall incidence by ethnic group and deprivation

The descriptive statistics by ethnic group (South Asian and non-South Asian) are shown in Table 1. Of the 1,459 children included in the study (3 did not have an ethnicity assigned), 11.1% were from a South Asian background. There were more children in the more deprived quintiles of deprivation and significantly fewer South Asian children in the less deprived deprivation quintiles than the non-South Asian children. In the diagnostic categories of cerebral palsy there were significantly more children in the South Asian group with a diagnosis of ataxic, athetoid or hypotonic cerebral palsy than in the non-South Asian group.

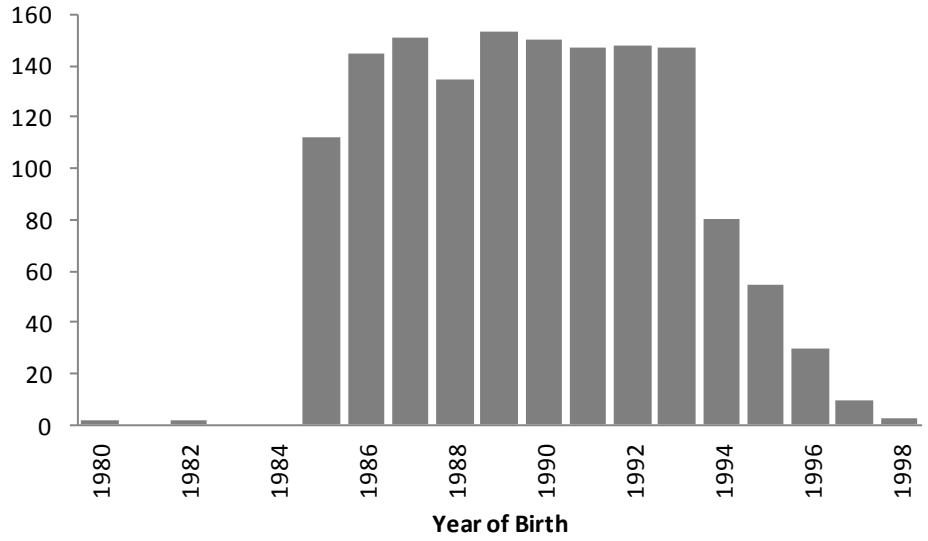
Table 1. Deprivation Distribution and Cerebral Palsy Diagnostic Categories by Ethnic Group

1980-1999	South Asian	%	Non-South Asian	%	X^2	p-value
Number of Children *	162	11.1	1,297	88.7		
Deprivation Category					11.4	.0200
1 (Least deprived)	9	5.6	93	7.2		
2	7	4.3	119	9.2		
3	18	11.1	183	14.1		
4	45	27.8	239	18.4		
5 (Most deprived)	51	31.5	452	34.8		
Not Known	32	19.8	211	16.3		
Diagnostic Category of Cerebral Palsy					20.3	0.001
Unilateral	26	16.0	296	22.8		
Bilateral	78	48.1	649	50.0		
Athetoid / Ataxic / Hypotonic	17	10.4	50	3.9		
Mixed	0	0	13	1.0		
Non-specific	33	20.4	247	19.0		
Not Known	8	4.9	42	3.2		

* Ethnicity unknown for 3 children

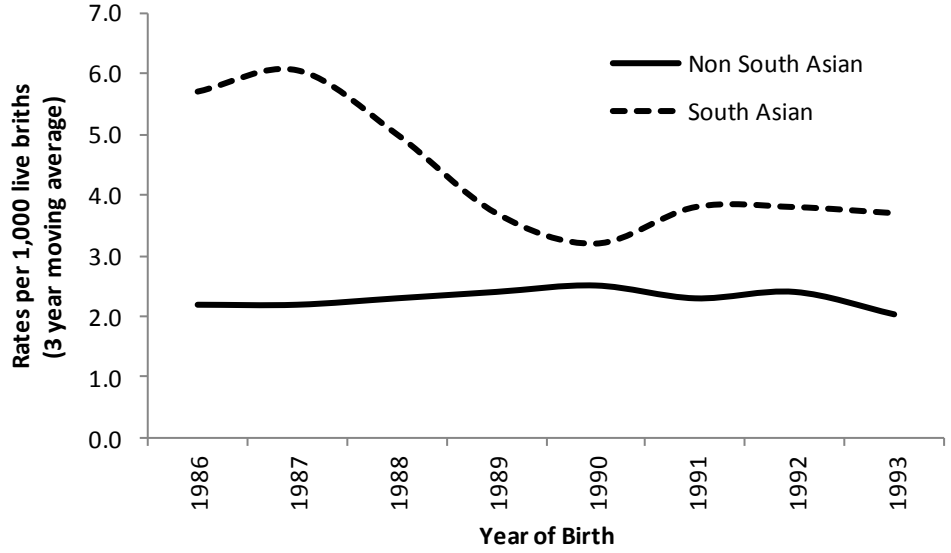
Fig. 1 shows that the notifications of children born before 1985 were sparse and that the numbers started to decline from 1995 (funding was not in place to collect data after 1999). Therefore, only the children born in the period 1985 to 1994 (inclusive) were included in the time-series analysis of incidence rates (n=1,363). The total live births in the region from 1985 to 1994 was 560,371.

Fig. 1: Number of Cases of Cerebral Palsy by Year of Birth



The overall incidence rate of CP was 2.4 per 1,000 births. The incidence rate of CP in non-South Asians was 2.2 per 1,000 live births and in the South Asian group the rate was 4.3 per 1,000 live births. Over time, the variation in the rates in the South Asian children was much larger than in the non-South Asian children but the rates in the South Asian group were higher in all years (3 year moving averages) (Fig. 2).

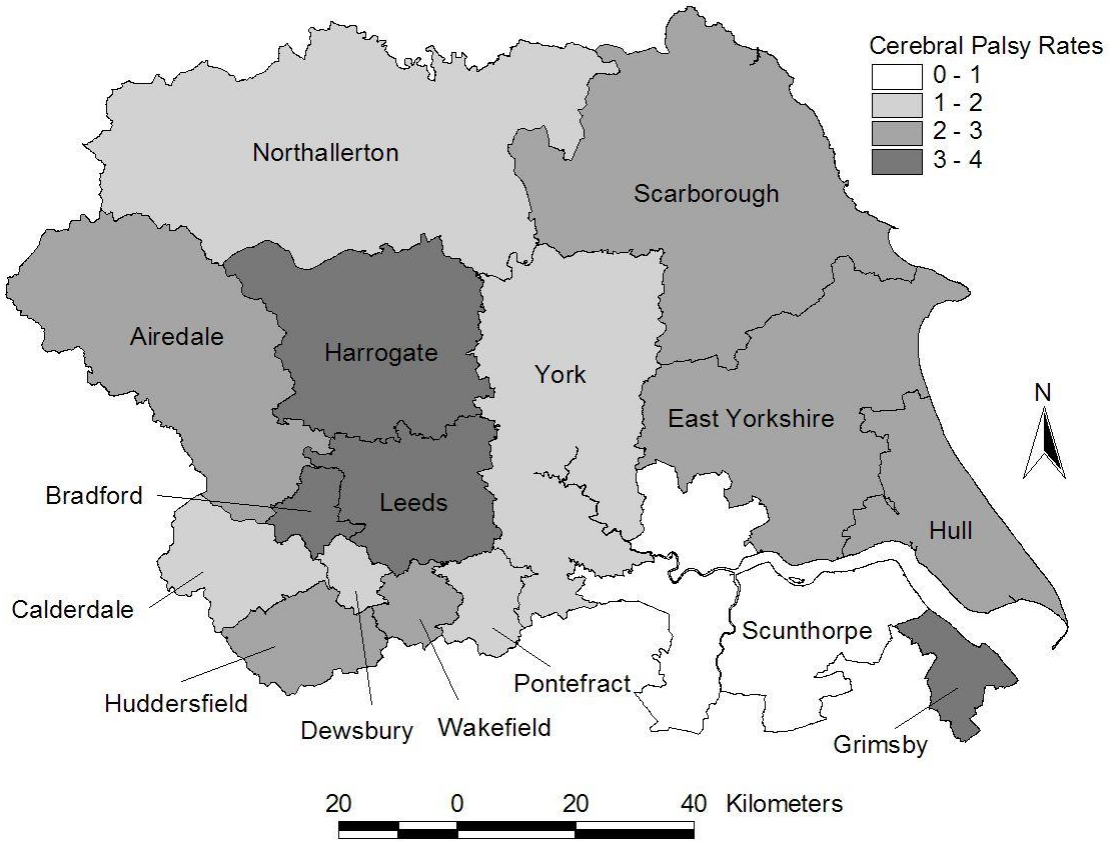
Fig. 2: Incidence of Cerebral Palsy by Ethnic Group



3.2 Geographical distribution

There was considerable variation in incidence by health authority: the highest overall CP rates were in Bradford (3.7 per 1,000 live births) and Leeds (3.3 per 1,000 live births) (Fig. 3). The total annual rates varied between 1.6 per 1,000 births and 2.7 per 1,000 births.

Fig. 3. Overall Rates of Cerebral Palsy (per 1,000 live births) by Health Authority, 1985-1999



4. Discussion

The overall incidence rate of cerebral palsy in this population of 2.4 per 1,000 live births is similar to results from other UK registers (Surman *et al.* 2009) and other western countries (Anderson *et al.* 2008; Holst *et al.* 2010). A European study found the rate per 1,000 live births varied from 1.49 (Ireland) to 2.63 (Denmark) with a mean rate of 2.08 per 1,000 live births (SCPE 2002). The higher rate of 4.3 per 1,000 live births in the South Asian population is slightly lower than the Bradford study which found 5.48 per

1,000 (Sinha *et al.* 1997) but the current study is likely to be more reliable as it has greater power with larger numbers relating to a wider geographical area. Ethnic differences in CP rates have been observed elsewhere with a multisite study from the USA reporting a significantly higher prevalence of cerebral palsy in Black non-Hispanic children compared to white non-Hispanic children (4.2 per 1,000 cf 3.3 per 1,000; $p<0.03$) (Yearsin-Allsopp 1992).

The sub-classification of cerebral palsy showed that approximately 50% of all CP cases were bilateral in nature (spastic quadriplegia or spastic diplegia). This is similar to the proportion found in the analyses of the five other UK registers where 53% of all CP were classified as spastic bilateral (Dolk *et al.* 2010). Unfortunately in the register used here there was no information on the functional capabilities of the children or other associated medical conditions. The severity of the CP could not therefore be assessed.

The increased proportion of children who were classified as having non-spastic CP (ataxic, athetoid or hypotonic) in the South Asian group may reflect a different aetiology. It has been estimated that as many as 50% of cases of ataxic CP are due to single gene defects (Hughes and Newton 1992) and a small study of four children with ataxic CP from a Asian multi-consanguineous family identified a potential gene on chromosome 9 (McHale *et al.* 2000). In the previous study from Bradford (Sinha *et al.* 1997) more than half of the families in the South Asian group were first cousin marriages whereas none of the non-South Asian families were consanguineous. Consanguinity is known to increase the risk of genetic disease, especially autosomal recessive conditions (Bittles 2001) and there is some evidence for an association between consanguineous marriages and CP in Saudi Arabia (Costeff 2004) and Turkey (Amor *et al.* 2001). Although we have no information on consanguinity for the children in this study it can be assumed that the rates of consanguinity would be higher in the South Asian families (Darr and Modell 1988; Hasan 2009) especially those in the Bradford area (Sheridan *et al.* 2013). A Swedish study found that overall 40% of all cases of CP have a genetic aetiology (Al-Rajeh *et al.* 1991). Athetoid CP is

associated with perinatal complications and thought to have less of a genetic component than other forms of CP (Serdaroglu *et al.* 2006).

The larger proportion of cases in both ethnic groups occurring in the higher two quintiles of deprivation is not unexpected. A recent study using data from the current UK registers found that the risk of postnatally acquired CP was much higher in the most deprived versus least deprived quintile (Dolk *et al.* 2010). This pattern has also been shown from other western countries; a study from Sweden showed children from households of higher deprivation were 49% more likely to have CP than children from affluent households (Hjern and Thorngreb-Jerneck 2008) and a multisite study from the USA showed that the prevalence of CP in households of low or middle income was higher than households of high income (Yearsin-Allsopp *et al.* 2008). The lower proportion of South Asian children in the least deprived quintile reflects the South Asian deprivation profile in Yorkshire but it is not possible in this dataset to differentiate between ethnic and deprivation effects.

The limited clinical information regarding gestation, birthweight and functional abilities restricts some of the conclusions that can be drawn from this dataset but the study has shown some important findings regarding the higher incidence and different sub-classifications of CP amongst the South Asian community in Yorkshire.

There is a significantly higher incidence rate of cerebral palsy in the South Asian population in Yorkshire. A higher proportion of children with cerebral palsy in these broad ethnic groups live in areas of high deprivation. These rates differed in the 16 health districts within the former Yorkshire Health Authority area. A higher proportion of South Asian children with cerebral palsy have a non-spastic sub-classification (athetoid / ataxic / hypotonic). The work here can be updated and carried out for the whole of England once a time-series of small area population estimates is complete to 2011 and data with the appropriate International Classification of Disease codes are extracted from the Hospital Episode Statistics (HES). This is important to do because other work shows that the prevalence of children with life limiting conditions increased during the 2000s (Fraser *et al.* 2012) most likely due to improved survival. These life

limiting conditions include cerebral palsy. Coupled with population growth in the South Asian ethnic group (Rees *et al.* 2012) mean that there could be increases in the number of children with cerebral palsy requiring care. Investigating differences by Indian, Pakistani and Bangladeshi ethnicities would be useful but the coding of ethnic group is incomplete in the HES though improving (HES 2009).

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