Ethnic-specific mortality of infants undergoing congenital heart surgery in England and Wales

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ABSTRACT

Purpose To investigate ethnic differences in mortality for infants with congenital heart defects (CHDs) undergoing cardiac surgery or interventional catheterisation.

Design Observational study of survival to age 1 year using linked records from routine national paediatric cardiac surgery and intensive care audits. Mortality risk was investigated using multivariable Poisson models with multiple imputation. Predictors included sex, ethnicity, preterm birth, deprivation, comorbidities, prenatal diagnosis, age and weight at surgery, preprocedure deterioration and cardiac diagnosis.

Setting All paediatric cardiac surgery centres in England and Wales.

Patients 5350 infants with CHDs born from 2006 to 2009.

Main outcome measure Survival at age 1 year.

Results Mortality was 83.9 (95% CI 76.3 to 92.1) per 1000 infants, with variation by ethnic group. Compared with those of white ethnicity, infants in British Asian (Indian, Pakistani and Bangladeshi) and ‘all other’ (Chinese, mixed and other) categories experienced significantly higher mortality by age 1 year (relative risk [RR] 1.52 [95% CI 1.19 to 1.95]; 1.62 [95% CI 1.20 to 2.20], respectively), specifically during index hospital admission (RR 1.55 [95% CI 1.07 to 2.26]; 1.64 [95% CI 1.05 to 2.57], respectively). Further predictors of mortality included non-cardiac comorbidities, prenatal diagnosis, older age at surgery, preprocedure deterioration and cardiac diagnosis. British Asian infants had higher mortality risk during elective hospital readmission (RR 1.86 [95% CI 1.02 to 3.39]).

Conclusions Infants of British Asian and ‘all other’ non-white ethnicity experienced higher postoperative mortality risk, which was only partly explained by socioeconomic deprivation and access to care. Further investigation of case-mix and timing of risk may provide important insights into potential mechanisms underlying ethnic disparities.

INTRODUCTION

Congenital heart defects (CHDs) contribute 10% of all infant mortality and represent one-third of deaths in the first year of life attributable to congenital anomalies. Several authors have reported higher mortality rates in infants from non-white ethnic groups with congenital anomalies compared with those of white ethnicity. Analysis of UK audit data relating to paediatric cardiac surgery demonstrated increased postoperative 30-day mortality associated with British Asian ethnicity, while in North America, longer inpatient stays and higher mortality after cardiac surgery have been reported for black and non-white Hispanic children. These variations in survival with CHDs persist into adulthood.

Despite a growing number of studies, it remains unclear whether ethnicity independently predicts mortality or if observed differences are related to associated factors, such as socioeconomic deprivation, immaturity-related conditions, maternal age and health, health-related behaviours or ethnic differences in the birth prevalence of complex CHDs. Preprocedure clinical deterioration, older age at surgery and failure to achieve a prenatal diagnosis have been proposed as markers of poor access to care, and non-white ethnicity has been associated with delayed diagnosis and access to healthcare. Although non-white
ethnic groups are over-represented within deprived communities in the UK, healthcare provision is universal; nevertheless, other factors may represent barriers to care that differentially affect ethnic groups.

We linked routinely collected national audit data from the National Congenital Heart Disease Audit (NCHDA) and Paediatric Intensive Care Audit Network (PICANet) to investigate ethnicity as a predictor of mortality for infants with significant structural CHDs who underwent a cardiac procedure, either cardiac surgery or interventional cardiac catheterisation, before age 1 year in England and Wales. The primary outcome was mortality by age 1 year. To further investigate associations and potential mechanisms of mortality, we explored different periods of risk including early postprocedure mortality during the index hospital admission, unexpected out-of-hospital death and death during a subsequent planned readmission.

PATIENTS AND METHODS
The Infant Heart Study linked NCHDA infant cardiac intervention records with PICANet paediatric intensive care unit (PICU) admission records to create an individual patient-level dataset. Babies who only had ligation for isolated patent ductus arteriosus or cardiac transplant were excluded. Infants without linked PICANet record (n=1780) were also excluded; these were predominantly infants with mild CHDs and no, or few, PICU admissions.

Children born with a significant structural CHD between 1 January 2006 and 31 December 2009 in England and Wales and who received their first interventional cardiac procedure while aged under 1 year were identified in NCHDA. NCHDA hierarchical classification algorithms defined one primary cardiac diagnosis per child. Survival status on 13 December 2012 was independently verified using death registrations. This paper focuses on mortality occurring between the index (or primary) cardiac surgery or interventional catheterisation, which was either a (1) definitive or (2) palliative staging procedure, and 1 year of age and excludes deaths prior to the procedure.

The final analysis dataset comprised 5350 infants. Linked data were essential as NCHDA records included cardiac-related clinical and procedure details, while PICANet provided comorbidity, ethnicity and PICU admission details.

Outcomes and definitions
The primary outcome was death within the first year of life (figure 1). Secondary outcomes were: (1) death during index hospital admission (for the index procedure), (2) unexpected death following hospital discharge (death outside hospital or after urgent readmission to intensive care) and (3) death during elective readmission. These last two groups included interstage deaths.

Children were grouped into four ethnic categories (UK Census): white (n=3968; 78%), British Asian (n=604; 12%), black British (n=240; 5%); and ‘all other’ (n=320; 6%; comprising Chinese, mixed and Other); 218 (4.1%) children without ethnicity data were excluded.

Weights were converted to age-standardised and sex-standardised z-scores. Area-based socioeconomic deprivation scores (Index of Multiple Deprivation [IMD]) were derived from residential postcode and subdivided into quintiles. Age at surgery was in weeks from birth. Read codes in PICAnet defined whether children had a congenital anomaly, acquired comorbidity or neurodevelopmental problem. Children had ‘preprocedure deterioration’ if their admission was ‘urgent’ or ‘unplanned’.

Statistical analyses
Descriptive statistics are presented as numbers and percentages; 95% CIs were estimated using binomial exact method. We fitted a Poisson regression model with robust variance estimates to determine the relative risk (RR) for the primary mortality

![Figure 1](https://example.com/figure1.png)

**Figure 1** Flow chart presenting infant deaths (primary and secondary outcomes). CHD, congenital heart defect.
outcomes using white ethnicity as the reference. Potential predictors (online supplementary table S1) were explored in univariable analyses, and a multivariable model was constructed to determine joint associations. Pearson goodness-of-fit test confirmed that the multivariable model including all predictors was a good fit for our data, and the inclusion of interaction terms did not improve the model.

Missing data were imputed for IMD, weight z-score, gestation and prenatal diagnosis (online supplementary table S2) using Markov chain imputation and assuming data were missing at random. Imputation was conditioned on variables associated with missingness, including non-cardiac congenital anomalies, acquired comorbidities, preprocedure deterioration, age at surgery and primary cardiac diagnosis. Results using 20 imputed datasets generated using 2000 iterations (n=5131 infants) were compared with those excluding infants with missing data (n=3011 ‘complete cases’).

We investigated secondary outcomes using the multivariable Poisson model for the primary outcome. All analyses were undertaken using Stata SE V.14 (Timberlake Consulting).

**RESULTS**

**Mortality**

Of 5350 infants with CHD undergoing a cardiac procedure, 449 died before age 1 year, representing an infant mortality rate of 83.9 (95% CI 76.3 to 92.1) per 1000 infants (table 1). Of these deaths, half occurred during the index admission and half after discharge home (figure 1; table 1). Compared with children of white ethnicity, the relative mortality risk was significantly higher for British Asian (RR 1.6 [95% CI 1.2 to 2.1]) and ‘all other’ ethnicity compared with white infants. Children of ‘all other’ ethnicity had significantly higher risk of unexpected postdischarge death (RR 1.85 [95% CI 1.07 to 3.20]) and British Asian infants experienced higher mortality during planned readmissions (RR 2.01 [95% CI 1.14 to 3.56]). With the exception of sex, birth gestation and weight z-score, all factors in univariable models were significant predictors at p<0.05 of the primary outcome.

**Secondary outcomes**

In multivariable secondary outcomes models using imputed data, infants of British Asian and ‘all other’ ethnicity experienced significantly higher mortality during planned readmissions (RR 1.86 [95% CI 1.02 to 3.39], respectively). Further predictors of higher mortality during the index admission, including acquired comorbidities and congenital anomalies, preprocedure deterioration and primary CHD diagnosis (table 2). Older age at procedure predicted lower infant mortality (RR 0.95 [95% CI 0.94 to 0.97] per week increased age).

**Risk factors**

Risk factors (online supplementary table S1) included individual characteristics (ethnicity, sex and birth gestation), non-cardiac clinical diagnoses (congenital anomalies, acquired comorbidities and neurodevelopmental problems), care-related factors (prenatal diagnosis and preprocedure deterioration), primary cardiac diagnosis, socioeconomic deprivation (IMD), weight z-score and age at index admission. Compared with the white ethnic group, more black British infants were girls (black British: 52.9%, white: 44.4%; difference 8.5% [95% CI 2.0 to 14.9]) and older than 3 months at surgery (black British: 50.4%, white 41.1%; difference 9.3% [95% CI 2.8 to 15.7]), and more British Asian children had neurodevelopmental problems (British Asian: 7.1%, white: 3.4%; difference 3.7% [95% CI 1.8 to 6.1]). Between 44.2% and 53.4% of non-white infants lived in the most deprived areas compared with 24.7% of white infants. The incidence of individual cardiac diagnoses varied by ethnic group.

**Unadjusted outcome models**

Compared with white infants, children in British Asian and ‘all other’ ethnic groups experienced significantly higher mortality risk before age 1 year (online supplementary table S2; British Asian RR 1.65 [95% CI 1.29 to 2.10]; ‘all other’ RR 1.73 [95% CI 1.27 to 2.36]) and during the index hospital admission (British Asian RR 1.60 [95% CI 1.11 to 2.29]; ‘all other’ RR 1.72 [95% CI 1.09 to 2.71], respectively), while children of ‘all other’ ethnicity had higher risk of unexpected postdischarge death (RR 1.85 [95% CI 1.07 to 3.20]) and British Asian infants experienced higher mortality during planned readmissions (RR 2.01 [95% CI 1.14 to 3.56]). With the exception of sex, birth gestation and weight z-score, all factors in univariable models were significant predictors at p<0.05 of the primary outcome.

**Primary outcome**

In the multivariable model using imputed data (table 2; figure 2), infants of British Asian and ‘all other’ ethnicity had significantly higher relative mortality risk during the first year of life (RR 1.52 [95% CI 1.19 to 1.95]; RR 1.62 [95% CI 1.20 to 2.20], respectively). Other independent predictors of mortality were primary cardiac diagnosis, non-cardiac congenital anomalies, acquired comorbidities, preprocedure deterioration and prenatal CHD diagnosis (table 2). Older age at procedure predicted lower infant mortality (RR 0.95 [95% CI 0.94 to 0.97] per week increased age).

**Secondary outcomes**

In multivariable secondary outcomes models using imputed data, infants of British Asian and ‘all other’ ethnicity experienced significantly higher mortality during index admission (RR 1.53 [95% CI 1.07 to 2.26]; 1.64 [95% CI 1.05 to 2.57], respectively; table 3; figure 2). Further predictors of higher mortality during the index admission, included acquired comorbidities and congenital anomalies, preprocedure deterioration and primary cardiac diagnosis.

Higher mortality risk for British Asian infants during planned readmissions (online supplementary table S3) persisted in multivariable models (RR 1.86 [95% CI 1.02 to 3.39]) after

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**Table 1** Mortality rates per 1000 infants undergoing a cardiac procedure aged under 1 year, born between 2006 and 2009 (n=5350)

|                  | Deaths in first year of life | Effect size | Deaths during index hospital admission | Unexpected death* following discharge | Death during planned readmission |
|------------------|------------------------------|-------------|----------------------------------------|-------------------------------------|---------------------------------|
| **Primary outcome** | Deaths | Rate per 1000 (95% CI) | Rate per 1000 (95% CI) | Rate per 1000 (95% CI) | Rate per 1000 (95% CI) |
| Total infants (n=5350) | 449 | 83.9 (76.3 to 92.1) | --- | 227 | 42.4 (37.1 to 48.3) |
| White (n=3968) | 287 | 72.3 (64.5 to 80.8) | --- | 146 | 27.3 (23.0 to 32.1) |
| British Asian (n=604) | 72 | 119.2 (94.4 to 147.8) | 1.7 (1.3 to 2.3) | 22 | 36.4 (23.0 to 54.6) |
| Black British (n=240) | 25 | 104.2 (68.6 to 149.9) | 1.5 (1.0 to 2.3) | 7 | 29.2 (11.8 to 59.2) |
| All other (n=320) | 40 | 125.0 (90.8 to 166.3) | 1.8 (1.3 to 2.6) | 14 | 43.8 (24.1 to 72.3) |
| **Secondary outcomes** | Deaths | Rate per 1000 (95% CI) | Rate per 1000 (95% CI) | Rate per 1000 (95% CI) | Rate per 1000 (95% CI) |
| Total infants (n=5350) | 449 | 83.9 (76.3 to 92.1) | --- | 227 | 42.4 (37.1 to 48.3) |
| White (n=3968) | 287 | 72.3 (64.5 to 80.8) | --- | 146 | 27.3 (23.0 to 32.1) |
| British Asian (n=604) | 72 | 119.2 (94.4 to 147.8) | 1.7 (1.3 to 2.3) | 22 | 36.4 (23.0 to 54.6) |
| Black British (n=240) | 25 | 104.2 (68.6 to 149.9) | 1.5 (1.0 to 2.3) | 7 | 29.2 (11.8 to 59.2) |
| All other (n=320) | 40 | 125.0 (90.8 to 166.3) | 1.8 (1.3 to 2.6) | 14 | 43.8 (24.1 to 72.3) |
| Not stated (n=218)† | 25 | 1.7 (1.1 to 2.6) | 9 | | 2 |
adjusted, whereas higher risk of unexpected postdischarge death in the ‘all other’ ethnic group was attenuated (RR 1.63 [0.93 to 2.85]). Independent predictors of unexpected postdischarge death (online supplementary table S4) were non-cardiac acquired comorbidities, congenital anomalies, preprocedure deterioration and hypoplastic left heart syndrome (HLH). Factors independently predicting death during planned readmission were prenatal CHD diagnosis, younger age at surgery, non-cardiac congenital anomalies and primary cardiac diagnosis.

**DISCUSSION**

**Key findings**

Compared with white infants, mortality was 53% higher for British Asians and 63% higher for ‘all other’ ethnicity by age 1 year. Independent predictors of higher mortality were non-cardiac congenital anomalies or comorbidities, prenatal CHD diagnosis, preprocedure clinical deterioration, younger age at surgery and presence of complex cardiac diagnoses. During index admission, infants of British Asian and ‘all other’ ethnicity experienced significantly higher mortality than white infants. Following hospital discharge, the British Asian group had higher mortality risk during planned readmissions for staged care. Potential causes for these differences include case-mix severity, socioeconomic deprivation, access to maternity and child health services and maternal early life experience, such as undernutrition. These could not be fully explored using routinely collected audit data, and further research into the mediators of ethnic variation is needed.

**Ethnicity**

Our finding of higher CHD mortality for British Asian ethnic groups is consistent with previous UK studies, and US studies. We identified that higher mortality risk experienced by British Asian infants was related to the index hospital admission and planned readmissions. This increased risk may be explained by case-mix factors that are not currently captured in routinely coded audit data, including cardiac defects that increase severity, such as isomerism, or associated comorbidities. Targeting healthcare initiatives at more severely affected infants, and coordinating specialist cardiac with general paediatric care to address multiple comorbidities, could disproportionately benefit British Asian infants.

In our adjusted analysis, the ‘all other’ (Chinese, mixed and other) ethnic group was at higher risk during the index admission but not of unexpected postdischarge death. In a previous study, children in the ‘other’ ethnic group (excluding those of Chinese or mixed) ethnicity did experience higher rates of out-of-hospital death. The small numbers in our study prevented further exploration of differences between infants of Chinese, mixed and other ethnicity comprising the ‘all other’ group; however, this would be important for future larger studies. Although black British infants experienced 23% higher mortality than white infants, this was not significant. This could be due to differences in the spectrum of primary cardiac diagnoses in black British infants who were dominated by septal defects.

Our analysis suggests key differences in the predictors and timing of risk for different ethnic groups; further investigation would provide important insights into the causative mechanisms underlying ethnic disparities.

**Access to care and deprivation**

Delayed access to care has been proposed as an underlying reason for ethnic differences in mortality in the USA, and higher risk of postoperative complications and mortality in non-white Hispanic and black US infants has been attributed to hospital referral and treatments approaches. In our study, preprocedure observation was lower for ‘all other’ ethnicity, but further exploration is needed.

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**Table 2 Relative risk of mortality during the first year of life by ethnic group (n=5131; multivariable analysis with multiple imputation)**

| Ethnicity (reference: white) | Relative risk (RR) (95% CI) | P value |
|-----------------------------|-----------------------------|---------|
| British Asian               | 1.52 (1.19 to 1.95)         | <0.001  |
| Black British               | 1.23 (0.85 to 1.78)         | 0.273   |
| All other (non-white)       | 1.62 (1.20 to 2.20)         | 0.002   |
| Sex (reference: boys)       |                             |         |
| Girls                       | 1.04 (0.86 to 1.24)         | 0.695   |
| Area deprivation (IMD) quintile (reference: quintile 5=least deprived) | | |
| Quintile 4                  | 1.27 (0.90 to 1.79)         | 0.181   |
| Quintile 3                  | 1.07 (0.75 to 1.53)         | 0.700   |
| Quintile 2                  | 1.32 (0.97 to 1.83)         | 0.079   |
| Quintile 1: most deprived   | 1.08 (0.78 to 1.49)         | 0.648   |
| Birth gestation (reference: term birth ≥37 weeks’ gestation) | | |
| Preterm (<37 weeks)         | 1.31 (0.90 to 1.90)         | 0.151   |
| Prenatal diagnosis (reference: not prenatally diagnosed) | | |
| Non-cardiac comorbidities/procedure-related clinical status (reference: no comorbidities) | | |
| Congenital anomalies        | 1.86 (1.49 to 2.31)         | <0.001  |
| Acquired comorbidities      | 1.59 (1.19 to 2.13)         | 0.002   |
| Neurodevelopmental problems | 0.88 (0.60 to 1.29)         | 0.523   |
| Preprocedure deterioration   | 1.52 (1.24 to 1.86)         | <0.001  |
| Index admission             |                             |         |
| Age (per week increase)     | 0.95 (0.94 to 0.97)         | <0.001  |
| Weight z-score              | 0.93 (0.84 to 1.03)         | 0.168   |
| Primary cardiac diagnoses (reference: VSD) | | |
| Hypoplastic left heart syndrome | 4.92 (3.03 to 7.99)         | <0.001  |
| Functionally univentricular heart | 3.99 (2.45 to 6.47)         | <0.001  |
| Common arterial trunk       | 2.53 (1.33 to 4.83)         | 0.005   |
| TGA with VSD/DORV-TGA type  | 0.93 (0.50 to 1.73)         | 0.817   |
| Interrupted aortic arch     | 2.15 (1.03 to 4.48)         | 0.041   |
| TGA with VSD                | 0.78 (0.34 to 1.78)         | 0.354   |
| Pulmonary atresia+IVS       | 2.96 (1.71 to 5.15)         | <0.001  |
| Pulmonary atresia+VSD       | 2.56 (1.46 to 4.47)         | <0.001  |
| Miscellaneous primary cardiac diagnoses | | |
| Complete AVCVSD             | 1.56 (0.94 to 2.59)         | 0.087   |
| Fallot’s tetralogy/DORV     | 1.23 (0.68 to 2.21)         | 0.495   |
| Aortic valve stenosis (isolated) | 3.60 (1.99 to 6.52)         | <0.001  |
| Tricuspid valve abnormality | 2.84 (1.19 to 6.77)         | 0.019   |
| Mitral valve abnormality    | 4.80 (2.46 to 9.37)         | <0.001  |
| TAPVC                        | 0.92 (0.36 to 2.36)         | 0.857   |
| Aortic arch obstruction     | 0.86 (0.48 to 1.53)         | 0.600   |
| Pulmonary stenosis          | 0.53 (0.16 to 1.71)         | 0.289   |
| ASD                          | 2.93 (1.28 to 6.71)         | 0.011   |
| PDA                          | 1.39 (0.57 to 3.38)         | 0.466   |
| Miscellaneous congenital terms | 0.83 (0.20 to 3.42)         | 0.801   |

Results from a multivariable Poisson model with 20 imputed datasets. Bold text indicates significant result at p<0.05.

AVSD, atrioventricular septal defect; ASD, atrial septal defect; DORV, double outlet right ventricle; IMD, Index of Multiple Deprivation; IVS, intact ventricular septum; PDA, persistent ductus arteriosus; TGA, transposition of the great arteries; TAPVC, totally anomalous pulmonary venous connection; VSD, ventricular septal defect.
deterioration, a potential marker of delayed healthcare access, independently predicted first-year mortality but only partly explained ethnic variations. Despite similar rates of prenatal diagnosis, there were higher rates of complex defects (e.g., HLH and UVH) at birth in British Asian and black British compared with white ethnic groups. This discrepancy could indicate failure to detect the most complex defects due to poorer access to prenatal diagnosis or ethnic differences in the acceptability of pregnancy termination. The higher rate of preprocedure deterioration observed in black British infants may also indicate delayed access to care; however, other influences, such as the spectrum of cardiac diagnoses, cannot be excluded.

We found no evidence that deprivation influenced CHD mortality within the UK healthcare system. However, non-white infants were highly clustered in more deprived areas, and our reliance on this single measure of socioeconomic status may have limited our ability to detect a difference. Other authors have reported an association between higher area deprivation and adverse CHD outcomes, but no evidence for ethnic differences by household income or health insurance. It is unclear which socioeconomic measures best reflect individual experience, particularly within non-white communities. British Asian children have higher prevalence of complex CHDs and are more likely to live in deprived areas, so they may experience multiple barriers to accessing specialist care, as well as stressors related to socioeconomic disadvantage.

The existing literature suggests multiple causes for ethnic variation in access to care, even within a universal healthcare system. Moreover, deprivation, language, biological and cultural differences are likely to have differing impact; for example, while recent migrants may experience language as a barrier, this is less likely to affect those who have been born in the UK. Understanding the differences in experience within ethnic groups is fundamental to developing appropriate interventions.

** strengths and limitations **

An important strength of our study was the linked national audit dataset representative of the multiethnic UK population. However, routinely collected audit data also have limitations with some variables incomplete; we could not account for deaths before surgery, comprising 5% of affected births, and 14% of NCHDA records were not matched to PICANet. Audit data did not fully capture some variables important to case-mix severity or unexpected collapse. Collection of these additional factors is improving, particularly in terms of case mix, and future analyses are likely to provide greater insight. Nevertheless, the audits are nationwide, mandatory, externally validated and have high case ascertainment, and death registrations provide a robust record of outcome; therefore, they contribute important evidence to the limited literature on ethnic variation in CHD deaths.
Table 3  Mortality during the index hospital admission (n=5131; multivariable analysis with multiple imputation)

| Relative risk (RR) (95% CI) | P value |
|-----------------------------|---------|
| Ethnicity (reference: white) |         |
| British Asian               | 1.55 (1.07 to 2.26) | 0.020 |
| Black British               | 1.39 (0.81 to 2.38) | 0.233 |
| All other                   | 1.64 (1.05 to 2.57) | 0.031 |
| Sex (reference: boys)       |         |
| Girls                       | 1.06 (0.81 to 1.40) | 0.675 |
| Area deprivation (IMD) quintile (reference: quintile 5=least deprived) |         |
| Quintile 4                  | 1.04 (0.63 to 1.71) | 0.879 |
| Quintile 3                  | 0.87 (0.52 to 1.46) | 0.610 |
| Quintile 2                  | 1.33 (0.86 to 2.06) | 0.203 |
| Quintile 1: most deprived   | 0.94 (0.60 to 1.48) | 0.796 |
| Birth gestation (reference: term birth ≥37 weeks’ gestation) |         |
| Preterm (<37 weeks)         | 1.25 (0.57 to 2.77) | 0.569 |
| Prenatal diagnosis (reference: not prenatally diagnosed) |         |
| Preterm (<37 weeks)         | 1.92 (1.41 to 2.64) | <0.001 |
| Non-cardiac comorbidities/procedure-related clinical status (reference: no comorbidities) |         |
| Congenital anomalies        | 1.58 (1.12 to 2.24) | 0.010 |
| Acquired comorbidities      | 1.58 (1.04 to 2.41) | 0.033 |
| Neurodevelopmental problems | 0.41 (0.18 to 0.94) | 0.035 |
| Preprocedure deterioration   | 1.52 (1.12 to 2.06) | 0.008 |
| Index admission             |         |
| Age (per week increase)     | 0.98 (0.96 to 0.99) | 0.020 |
| Weight z-score              | 0.97 (0.80 to 1.19) | 0.769 |
| Primary cardiac diagnoses (reference: VSD) |         |
| Hypoplastic left heart syndrome | 8.27 (3.61 to 18.96) | <0.001 |
| Functionally univentricular heart | 6.34 (2.79 to 14.43) | <0.001 |
| Common arterial trunk       | 6.74 (2.62 to 17.35) | <0.001 |
| TGA with VSD/DORV-TGA type  | 1.96 (0.75 to 5.08) | 0.168 |
| Interrupted aortic arch     | 6.71 (2.42 to 18.58) | <0.001 |
| TGA+IVS                     | 0.81 (0.17 to 3.83) | 0.790 |
| Pulmonary atresia+IVS       | 6.45 (2.71 to 15.36) | <0.001 |
| Pulmonary atresia+VSD       | 6.32 (2.68 to 14.94) | <0.001 |
| Miscellaneous primary cardiac diagnoses |         |
| Complete AVSD              | 2.88 (1.14 to 7.25) | 0.025 |
| Fallot’s tetralogy/DORV/Fallot type | 1.96 (0.80 to 4.85) | 0.143 |
| Aortic valve stenosis       | 7.18 (2.80 to 21.42) | <0.001 |
| Mitral valve abnormality    | 5.99 (1.84 to 19.50) | 0.003 |
| Tricuspid valve abnormality | 8.01 (2.81 to 27.72) | <0.001 |
| TAPVC                       | 0.71 (0.09 to 5.75) | 0.752 |
| Aortic arch obstruction     | 1.14 (0.42 to 3.09) | 0.794 |
| Pulmonary stenosis          | 1.11 (0.24 to 5.09) | 0.892 |
| ASD                         | 5.89 (1.81 to 19.16) | 0.003 |
| PDA                         | 0.93 (0.13 to 6.92) | 0.945 |
| Miscellaneous congenital terms | too few events |        |

Results from a multivariable Poisson model with 20 imputed datasets. Bold text indicates significant result at P<0.05.

CONCLUSION

CHDs are an important contributor to infant mortality and significant ethnic differences have been reported. Although we were unable to fully explore all potential mediators of ethnic variation using routine data, we identified higher mortality and differences in the timing of risk for UK infants from British Asian and ‘all other’ non-white ethnic groups compared with those of white ethnicity. It is important to understand how and why ethnicity influences mortality as there may be potential to ameliorate this by enhancing healthcare approaches that improve equity. For example, where access is restricted by language, cultural beliefs or lack of familiarity with healthcare systems, additional support or innovative approaches to providing care may reduce ethnic variation. Further research should explore the relative impact of case-mix complexity, cultural beliefs and health-seeking behaviours and other potential barriers to care that influence ethnic variation. This would inform the development of targeted interventions that address these ethnic-specific risk factors, improve health equity and result in better CHD outcomes overall within a multiethnic population.

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