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Racial/ethnic differences in hospital use and cost among a statewide population of children with Down syndrome

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Abstract

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Children with Down syndrome (DS) use hospital services more often than children without DS, but data on racial/ethnic variations are limited. This study generated population-based estimates of hospital use and cost to 3 years of age by race/ethnicity among children with DS in Massachusetts using birth certificates linked to birth defects registry and hospital discharge data from 1999 to 2004. Hospital use (≥1 post-birth hospitalization and median days hospitalized birth and post-birth) and reasons for hospitalization were compared across maternal race/ethnicity using relative risk (*RR*) and Wilcoxon rank sums tests, as appropriate. Costs were calculated in 2011 United States dollars. Greater hospital use was observed among children with DS with Hispanic vs. Non-Hispanic White (NHW) mothers (post-birth hospitalization: *RR* 1.4; median days hospitalized: 20.0 vs. 11.0, respectively). Children with DS and congenital heart defects of Non-Hispanic Black (NHB) mothers had significantly greater median days hospitalized than their NHW counterparts (24.0 vs. 16.0, respectively). Respiratory diagnoses were listed more often among children with Hispanic vs. NHW mothers (50.0% vs. 29.1%, respectively), and NHBs had more cardiac diagnoses (34.1% vs. 21.5%, respectively). The mean total hospital cost was nine times higher among children with DS ($40,075) than among children without DS ($4053), and total costs attributable to DS were almost $18 million. Median costs were $22,781 for Hispanics, $18,495 for NHBs, and $13,947 for NHWs. Public health interventions should address the higher rates of hospital use and hospitalizations for respiratory and cardiac diseases among racial/ethnic minority children with DS in Massachusetts.

Keywords

Down syndrome; Congenital heart defects; Hospital use; Hospital cost; Racial/ethnic disparities

1. Introduction

Down syndrome (DS) affects more than one in 1000 live births in the United States (US), with high rates of neonatal comorbidities and hospital use and related costs in the first years of life in comparison to children without DS (Boulet, Molinari, Grosse, Honein, & Correa, 2008; Centers for Disease Control and Prevention, 2007; Cleves et al., 2007; Rasmussen, Whitehead, Collier, & Frías, 2008; So et al., 2007; Torfs & Christianson, 1998). Documented improvements in survival for children with DS (Centers for Disease Control and Prevention, 2001; Rasmussen, Wong, Correa, Gambrell, & Friedman, 2006; Yang, Rasmussen, & Friedman, 2002) mean that the number of children growing up with DS is increasing as are the need and demand for specialized health services for people with DS. Consequently, there is a need for more current information on the extent and cost implications of health service needs.

Persistent, unexplained racial/ethnic disparities in survival for children with DS favoring Non-Hispanic Whites (NHWs) over Non-Hispanic Blacks (NHBs; Centers for Disease Control and Prevention, 2001; Rasmussen et al., 2006; Yang et al., 2002), raise questions about the potential contributions of differences in access to and use of health services to disparities in health outcomes. However, published studies examining possible racial/ethnic variations in these factors among children with DS have been limited. In contrast, numerous studies have documented racial/ethnic differences in preventable hospitalizations for other

chronic conditions such as asthma (e.g., Ash & Brandt, 2006; Crocker et al., 2009; Erickson, Iribarren, Tolstykh, Blanc, & Eisner, 2007; Jones, Lin, Munsie, Radigan, & Hwang, 2008; Laditka & Laditka, 2006; Lu & Kuo, 2012; Roy, McGinty, Hayes, & Zhang, 2010).

Information on hospital use and cost is important for deliberations on cost-effective approaches for providing health services to a growing population of children, adolescents, and adults with DS. Recent US-based studies (Boulet et al., 2008; Centers for Disease Control and Prevention, 2007; Russo & Elixhauser, 2007; So et al., 2007) have provided some of this information. However, such studies used hospital administrative databases in which ascertainment of DS and co-occurring birth defects was based on International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis codes alone, a method that is less accurate compared to active case ascertainment methods used in several state birth defects registries (Frohnert et al., 2005). The generalizability of the findings reported by Boulet and colleagues (2008) is further limited because it was based on a privately insured sample. Moreover, comparisons of hospital use and cost among privately insured children with DS to those with other types of insurance would generate useful data on the cost-effectiveness of alternative approaches to health care coverage. The study by Russo and Elixhauser (2007) generated data on rates of use or cost per hospital visit, not per individual with DS, and the study by the Centers for Disease Control and Prevention (CDC, 2007) was limited to hospitalizations of children under 10 days old and excluded birth hospitalization costs. Data on costs per individual for longer periods of time are needed to estimate the potential benefits and cost-savings of prevention interventions.

Population-based research using linked data systems that include birth defects registries could improve existing information on the extent to which children with DS in the US use hospital-related services, the reasons for and costs of those hospitalizations, how other characteristics impact use and cost, and, importantly, how differential use and cost may be related to racial/ethnic disparities in morbidity and mortality. This study used such a data system in Massachusetts to address three questions: (1) Do patterns of hospital use from birth to age three among children with DS differ from those among children without DS by maternal race/ethnicity, delivery payer source, and presence of other comorbidities; (2) Among children with DS, are there differences in patterns of hospital use by race/ethnicity; and (3) Do racial/ethnic differences in hospital use and cost among children with DS correspond to previously reported racial/ethnic disparities in survival?

2. Material and methods

2.1. Data source

Data came from the population-based Massachusetts Pregnancy to Early Life Longitudinal (PELL) Data System. PELL consists of a core linkage, performed as described elsewhere (Declercq et al., 2007; Weiss et al., 2009), between birth certificates and infant/maternal birth/delivery hospital records (core linkage rate 99.5%) that is then longitudinally linked to birth defects registry data from the Massachusetts Birth Defects Monitoring Program (MBDMP), death certificates, and hospital discharge records for post-birth hospital stays (as well as other databases not used in this study). The MBDMP ascertains major birth defects among all live births to age one year by using active surveillance methods (Lynberg &

Edmonds, 1992). The longitudinal linkage rate was 82.0% for post-birth inpatient hospital admissions of Massachusetts resident children under three years of age born from 1998 to 2008 (specific data on the 1999–2004 study population are not available; see Section 2.2). This study was approved by the Institutional Review Boards of the Massachusetts Department of Public Health and Boston University Medical Center.

2.2. Study population

The study population was defined as children born alive between January 1, 1999 and December 31, 2004 to Massachusetts resident mothers in a Massachusetts maternity hospital with a core linkage between birth certificates and hospital discharge birth records and with complete data on hospital admission and discharge dates. The study group was identified using International Classification of Diseases, Ninth Revision, Clinical Modification/British Paediatric Association (ICD-9-CM/BPA) codes 758.000, 758.020, 758.030, and 758.040 in MBDMP data indicating a cytogenetically confirmed diagnosis of DS. We excluded six children identified with DS in the MBDMP data: four were not born in a maternity hospital and the other two did not have a core birth certificate to hospital birth record linkage. The comparison group consisted of all children without a DS diagnosis to allow for an unbiased estimate of the impact of DS on hospital use and costs, as exclusion of children with birth defects from the control group would overstate the impact of DS. We excluded 5654 children from the comparison group: 3335 not born in a maternity hospital and 2319 with no core linkage).

All children were classified by presence or absence of congenital heart defects (CHD) or other major (non-cardiac) defects (OMBD) using ICD-9-CM/BPA codes from MBDMP data. For children with DS and CHD, a second stage case review was performed by clinicians with training in cardiology. Using standard clinical nomenclature adapted from the Society of Thoracic Surgeons (Riehle-Colarusso et al., 2007) and a developmental schema, the clinicians reclassified 22 children with newborn- and prematurity-related or non-structural heart defects into the DS without CHD group.

2.3. Sociodemographic characteristics and birth outcomes

Birth certificates provided data on maternal race/ethnicity (NHW, NHB, and Hispanic), child gender, birth weight (low birthweight: <2500 g; vs. normal), gestational age (preterm: <37 weeks completed gestation; vs. term). Delivery payer source was based on a combination of data from the birth certificate and hospital discharge delivery record for the mother, categorized dichotomously as private insurance or not private if either record indicated a public payer, self-pay, or free care.

2.4. Hospital use: number of post-birth hospitalizations and days hospitalized

Hospital use was defined by number of post-birth hospitalizations (PBH) and the total number of days hospitalized. Birth and post-birth stay episodes were defined as the index hospitalization plus transfers or re-admissions to the same or to a different hospital on the same or next day following discharge from the index hospitalization (Weiss et al., 2009). The total number of PBH in an acute care hospital from 1999 to 2007 was calculated for children up to three years of age. Children were categorized as having 0 or ≥1 PBH.

Number of days hospitalized was calculated by subtracting the date of admission from the date of discharge and adding one. Mean and median numbers of days hospitalized were calculated for the birth hospitalization, all PBH up to age three years, and total hospitalizations (Birth + PBH).

2.5. Reasons for hospitalization

The reasons that children were hospitalized were measured by tallying ICD-9-CM diagnosis codes across all 15 fields available for birth and post-birth hospitalizations. The primary diagnosis code was also examined for post-birth hospitalizations. Codes were grouped into the 18 Level I conditions of the Hospital Cost and Utilization Project Clinical Classification Software (2012) version 1.2 (2012) and then further grouped into chronic conditions related to the following: (1) circulatory system, (2) respiratory system, (3) digestive system, (4) infections/parasites, (5) neoplasms, (6) endocrine, nutritional, metabolic, immune systems, and (7) disorders affecting five other CCS categories of potential importance which we grouped due to small cell sizes: mental health, blood and blood-forming organs, the nervous system, the genitourinary system, and the musculoskeletal system. We did not analyze the remaining seven Clinical Classification Software categories for several reasons. We wanted to capture non-birth-defect related comorbidities, so we did not analyze congenital anomalies as recorded in hospital data. The remaining six categories were not something for which a young child could be hospitalized (e.g., complications of pregnancy; childbirth; and the puerperium), overly general (e.g., residual codes), and/or did not capture conditions particularly influential for mortality (e.g., skin/subcutaneous tissue conditions).

2.6. Data analysis

Differences in distributions of co-occurring birth defects, sociodemographic characteristics, and birth outcomes were examined using chi-squared tests and relative risk with 95% confidence intervals (CI) to make comparisons (1) between children with and without DS and (2) among children with DS. Between and within group comparisons of median days hospitalized were made using Wilcoxon rank-sums tests. Significance was defined by $p \leq .05$ for all tests. Patterns of differences in hospital use among children with DS by race/ethnicity were then compared to patterns of differences in survival from other studies. Data were analyzed using SAS 9.2 (SAS Institute, Inc., Cary, NC).

2.7. Cost analysis

Costs were estimated by multiplying the total charges reported on the hospital discharge record with annual hospital-specific cost-to-charge ratios (including capital costs) obtained from the Massachusetts Division of Health Care Finance and Policy. The average cost-to-charge ratio for all hospitalizations (birth and post-birth) in this study was 0.58, indicating that charges were on average almost double the estimated costs. Costs were adjusted for inflation to 2011 US dollars (Producer Price Index Industry Data for Hospitals; Department of Labor, 2012). The incremental cost of hospitalizations attributable to DS was calculated at the individual level as the difference between the mean costs for children with DS and for all other children without DS, and at the population level by multiplying that difference by the number of children born with DS (Amendah, Mvundura, Kavanagh, Sprinz, & Grosse,

2010). The mean, median and 95th percentile costs were calculated for the birth hospitalization, all PBH, and total birth plus PBH. PBH costs were also calculated for children under age one year at admission.

3. Results

There were 504 children with DS, including 21 (4.2%) children who died before age three years, and 468,600 children without DS, with 2119 (0.5%) deaths. The prevalence of DS in this study was 10.7/10,000 live births.

3.1. Hospital use

3.1.1. Number of post-birth hospitalizations (PBH)—Almost half (46.8%) of children with DS had one or more PBH by the age of three years, which was 4.5 times higher than observed for children without DS (10.4%; Table 1). The DS–nonDS risk of a PBH was consistently more than three times higher for all characteristics except CHD (*RR* 1.1, 95% CI 1.0, 1.3) and OMBD (*RR* 1.1, 95% CI 0.9, 1.3).

Among children with DS, children of Hispanic mothers had a significantly higher percentage with a PBH (60.9%) than children of NHW mothers (44.0%), and children of NHB mothers had a non-significantly lower rate (39.0%; Table 1). *RRs* of PBH were significantly higher for children with CHD, OMBD, low birthweight, or preterm birth than those without these characteristics. Similar patterns were observed among children without DS, with the exception that children of NHW mothers had the lowest PBH percentage among the maternal racial/ethnic groups.

Among children with CHD, there were no DS–nonDS differences by race/ethnicity in PBH (Table 2). For children without CHD, children with DS of Hispanic or NHW mothers had over three-fold greater *RR* of PBH than children without DS in those racial/ethnic groups. Among children with DS, there was no racial/ethnic difference in the risk of PBH for those with CHD, but for those without CHD, children of Hispanic mothers had a 60% greater risk and children of NHB mothers had a marginally non-significant 60% lower risk of PBH compared to NHWs (Table 2).

3.1.2. Days hospitalized at birth and post birth to age three years—Children with DS had a greater mean number of days hospitalized at birth (14.7) and post-birth (8.5) than children without DS (4.8 and 0.7, respectively). Children with DS also had higher median days hospitalized at birth and in the total birth to three period than children without DS (birth: 7 vs. 3 days, respectively; total: 12 vs. 3 days, respectively), while post-birth medians were 0 for both groups (data not shown). This pattern of greater DS means and greater/equal DS medians was observed across all characteristics and time periods (data not shown), with the exception of mean post-birth days hospitalized among children with OMBD (DS: 11.1; non-DS: 14.8).

Among children with DS, there were significant Hispanic-NHW post-birth and total differences (Table 3). Privately insured children with DS had significantly fewer median post-birth days hospitalized than those without private insurance. Children with DS and

other birth defects or who were low birthweight or preterm had significantly higher birth and post-birth median days hospitalized than children with DS without these conditions.

Among children with CHD, there was a statistically significant 3-day difference between children with and without DS of NHW mothers in median days hospitalized for the total period (Table 4). The DS–nonDS median differences were larger but not statistically significant for children with CHD born to NHB and Hispanic mothers (9 and 9.5 days, respectively). There was a different pattern for children without CHD, where the DS–nonDS median differences were 15 days for Hispanics ($p < 05$), 5 days for NHWs ($p < .05$), and 3 days for NHBs ($p < .10$).

Within-DS comparisons by presence of CHD revealed no racial/ethnic differences for those with CHDs in the birth or post-birth periods (Table 4). For the total period, children with DS and CHD of NHB mothers were hospitalized for significantly more days than children of NHW mothers. For the non-CHD group, children of Hispanic mothers had significantly more days hospitalized post-birth and overall compared to children of NHW mothers.

3.2. Reasons for hospitalization

The most common diagnoses at birth were infectious/parasitic conditions, affecting almost one third of children with DS (Table 5). Children with DS who were born to NHW mothers had significantly higher frequencies of infectious/parasitic comorbid diagnoses (34.8%) than among children with DS born to Hispanic mothers (20.3%).

Children with DS visited the hospital after birth most often for cardiovascular (22.6%), respiratory (31.9%), or endocrine/nutritional/metabolic/immunity (22.4%) diseases (Table 5). Cardiovascular diseases were significantly more common among children of NHB mothers (34.1%) than among children of NHW mothers (21.5%). Half of children born to Hispanic mothers had a respiratory diagnosis, compared to 29.1% among children of NHW mothers ($p < .01$). Children with Hispanic mothers also had a significantly greater frequency of endocrine/nutritional/metabolic/immunity diagnoses (34.4%) compared to NHWs (19.8%).

3.3. Cost of hospitalizations

The total cost associated with hospitalizations from 1999 to 2007 among 504 children with DS was almost $20.2 million in 2011 US dollars (Table 6). Birth hospitalization costs totaled $10.5 million, and PBH costs totaled $9.7 million. Over half of the PBH costs (52.7%) were incurred prior to six months of age (data not shown). Mean incremental cost for children with DS vs. those without was $17,365 at birth, $18,207 post-birth, and $35,572 total. Multiplying the mean incremental costs by the number of infants with DS, the total hospitalization costs attributable to DS in Massachusetts were $8.8 million and $9.2 million during birth and post-birth hospitalizations, respectively, for a total of $17.9 million.

Mean total hospital costs were $40,075 for children with DS, nine times higher than the mean for children without DS ($4503; Table 6). The $20,788 mean birth hospitalization cost for children with DS was higher than their $19,287 mean PBH cost. For hospitalizations from birth to age 1, the mean cost for children with DS was $34,069 (data not shown).

Mean costs among children with DS varied considerably by maternal race/ethnicity. Children of NHB mothers had the highest mean birth hospitalization cost of $23,391, followed closely by children of Hispanic mothers at $22,939, and children with NHW mothers had the lowest mean of $20,667. In the post-birth period, children of NHB mothers also had the highest mean cost ($27,976), followed by Hispanics ($23,740) and NHWs ($17,914).

Stratification by insurance type revealed lower mean birth costs but higher mean post-birth costs for children with DS without private insurance at delivery (Table 6). Birth hospitalization costs were almost two-fold greater for children with DS and CHD or OMBD and approximately 2.5 times greater for low birthweight or preterm compared to children without these conditions. Mean PBH cost differences were smaller for children with DS and OMBD and those born low birthweight or preterm vs. those without these conditions, but differences increased for CHD.

The overall median cost of hospital use per child was $15,811, over 13 times greater than the median for children without DS ($1188; Table 6). The birth hospitalization median cost for children with DS was $8589; and the post-birth median cost was $0. The median cost for all hospitalizations was much higher than either the birth or post-birth hospitalization medians due to children with high-cost birth hospitalizations and no PBH. There were 117 children with no PBH and a birth hospital cost greater than the median (44% of the 268 children with no PBH). Costs comparisons across maternal race/ethnicity indicated that children of NHB mothers had the highest birth hospitalization median cost ($10,170), but children of Hispanic mothers had the highest PBH median cost ($6888). The median cost differences across birth defects, insurance, low birthweight, and preterm birth were similar to the mean differences described above.

4. Discussion

This study provides statewide, population-based, longitudinal estimates of hospital use and cost, as well as the reasons for those hospitalizations, among infants and toddlers with DS in Massachusetts who were identified using birth defects registry data. Almost half of children with DS born in Massachusetts maternity hospitals to Massachusetts residents from 1999 to 2004 had at least one post-birth hospitalization by the time they turned three years of age. Respiratory and cardiac conditions were the most common hospital-recorded PBH diagnoses. Roughly 90% of the total cost of all hospitalizations from birth to age three years in this cohort was attributable to DS and its complications. Importantly, this study provides novel evidence of significantly greater hospital use and cost among children of racial/ethnic minority mothers compared to NHW mothers, greater respiratory disease burden among children with Hispanic mothers, and greater cardiac disease burden among children with NHB mothers.

4.1. Hospital use

We found similar rates of PBH (46.8%) to those reported in a longitudinal Tennessee study, where 49.8% of children with DS who survived their birth hospitalization had a post-birth hospitalization (So et al., 2007). However, we found a lower relative risk of PBH for those

with vs. without CHD (*RR* 1.5) than reported by So and colleagues (*RR* 2.3; 2007). This is likely due largely to differences in ascertainment and CHD classification methods. So et al. (2007) ascertained CHDs using ICD-9-CM codes from hospital diagnoses, a method that has been shown to result in substantial false positive classifications (Frohnert et al., 2005), and all ICD-9-CM codes for cardiac defects were classified in the CHD group. We used ascertainment using birth defects registry data independent of hospitalization data, which is considered the gold standard in birth defects measurement. We further classified infants with non-structural and prematurity-related heart defects in the non-CHD group.

We hypothesized that maternal racial/ethnic patterns of hospital use among all children with DS would reveal greater NHW–NHB differential use and equivalent NHW-Hispanic use, corresponding to racial/ethnic patterns of survival (Day, Strauss, Shavelle, & Reynolds, 2005; Yang et al., 2002). Our findings did not completely support this hypothesis. The greatest differences in both PBH and days hospitalized were observed among children of Hispanic vs. NHW mothers. In contrast, differences between children of NHB and NHW mothers were not significant or uniform in direction. Although fewer children with DS of NHB mothers had a PBH, they spent slightly more time in the hospital than children with DS of NHW mothers.

Among children with DS and CHD, we found greater hospital use for both Hispanic and NHB mothers relative to NHW mothers. The NHW-Hispanic difference was not consistent with our hypothesis, while the NHB–NHW difference was, with potential implications for survival. Oster, Strickland, and Mahle (2011) reported approximately 30% higher adjusted odds of in-hospital mortality for children with CHD with NHB vs. NHW mothers, controlling for presence of a genetic syndrome, such as DS, and access to care measures. However, another study found that infants with DS of NHB mothers had an increased risk of dying only if they did not have a CHD (Rasmussen et al., 2006); the investigators suggested that this group may have had undiagnosed CHDs or that access to care might be an issue.

The present study documented a significantly lower risk for PBH for children of NHB mothers with DS but no CHD compared to their NHW reference group. This could suggest limited access to needed care among the NHB group, a hypothesis consistent with data from the National Survey of Children with Special Health Care Needs. Children with DS are less likely to have a medical home and more likely to have unmet healthcare needs than other children with special health care needs (McGrath, Stransky, Cooley, & Moeschler, 2011). NHB children with special health care needs are also less likely to have a medical home (Strickland et al., 2009). A medical home is described as “a convenient reliable source for comprehensive care, where families are welcomed and encouraged to be involved in their child’s care and where comprehensive services are provided and coordinated” (Strickland et al., 2009, p. e996). Medical home care is considered by experts to be more effective and less costly (American Academy of Pediatrics, 2002). If NHB children with DS are less likely than their NHW counterparts to have a medical home, they might have less access to needed hospital care. When they do access hospital care it is more costly, as documented in this study, and it may be less effective. This may also have implications for disparities in survival.

Greater hospital use among children with DS in the maternal Hispanic and NHB groups relative to the NHW group might be explained in part by greater use of prenatal diagnosis and elective termination among NHW women (Bishop, Huether, Torfs, Lorey, & Deddens, 1997; Grosse, 2010; Khoshnood, Pryde, Blondel, & Lee, 2003). Lower use of prenatal services could result in more live births of infants with DS to NHB and Hispanic mothers. These infants might be more medically involved and therefore hospitalized to a greater extent.

Children with DS who did not have private insurance at delivery had greater post-birth hospital utilization than those with private insurance for both the occurrence and days hospitalized measures. This was similar to the pattern observed among children without DS. Notably, privately insured children with DS had over five-fold greater risk of PBH than privately insured without DS (payer status assessed at delivery). Among children without private insurance at delivery, those with DS had only 3.8 times greater risk of PBH compared to those without DS. This DS–nonDS difference for privately insured children was the largest among all strata of children with and without DS.

4.2. Reasons for hospitalization

More than 20% of children with DS were hospitalized post-birth for cardiovascular, respiratory, digestive, or endocrine/nutritional/metabolic/immunity disorders, which are well-documented comorbidities among this population (Hickey, Hickey, & Summar, 2012). Respiratory diagnoses were the most common (31.9%) followed by cardiovascular diseases (24.0%), which is generally consistent with other research (So et al., 2007; Thomas et al., 2011; van Trotsenburg, Heymans, Tijssen, de Vijlder, & Vulsma, 2006; Zachariah, Ruttenber, & Simões, 2012). This study goes further by documenting significant differences by maternal race/ethnicity by comorbidity. Children with DS of Hispanic mothers were observed to have significantly greater respiratory, digestive, infectious/parasitic, and endocrine/nutritional/metabolic/immune disease burden compared to children of NHW mothers, while children of NHB mothers had greater post-birth cardiac disease burden. These results are consistent with the findings in the present study of greater hospital use among children with DS of Hispanic vs. NHW mothers and among children with DS and CHD born to NHB mothers vs. their NHW counterparts.

4.3. Cost of hospitalization

In Massachusetts from 1999 to 2004, the average cost of hospitalizations from birth to age three years per child with DS was $40,075 in 2011 US dollars. Slightly more than half of this figure ($20,788) was associated with the birth hospitalization. Eighty-five percent of these costs ($34,069) accrued from birth to age one year. Two recent studies on costs associated with hospitalizations of children with DS in the US provide estimates based on cross-sectional data per hospitalization rather than longitudinal data per child with DS. The first study reported comparable newborn/birth costs, while the second study provided much higher three-year estimates. The average charge per hospital stay during the newborn period, including birth hospitalizations, for a nationally representative cross-section of infants with DS was estimated by the CDC (2007) to be $38,745 in 2003. Adjusting for inflation and the differences in charges and costs, this translates to $19,800 in 2011. In contrast, the estimated

average inpatient expenditure per child with DS under age three years from a privately insured cross-section was $39,054 in 2011 (Boulet et al., 2008). This translates to a three-year estimate of $117,162, which is almost 3 times higher than our estimate of $40,075. A similar differential in cost estimates for the same two sources of data has also been reported for infants with craniofacial malformations (Boulet, Grosse, Honein, & Correa, 2009; Weiss et al., 2009).

Novel findings indicate that overall hospital-associated costs were substantially higher for children with DS born to NHB or Hispanic mothers than for children born to NHW mothers. The mean cost for children with DS with NHB mothers was the highest among the three groups. However, the median cost was intermediate, reflecting the influence of a few outliers with high costs among the maternal NHB group. This may be attributable to children with DS and CHD in the maternal NHB group, who had greater hospital use than children with DS and CHD born to NHW mothers. The substantial difference between means and medians for all groups reveals the influence of small numbers of relatively high-cost cases. The difference in mean and median costs is higher for the NHW and NHB groups than for the Hispanic group.

4.4. Limitations and strengths

Case ascertainment is the primary limitation for any study based on administrative data. Because MBDMP case ascertainment ends at age one year, we might have missed a few newborns with DS born in Massachusetts. Nevertheless, birth defects registry data based on active ascertainment are considered to be the gold standard and improve upon data from previous studies that use only hospital diagnoses-based ascertainment. Birth certificate and hospital data quality could not be verified. Birth certificate data on maternal race/ethnicity, birth weight, and gestational age have been shown to have good reliability (DiGiuseppe, Aron, Ranbom, Harper, & Rosenthal, 2002; Zollinger, Przybylski, & Gamache, 2006). Mother's health insurance at delivery was measured using both birth certificate and hospital data to identify those with private insurance only. This variable was used in all analyses in order to have one consistent measure of insurance type for children with and without post-birth hospitalizations, although mothers' delivery insurance may differ from children's health insurance for post-birth hospitalizations.

Small sample sizes, particularly among NHB children with DS, may have led to type II errors in comparisons with NHW children with DS. Multiple comparisons may have led to finding significant differences by chance. Generalizability beyond Massachusetts is limited by lower racial/ethnic diversity and by the widespread availability of high quality hospital care in Massachusetts in comparison to other states in the US.

Another limitation is the limited control for socioeconomic status. In particular, socioeconomic status is strongly correlated with race/ethnicity, with NHB and Hispanic mothers much more likely to have public delivery insurance without private health insurance. Although we did assess insurance status at the bivariate level in this study, the number of children with DS in the sample was too small to conduct a multivariable analysis.

The longitudinal linkage rate was 82%, which means that we may have underestimated hospital use and costs for children whose post-birth hospital records could not be linked to their birth hospital records. Our data use agreement prohibits access to unlinked data needed for bias analyses of these factors.

Limitations of cost data include the fact that charges in hospital discharge data do not include physician fees, hence understating costs to some extent. Some data on hospital charges were missing (3.4% of records) or zero (0.2% of records). The use of average cost-to-charge ratios to adjust charges to estimated costs also decreases precision.

The strengths of this study lie in the use of a statewide, population-based data system with all in-state births to residents with linkage to an active ascertainment birth defects registry and the reporting of data by all hospitals in the state, both of which improve upon methods used in existing studies. The clinical ascertainment of the presence of CHDs provides a more precise measure of the influence of CHDs than has been used in other studies. Finally, to our knowledge, this is the first published study to examine differences in hospital use and cost among children with DS by maternal race/ethnicity.

5. Conclusions

Patterns of hospital use from birth to age three among children with DS were found to differ by maternal race/ethnicity, payer source, and presence of CHD, OMBD, low birthweight, and preterm birth. Differences in hospital use by maternal race/ethnicity were less pronounced among children with DS of NHB vs. NHW mothers than among children with Hispanic vs. NHW mothers. Findings from this study do not support the hypothesis that greater hospital use in early life may signify greater morbidity among children of NHB mothers and explain their greater mortality rate. It is possible that the opposite is true, that infants with DS born to NHB mothers are not accessing needed medical care, which leads to greater mortality. More research is needed, particularly on the severity of CHD among children with DS across maternal racial/ethnic groups, and on the medical conditions of those without CHD in order to better understand the how hospital use may illuminate mechanisms behind survival disparities.

Our study documents the burden of health problems among children with DS of Hispanic mothers and among children with DS and CHD of NHB mothers, relative to children with DS of NHW mothers. Targeted secondary prevention efforts, for example, focusing on the prevention and management of respiratory disorders among Hispanic families of children with DS, might reduce these disparities as has been shown for other pediatric conditions. For example, an asthma management program targeted to urban minority children has been show to substantially reduce the elevated rates of preventable hospitalization among NHB and Hispanic children (Cloutier, Jones, Hinckson, & Wakefield, 2008). Findings of lower post-birth hospital use among children with DS born to NHB mothers but no CHD relative to children born to NHW mothers suggests the possibility that the former group has less optimal access to needed care. If this hypothesis is confirmed in future studies, improving systems of care may be one avenue to address racial/ethnic disparities in morbidity and mortality among people with DS.tpb 9pt

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References

Amendah DD, Mvundura M, Kavanagh PL, Sprinz PG, Grosse SD. Sickle cell disease-related pediatric medical expenditures in the U.S. American Journal of Preventive Medicine. 2010; 38:S550–S556. [PubMed: 20331957]

Academy of Pediatrics. Policy statement: Medical Home Initiatives for Children With Special Needs Project Advisory Committee – The Medical Home. Pediatrics. 2002; 110:184–186. [PubMed: 12093969]

Ash M, Brandt S. Disparities in asthma hospitalization in Massachusetts. American Journal of Public Health. 2006; 96:358–362. [PubMed: 16380574]

Bishop J, Huether CA, Torfs C, Lorey F, Deddens J. Epidemiologic study of Down syndrome in a racially diverse California population, 1989–1991. American Journal of Epidemiology. 1997; 145:134–147. [PubMed: 9006310]

Boulet SL, Grosse SD, Honein MA, Correa A. Children with orofacial clefts: Health care use and costs among a privately insured population. Public Health Reports. 2009; 124:447–453. [PubMed: 19445422]

Boulet SL, Molinari N, Grosse SD, Honein MA, Correa A. Health care expenditures for infants and young children with Down syndrome in a privately insured population. Journal of Pediatrics. 2008; 153:241–246. [PubMed: 18534234]

Centers for Disease Control and Prevention. Racial disparities in median age at death of persons with Down syndrome – United States, 1968–1997. MMWR – Morbidity & Mortality Weekly Report. 2001; 50:463–465. [PubMed: 11414598]

Centers for Disease Control and Prevention. Hospital stays, hospital charges, and in-hospital deaths among infants with selected birth defects – United States, 2003. MMWR – Morbidity & Mortality Weekly Report. 2007; 56:25–29. [PubMed: 17230142]

Cleves MA, Hobbs CA, Cleves PA, Tilford JM, Bird TM, Robbins JM. Congenital defects among liveborn infants with Down syndrome. Birth Defects Research Part A: Clinical and Molecular Teratology. 2007; 79:657–663.

Cloutier MM, Jones GA, Hinckson V, Wakefield DB. Effectiveness of an asthma management program in reducing disparities in care in urban children. Annals of Allergy, Asthma and Immunology. 2008; 100:545–550.

Crocker D, Brown C, Moolenaar R, Moorman J, Bailey C, Mannino D, et al. Racial and ethnic disparities in asthma medication usage and health-care utilization: Data from the National Asthma Survey. Chest. 2009; 136:1063–1071. [PubMed: 19567492]

Day SM, Strauss DJ, Shavelle RM, Reynolds RJ. Mortality and causes of death in persons with Down syndrome in California. Developmental Medicine and Child Neurology. 2005; 47:171–176. [PubMed: 15739721]

Declercq E, Barger M, Cabral HJ, Evans SE, Kotelchuck M, Simon C, et al. Maternal outcomes associated with planned primary cesarean births compared with planned vaginal births. Obstetrics and Gynecology. 2007; 109:669–677. [PubMed: 17329519]

DiGiuseppe DL, Aron DC, Ranbom L, Harper DL, Rosenthal GE. Reliability of birth certificate data: A multi-hospital comparison to medical records information. Maternal and Child Health Journal. 2002; 6:169–179. [PubMed: 12236664]

Erickson SE, Iribarren C, Tolstykh IV, Blanc PD, Eisner MD. Effect of race on asthma management and outcomes in a large, integrated managed care organization. Archives of Internal Medicine. 2007; 167:1846–1852. [PubMed: 17893305]

Frohnert BK, Lussky RC, Alms MA, Mendelsohn NJ, Symonik DM, Falken MC. Validity of hospital discharge data for identifying infants with cardiac defects. Journal of Perinatology. 2005; 25:737–742. [PubMed: 16163368]

Grosse, SD. Sociodemographic characteristics of families of children with Down syndrome and the economic impacts on families of child disability. In: Urbano, R., editor. Health issues in persons with Down syndrome. Vol. Vol. 39. Elsevier Inc. Academic Press; San Diego, CA: 2010. p. 257-294.

Healthcare Cost and Utilization Project (HCUP). Clinical Classifications Software (CCS) for ICD-9-CM [Computer Software]. Agency for Healthcare Research and Quality; Rockville, MD: 2012.

Hickey F, Hickey E, Summar KL. Medical update for children with down syndrome for the pediatrician and family practitioner. Advances in Pediatrics. 2012; 59:137–157. [PubMed: 22789577]

Jones R, Lin S, Munsie JP, Radigan M, Hwang SA. Racial/ethnic differences in asthma-related emergency department visits and hospitalizations among children with wheeze in Buffalo, New York. Journal of Asthma. 2008; 45:916–922. [PubMed: 19085583]

Khoshnood B, Pryde P, Blondel B, Lee KS. Socioeconomic and state-level differences in prenatal diagnosis and live birth prevalence of Down's syndrome in the United States. Revue d'épidémiologie et de Santé Publique. 2003; 51:617–627.

Laditka JN, Laditka SB. Race, ethnicity and hospitalization for six chronic ambulatory care sensitive conditions in the USA. Ethnicity and Health. 2006; 11:247–263. [PubMed: 16774877]

Lu S, Kuo DZ. Hospital charges of potentially preventable pediatric hospitalizations. Academic Pediatrics. 2012; 12:436–444. [PubMed: 22922047]

Lynberg, MC.; Edmonds, LD. Surveillance of birth defects. In: Halperin, W.; Baker, ER., editors. Public health surveillance. Van Nostrand Reinhold; New York, NY: 1992. p. 157-177.

McGrath RJ, Stransky ML, Cooley WC, Moeschler JB. National profile of children with down syndrome: Disease burden, access to care, and family impact. The Journal of Pediatrics. 2011; 159(535–540):e532.

Oster ME, Strickland MJ, Mahle WT. Racial and ethnic disparities in post-operative mortality following congenital heart surgery. The Journal of Pediatrics. 2011; 159:222–226. [PubMed: 21414631]

Rasmussen SA, Whitehead N, Collier SA, Frías JL. Setting a public health research agenda for Down syndrome: Summary of a meeting sponsored by the Centers for Disease Control and Prevention and the National Down Syndrome Society. American Journal of Medical Genetics Part A. 2008; 146A:2998–3010. [PubMed: 19006076]

Rasmussen SA, Wong L-Y, Correa A, Gambrell D, Friedman JM. Survival in infants with Down syndrome, Metropolitan Atlanta, 1979–1998. The Journal of Pediatrics. 2006; 148(806–812):e801.

Riehle-Colarusso T, Strickland M, Reller M, Mahle W, Botto L, Siffel C, et al. Improving the quality of surveillance data on congenital heart defects in the metropolitan Atlanta congenital defects program. Birth Defects Research Part A: Clinical and Molecular Teratology. 2007; 79:743–753.

Roy SR, McGinty EE, Hayes SC, Zhang L. Regional and racial disparities in asthma hospitalizations in Mississippi. Journal of Allergy and Clinical Immunology. 2010; 125:636–642. [PubMed: 20226297]

Russo, CA.; Elixhauser, A. Hospitalizations for birth defects, 2004. US Agency for Healthcare Research and Quality (AHRQ); Rockville, MD: 2007. HCUP Statistical Brief #24

So SA, Urbano RC, Hodapp RM. Hospitalizations of infants and young children with Down syndrome: Evidence from inpatient person-records from a statewide administrative database. Journal of Intellectual Disability Research. 2007; 51:1030–1038. [PubMed: 17991010]

Strickland BB, Singh GK, Kogan MD, Mann MY, van Dyck PC, Newacheck PW. Access to the Medical Home: New Findings From the 2005–2006 National Survey of Children With Special Health Care Needs. Pediatrics. 2009; 123:e996–e1004. [PubMed: 19482751]

Thomas K, Bourke J, Girdler S, Bebbington A, Jacoby P, Leonard H. Variation over time in medical conditions and health service utilization of children with down syndrome. The Journal of Pediatrics. 2011; 158(194–200):e191.

Torfs CP, Christianson RE. Anomalies in Down syndrome individuals in a large population-based registry. American Journal of Medical Genetics. 1998; 77:431–438. [PubMed: 9632176]

van Trotsenburg ASP, Heymans HSA, Tijssen JGP, de Vijlder JJM, Vulsma T. Comorbidity, hospitalization and medication use and their influence on mental and motor development of young infants with Down syndrome. Pediatrics. 2006; 118:1633–1639. [PubMed: 17015556]

Weiss J, Kotelchuck M, Grosse SD, Manning SE, Anderka M, Wyszynski DF, et al. Hospital use and associated costs of children aged zero-to-two years with craniofacial malformations in Massachusetts. Birth Defects Research Part A: Clinical and Molecular Teratology. 2009; 85:925–934.

Yang Q, Rasmussen SA, Friedman JM. Mortality associated with Down's syndrome in the USA from 1983 to 1997: A population-based study. The Lancet. 2002; 359:1019–1025.

Zachariah P, Ruttenber M, Simões EAF. Down syndrome and hospitalizations due to respiratory syncytial virus: A population-based study. The Journal of Pediatrics. 2012; 160(827–831):e821.

Zollinger TW, Przybylski MJ, Gamache RE. Reliability of Indiana birth certificate data compared to medical records. Annals of Epidemiology. 2006; 16:1–10. [PubMed: 16039875]

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Table 1

Prevalence of post-birth hospitalization (PBH) for children with and without Down syndrome (DS) by sociodemographic characteristics, major birth defects and birth outcomes, Massachusetts.[a]

	Children with DS					Children without DS				
	Overall		≥1 PBH		PBH: RR^b within DS compared to reference	Overall		≥1 PBH[c]		PBH: RR^b between DS vs. non-DS
	n	%	*n*	%		*n*	%	*n*	%	
All children	504	100.0	236	46.8		468,600	100.0	48,518	10.4	**4.5 (4.1, 5.0)** ***
Maternal race/ethnicity										
NHB	41	8.2	16	39.0	0.9 (0.6, 1.3)	34,719	7.4	4417	12.7	**3.1 (2.1, 4.5)** ***
Hispanic	64	12.8	39	60.9	**1.4 (1.1, 1.7)** *	55,892	11.9	8771	15.7	**3.8 (3.2, 4.7)** ***
NHW	368	73.3	162	44.0	(reference)	338,948	72.4	31,135	9.2	**4.8 (4.3, 5.4)** ***
Delivery payer source										
Not private	154	30.6	80	52.0	1.2 (1.0, 1.4)	152,229	32.5	21,020	13.8	**3.8 (3.2, 4.4)** ***
Private	350	69.4	156	44.6	(reference)	316,356	67.5	27,498	8.7	**5.1 (4.6, 5.8)** ***
Sex										
Male	277	55.0	142	51.3	**1.2 (1.0, 1.5)** *	239,648	51.1	27,279	11.4	**4.5 (4.0, 5.1)** ***
Female	227	51.1	135	48.7	(reference)	228,950	48.9	21,239	9.3	**4.5 (3.8, 5.2)** ***
CHD[d]										
Yes	219	43.5	128	58.5	**1.5 (1.3, 1.9)** ***	1968	0.4	1010	51.3	**1.1 (1.0, 1.3)** *
No	285	56.6	108	37.9	(reference)	466,632	99.6	47,508	10.2	**3.7 (3.2, 4.3)** ***
OMBD										
Yes	77	15.3	45	58.4	**1.3 (1.1, 1.6)** *	729	0.2	402	55.1	**1.1 (0.9, 1.3)**
No	427	84.7	191	44.7	(reference)	467,871	99.8	48,116	10.3	**4.3 (3.9, 4.8)** ***
LBW										
Yes	105	21.0	59	56.2	**1.3 (1.0, 1.5)** *	33,798	7.2	5323	15.8	**3.6 (3.0, 4.2)** ***
No	394	79.0	175	44.4	(reference)	432,914	92.8	42,999	9.9	**4.5 (4.0, 5.0)** ***
PTB										
Yes	127	25.4	71	55.9	**1.3 (1.0, 1.5)** *	47,969	10.3	7117	14.8	**3.8 (3.2, 4.4)** ***

	Children with DS				PBH: *RR*[b] within DS compared to reference	Children without DS				PBH: *RR*[b] between DS vs. non-DS
	Overall		≥1 PBH			Overall		≥1 PBH[c]		
	n	**%**	***n***	**%**		***n***	**%**	***n***	**%**	
No	373	74.6	164	44.0	(reference)	418,502	89.7	41,178	9.8	**4.5 (4.0, 5.0)** ***

Note: Boldface figures highlight statistically significant comparisons.

Abbreviations: CHD, congenital heart defects; LBW, low birth weight (<2500 g); NHB, Non-Hispanic Black; NHW, Non-Hispanic White; OMBD, other major (non-cardiac) birth defects; PTB, preterm birth < 37 weeks completed gestation; ref., reference group; *RR*, relative risk.

[a] Births from 1999 to 2004, hospitalizations from 1999 to 2007.

[b] 95% confidence intervals in parentheses.

[c] $p < .0001$ for all within non-DS comparisons across characteristics.

[d] Presence of CHD for Down syndrome cases classified using *International Classification of Diseases, 9th Edition, Clinical Modification/British Pediatric Association* (ICD-9-CM/BPA) codes and review by clinician; non-DS cases classified using ICD-9-CM/BPA codes.

* $p < .05$.

** $p < .01$.

*** $p < .0001$.

† $p < .10$.

Table 2

Maternal racial/ethnic distribution by presence of congenital heart defects (CHD) among children with and without Down syndrome (DS), overall and with ≥ one post-birth hospitalization (PBH), Massachusetts.[a]

	PBH: *RR*[b] DS vs. non-DS	Children with DS				PBH: *RR*[b] within DS compared to reference	Children without DS			
		Overall		≥1 PBH			Overall		≥1 PBH[c]	
		n	%	*n*	%		*n*	%	*n*	%
CHD[d]										
NHB	1.2 (0.8, 1.7)	21	51.2	13	61.9	1.1 (0.8, 1.6)	185	0.5	95	51.4
Hispanic	1.2 (0.9, 1.5)	25	39.1	17	68.0	1.2 (0.9, 1.6)	252	0.5	149	59.1
NHW	1.1 (1.0, 1.3)	160	43.5	90	56.3	(reference)	1389	0.4	688	49.5
No CHD										
NHB	1.2 (0.2, 3.5)	20	48.8	3	15.0	0.4 (0.1, 1.3)†	34,534	99.5	4322	12.5
Hispanic	**3.6 (2.8, 4.8)** ***	39	60.9	22	*56.4*	**1.6 (1.2, 2.3)** *	55,640	99.5	8622	15.5
NHW	**3.8 (3.2, 4.6)** ***	208	56.5	72	*34.6*	(reference)	337,559	99.6	30,447	9.0

Note: Boldface figures highlight statistically significant comparisons.

Abbreviations: NHB, Non-Hispanic Black; NHW, Non-Hispanic White; *RR*–relative risk.

[a] Births from 1999 to 2004, hospitalizations from 1999 to 2007.

[b] 95% confidence intervals in parentheses.

[c] For non-DS CHD: $p < .05$ Hispanic vs. NHW; the NHB vs. NHW comparison was not significant. For non-DS no CHD: $p < .0001$ NHB vs. NHW and for Hispanic vs. NHW.

[d] Presence of CHD for Down syndrome cases classified using *International Classification of Diseases, 9th Edition, Clinical Modification/British Pediatric Association* (ICD-9-CM/BPA) codes and review by clinician; non-DS cases classified using ICD-9-CM/BPA codes.

* $p < .05$.

** $p < .01$.

*** $p < .0001$.

† $p < .10$.

Table 3

Mean and median number of days hospitalized per child with Down syndrome (DS) from birth to age three years by sociodemographic characteristics, major birth defects and birth outcomes, Massachusetts.[a]

	N	No. of days hospitalized at birth[b]		No. of days hospitalized post-birth[c]		No. of days hospitalized at birth & post-birth	
		Mean	Median	Mean	Median	Mean	Median
All Children	504	14.7	7.0	8.5	0.0	23.0	12.0
Race/ethnicity							
NHB	41	16.6	8.0	8.8	0.0	25.4	12.0
Hispanic	64	20.3	8.5	**15.7**	**5.0**	**36.0**	**20.0**
NHW	368	13.8	7.0	**7.3**	**0.0**	**21.1**	**11.0**
Delivery payer source							
Not Private	154	15.2	7.0	**12.2**	**2.0**	27.4	14.0
Private	350	14.5	7.0	**6.9**	**0.0**	21.4	12.0
Sex							
Male	277	15.5	8.0	**8.9**	**2.0**	**24.3**	**14.0**
Female	227	13.8	7.0	**8.1**	**0.0**	**21.8**	**10.0**
CHD							
Yes	219	**18.0**	**9.0**	**12.3**	**5.0**	**30.3**	**17.0**
No	285	**12.2**	**6.0**	**5.6**	**0.0**	**17.7**	**9.0**
OMBD							
Yes	77	**24.1**	**16.0**	**11.1**	**4.0**	**35.2**	**24.0**
No	427	**13.0**	**7.0**	**8.0**	**0.0**	**21.0**	**11.0**
LBW							
Yes	105	**29.2**	**18.0**	**11.3**	**3.0**	**40.6**	**29.0**
No	394	**10.9**	**6.0**	**7.8**	**0.0**	**18.6**	**10.0**
PTB							
Yes	127	**26.0**	**15.0**	**10.6**	**3.0**	**36.6**	**23.0**
No	373	**10.8**	**6.0**	**7.8**	**0.0**	**18.6**	**10.0**

Note: Boldface figures indicate significant Wilcoxon rank sum test ($p < .05$) differences among children with DS across characteristics.

Abbreviations: CHD, congenital heart defects; LBW, low birth weight (<2500 g); NHB, Non-Hispanic Black; NHW, Non-Hispanic White; OMBD, other major (non-cardiac) birth defects; PTB, preterm birth < 37 weeks completed gestation; ref., reference group.

[a] Births from 1999 to 2004, hospitalizations from 1999 to 2007.

[b] Birth hospitalizations include children who were readmitted or transferred to another acute care hospital <2 days following discharge from their initial birth hospitalization, as well as children readmitted <2 days following discharge from the transfer hospital.

[c] Up to age three years.

Table 4

Mean and median number of days hospitalized per child with and without Down syndrome (DS) from birth to age three years stratified by presence of congenital heart defects (CHD) across maternal race/ethnicity, Massachusetts.[a]

	No. of days hospitalized at birth[b]				No. of days hospitalized post-birth[c]				No. of days hospitalized at birth & post-birth				*N*	
	DS		No DS		DS		No DS		DS		No DS		DS	No DS
	Mean	**Median**	**Mean**	**Median**	**Mean**	**Median**	**Mean**	**Median**	**Mean**	**Median**	**Mean**	**Median**		
CHD	**18.0**	**9.0**	**17.4**	**6.0**	**12.3**	**5.0**	**10.2**	**2.0**	**30.3**	**17.0**	**27.7**	**13.0**	219	1968
NHB	23.5	17.0	**24.8**	**8.0**	16.0	6.0	11.4	2.0	**39.5**	**24.0**	**36.2**	**15.0**	21	185
Hispanic	24.8	9.0	17.7	5.5[d]	26.5	8.0	**12.8**	**3.0**	51.3	23.0	30.5	13.5[e]	25	252
NHW	16.8	9.0	**16.6**	**6.0** [d]	9.8	4.0	**9.6**	**0.0**	**26.6**	**16.0**	**26.2**	**13.0** [d]	160	1389
No CHD	**12.2**	**6.0**	**4.8**	**3.0**	**5.6**	**0.0**	**0.6**	**0.0**	**17.7**	**9.0**	**5.4**	**3.0**	285	466,632
NHB	9.3	6.0	**5.8**	**3.0** [d]	1.3	0.0	**0.8**	**0.0** [e]	10.6	6.0	**6.7**	**3.0** [e]	20	34,534
Hispanic	17.3	8.0	**4.9**	**3.0** [d]	**8.8**	**3.0**	**1.0**	**0.0** [d]	**26.1**	**18.0**	**5.9**	**3.0** [d]	39	55,640
NHW	11.5	6.0	**4.7**	**3.0** [d]	**5.4**	**0.0**	**0.5**	**0.0** [d]	**16.9**	**8.0**	**5.2**	**3.0** [d]	208	337,559

Note: Boldface figures indicate significant within-strata differences, Wilcoxon rank sum test $p < 05$.

Abbreviations: NHB, Non-Hispanic Black; NHW, Non-Hispanic White; No., number.

[a] Births from 1999 to 2004, hospitalizations from 1999 to 2007.

[b] Birth hospitalizations include children who were readmitted or transferred to another acute care hospital <2 days following discharge from their initial birth hospitalization, as well as children readmitted <2 days following discharge from the transfer hospital.

[c] Up to age three years.

[d] $p < .05$, DS vs. nonDS.

[e] $p < .10$, DS vs. nonDS.

Table 5

Differences by maternal race/ethnicity in reasons for hospitalization from birth to age three years among children with Down syndrome (DS), Massachusetts hospitalizations 1999–2007.

	N	Birth		Post birth		Post birth	
		All diagnoses		All diagnoses		Primary diagnoses	
		n	%	*n*	%	*n*	%
Diseases of the cardiovascular system	504	34	6.7	114	22.6	22	4.4
Non-Hispanic Black	41	4	9.8	**14**	**34.1** *	4	9.8†
Hispanic	64	5	7.8	15	23.4	4	6.3
Non-Hispanic White	368	23	6.3	**79**	**21.5**	12	3.3
Diseases of the respiratory system	504	15	3.0	161	31.9	122	24.2
Non-Hispanic Black	41	0	0.0	11	26.8	6	14.6
Hispanic	64	2	3.1	**32**	**50.0** **	**29**	**45.3** **
Non-Hispanic White	368	12	3.3	**107**	**29.1**	**78**	**21.2**
Diseases of the digestive system	504	27	5.4	108	21.4	29	5.8
Non-Hispanic Black	41	1	2.4	7	17.1	1	2.4
Hispanic	64	7	10.9†	21	32.8†,*a*	6	9.4
Non-Hispanic White	368	18	4.9	71	19.3	21	5.7
Infectious and parasitic diseases	504	166	32.9	85	16.9	13	2.6
Non-Hispanic Black	41	12	29.3	9	22.0	1	2.4
Hispanic	64	**13**	**20.3** *	15	23.4	2	3.1
Non-Hispanic White	368	**128**	**34.8**	54	14.7	7	1.9
Endocrine; nutritional; and metabolic diseases and immunity disorders	504	18	3.6	113	22.4	35	6.9
Non-Hispanic Black	41	0	0.0	10	24.4	3	7.3
Hispanic	64	3	4.7	**22**	**34.4** *	6	9.4
Non-Hispanic White	368	13	3.5	**73**	**19.8**	22	6.0

Note: Boldface figures highlight statistically significant comparisons.

a Combining birth & post-birth diagnoses results in $p < .01$.

* $p < .05$.

** $p < .01$.

*** $p < .0001$.

† $p < .10$.

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Table 6

Costs[a] associated with hospitalizations from birth to age three years among children with Down syndrome (DS) by sociodemographic characteristics, major birth defects and birth outcomes, Massachusetts.[b]

	N[c]	Birth hospitalization only				PBH to three years				Birth and PBH			
		Total	Mean	Median	95th percentile	Total	Mean	Median	95th percentile	Total	Mean	Median	95th percentile
Total DS	504	10,477,190	20,788	8589	88,065	9,720,443	19,287	0	91,822	20,197,634	40,075	15,811	160,099
Total non-DS	468,600	1,604,110,777	3423	1099	7832	505,904,543	1080	0	3606	2,110,015,320	4503	1188	12,970
Children with DS													
Race/ethnicity													
NHB	41	959,018	23,391	10,170	82,969	1,147,024	27,976	0	122,838	2,106,042	51,367	18,495	222,740
Hispanic	64	1,468,067	22,939	8677	107,563	1,519,356	23,740	6888	66,699	2,987,422	46,679	22,781	204,907
NHW	368	7,605,514	20,667	8589	88,065	6,592,318	17,914	0	94,275	14,197,832	38,581	13,947	153,245
Delivery payer source													
Not private	154	2,814,721	18,277	6898	91,973	3,476,721	22,576	1969	91,519	6,291,442	40,854	16,521	176,434
Private	350	7,662,470	21,893	9222	88,065	6,243,722	17,839	0	94,275	13,906,192	39,732	15,702	155,970
Sex													
Male	277	6,318,082	22,809	9499	96,433	5,645,509	20,381	1042	94,275	11,963,591	43,190	18,625	173,847
Female	227	4,159,108	18,322	7779	85,546	4,074,934	17,951	0	84,594	8,234,043	36,273	12,651	153,245
CHD													
Yes	219	6,218,628	28,396	11,074	119,977	7,193,125	32,845	5339	143,575	13,411,753	61,241	39,418	250,179
No	285	4,258,562	14,942	5980	49,840	2,527,318	8868	0	46,066	6,785,881	23,810	10,730	100,846
OMBD													
Yes	77	2,653,886	34,466	21,659	102,526	2,016,372	26,187	8305	103,738	4,670,259	60,653	37,765	191,841
No	427	7,823,304	18,322	7526	69,795	7,704,071	18,042	0	88,308	15,527,375	36,364	13,193	145,647
LBW													
Yes	105	4,258,862	40,561	17,499	173,847	2,616,621	24,920	3158	107,182	6,875,483	65,481	39,789	236,995
No	394	6,044,530	15,341	6761	50,651	6,961,629	17,669	0	88,308	13,006,159	33,011	12,791	125,651
PTB													
Yes	127	4,693,935	36,960	16,274	173,847	2,808,147	22,111	4770	91,519	7,502,081	59,072	35,498	210,694
No	373	5,730,403	15,363	6578	47,587	6,818,022	18,279	0	91,822	12,548,425	33,642	12,236	144,006

Abbreviations: CHD, congenital heart defects; LBW, low birth weight (<2500 g); NHB, Non-Hispanic Black; NHW, Non-Hispanic White; OMBD, other major (non-cardiac) birth defects; PBH, post-birth hospitalization; PTB, preterm birth < 37 weeks completed gestation.

[a] Costs in 2011 US dollars.

[b] Births from 1999 to 2004, hospitalizations from 1999 to 2007.

[c] *N* is for all children in study population, but birth hospitalization cost data was missing for 16 children without DS, so the mean will not exactly equal *N*/total.