



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



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ABSTRACT

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.

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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, & Frias, 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

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