Health Inequity in Children and Youth With Chronic Health Conditions

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**KEY WORDS**
children, chronic disease, disability, disparity, epidemiology, incidence, prevalence, survival, special needs

**ABBREVIATIONS**
CYSHCN—children and youth with special health care needs
ADHD—attention-deficit/hyperactivity disorder
CP—cerebral palsy
CF—cystic fibrosis
DM—diabetes mellitus
SCA—sickle cell anemia
TBI—traumatic brain injury
CDG—Centers for Disease Control and Prevention
CI—confidence interval

www.pediatrics.org/cgi/doi/10.1542/peds.2010-1466D
doi:10.1542/peds.2010-1466D

Accepted for publication Sep 1, 2010

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**FINANCIAL DISCLOSURE:** The authors have indicated they have no financial relationships relevant to this article to disclose.

**abstract**

**BACKGROUND:** Over the last decades, there have been great advances in health care delivered to children with chronic conditions, but not all children have benefitted equally from them.

**OBJECTIVES:** To describe health inequities experienced by children with chronic health conditions.

**METHODS:** We performed a literature review of English-language studies identified from the Medline, Centers for Disease Control and Prevention, National Cancer Institute, and Cystic Fibrosis Foundation Web sites that were published between January 1985 and May 2009, included children aged 0 to 18 years, and contained the key words “incidence,” “prevalence,” “survival,” “mortality,” or “disparity” in the title or abstract for the following health conditions: acute leukemia, asthma, attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorders, cerebral palsy, cystic fibrosis, diabetes mellitus, Down syndrome, HIV/AIDS, major congenital heart defects, major depressive disorder, sickle cell anemia, spina bifida, and traumatic brain injury.

**RESULTS:** Black children had higher rates of cerebral palsy and HIV/AIDS, were less likely to be diagnosed with ADHD, had more emergency department visits, hospitalizations, and had higher mortality rates associated with asthma; and survived less often with Down syndrome, type 1 diabetes, and traumatic brain injury when compared with white children. Hispanic children had higher rates of spina bifida from Mexico-born mothers, had higher rates of HIV/AIDS and depression, were less likely to be diagnosed with ADHD, had poorer glycemic control with type 1 diabetes, and survived less often with acute leukemia compared with white children.

**CONCLUSIONS:** Serious racial and ethnic health and health care inequities persist for children with chronic health conditions. *Pediatrics* 2010;126:S111–S119
One in 6 US children and youth has a chronic medical condition or disability, and many of these conditions seriously impair their function. Over the past 25 years, great gains in health care delivered to children and youth with special health care needs (CYSHCN) have resulted from improved identification and classification of disabling conditions, new medical and surgical interventions, the Individuals With Disabilities Education Act, and the promotion of school and community inclusion programs. CYSHCN are finding new opportunities in the adult world with increased educational, work, and recreational supports and inclusionary programs.

Despite this good news, many CYSHCN do not reap all the benefits of these advances as a result of socioeconomic, racial, and ethnic health disparities. Black children have higher disability rates than white children. Minority CYSHCN are less likely to have a usual source of care or receive care within a medical home and are more likely to use emergency care. Minority children with asthma are 40% to 100% more likely to be hospitalized for asthma. In 2003, the Institute of Medicine report, Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, provided significant insight into adult health disparities but had minimal focus on children. This report elicited commentaries on the need to increase awareness and provide a framework for a research agenda in child health disparities.

In 2005, the National Institute on Disability and Rehabilitation Research funded the Opening Doors Project to improve health and educational equity for CYSHCN from minority and underserved communities. The project is a collaborative effort that has involved the Institute of Community Inclusion at the University of Massachusetts (Boston), Children’s Hospital Boston, 10 community-based organizations, and the Parent Advocacy Coalition for Educational Rights Center (Minneapolis, MN). Opening Doors research focuses on issues related to health and developmental disparities, specifically (1) early identification of childhood disability in various racial and ethnic populations, (2) community inclusion of CYSHCN from traditionally underserved communities in exercise and fitness programs, and (3) college entrance for youth with disabilities and special health care needs from urban environments, focusing on health issues in the college environment. In addition, Opening Doors sponsors training and dissemination activities to improve health and developmental services for underserved communities.

In this article we present key findings from a comprehensive literature review to help inform the Opening Doors research agenda. We present recent prevalence and survival data on children and youth with selected chronic medical conditions, examine trends in prevalence data over time when possible, and describe health disparities among the conditions.

METHODS

We reviewed studies on acute leukemia, asthma, attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorders, cerebral palsy (CP), cystic fibrosis (CF), diabetes mellitus (DM), Down syndrome, HIV/AIDS, major congenital heart defects, major depressive disorder, sickle cell anemia (SCA), spina bifida, and traumatic brain injury (TBI). We selected these conditions as descriptive examples of sources of special health care needs and disabilities while recognizing that they are not all-inclusive or representative of all childhood chronic health conditions.

We searched the Medline (www.pubmed.org), Centers for Disease Control and Prevention (CDC), National Cancer Institute, and Cystic Fibrosis Foundation Web sites. We identified condition-specific articles on the basis of Medical Subject Heading and keyword searches. Two independent reviewers then reviewed the titles and abstracts of English-language articles generated by the condition searches that were published between January 1985 and May 2009, included children aged 0 to 18 years, and contained the key words “incidence,” “prevalence,” “survival,” “mortality,” or “disparity” in the title or abstract. The reviewers preferentially reviewed articles in which studies with national US settings (as opposed to those with local or regional settings) and those with primary data (original data on the condition’s epidemiology or disparities) were described. Given the small number of articles that met our inclusion criteria for each condition, we did not perform a meta-analysis. We present here descriptive data for each condition.

RESULTS

Summarized epidemiology and health-disparity data for each condition are presented in Table 1 and Fig 1.

Acute Leukemia

The Surveillance, Epidemiology, and End Results of the National Cancer Institute has reported an acute leukemia incidence range for children and youth aged 0 to 19 years of 2.8 to 3.4 per 100,000 in 2000–2003. The acute leukemia prevalence for children aged 10 to 19 was 25.4 per 100,000. The acute lymphoblastic leukemia incidence was higher in white children aged 1 to 4 (9.4 per 100,000) than black children (4.0 per 100,000).

In the 1980s, an estimated 40% of children with acute leukemia survived to the age of 5 years. By 2002, >83% of children with acute leukemia survived at least 5 years after diagnosis.
panic children have had poorer 5-year survival rates than non-Hispanic white children.13

Asthma

Asthma prevalence in the United States has increased in the last 3 decades. The National Health Interview Survey revealed an asthma prevalence of 3.6% in the 1980s and 6.2% in 1996 among all children.14 The Third National Health and Nutritional Examination Survey reported an asthma prevalence of 6.7% in 1994.15

Recent CDC estimates of asthma prevalence have shown wide racial variation.16 The prevalence of asthma among all children in 2004–2005 was 8.7%; however, the rate was 12.7% in non-Hispanic black children, 19.2% in Puerto Rican children, and 8.0% in non-Hispanic white children. Asthma care and outcomes also varied considerably according to race. Non-Hispanic black children were 2.6 times more likely to have an emergency department visit, 2.0 times more likely to be admitted to the hospital, and almost 5.0 times more likely to die of asthma than non-Hispanic white children.16

ADHD

The CDC estimated that the prevalence of ADHD among 6- to 17-year-olds was higher than 8% in 2006.17 The prevalence of ADHD between 1997 and 2006 was 6.5%.17 The CDC study17 and other nationally representative studies18,19 have revealed that ADHD prevalence is highest among poor children. Froehlich et al18 reported an adjusted odds ratio of ADHD prevalence of 2.3 (95% confidence interval [CI]: 1.4–3.9) for the poorest quintile compared with the wealthiest quintile. In addition, poor children were less likely than their wealthier peers to be treated consistently with medication (odds ratio: 3.4 [95% CI: 1.3–9.1]).18 Children with Medicaid coverage have been more likely to be diagnosed with ADHD (12%) than those with private insurance (8%).17 Furthermore, black children have shown more ADHD symptoms than non-Hispanic white children, but they have been diagnosed with ADHD only two-thirds as often as non-Hispanic white children.19

Autism Spectrum Disorders

Since 1991, the incidence and prevalence of autism and pervasive developmental disorder (autism spectrum dis-
Cerebral Palsy

One-year-old children in metropolitan Atlanta, Georgia, had a 15% increase (170 to 200 per 100,000) in the prevalence of CP between 1975 and 1991. The CP prevalence in 8-year-old children has been reported as 310 to 360 per 100,000. CP prevalence has been highest among black term infants and black male children (410 per 100,000). Severity of illness influences CP survival rates; in 1 study, 80% of children with CP who could feed themselves survived to the age of 16 compared with 20% who were nourished with a feeding tube. Results of some studies have shown that up to 99% of children with mild CP survive to adulthood.

Congenital Heart Disease

The aggregate birth prevalence of major congenital heart disease, including hypoplastic left heart syndrome, transposition of the great arteries, truncus arteriosus, total anomalous pulmonary venous return, and tetralogy of Fallot, has been reported as 105 per 100,000. In the early 1980s, the expected survival rate to the age of 20 of children with major congenital heart disease who required cardiac surgery was 20%. Authors of more recent studies reported improved long-term survival rates: in 1 study, 39% of children with hypoplastic left heart syndrome survived to the age of 15 years, and in another study, 89% of the children with tetralogy of Fallot survived to the age of 20 years. Shorter survival times have been reported for black children with transposition of the great arteries and tetralogy of Fallot than for white children. Black children have waited longer for stages II and III of surgical palliation for single-ventricle physiology than children of other racial/ethnic groups.

Cystic Fibrosis

The authors of 2 recent state and 1 national registry study reported a CF incidence rate of 25 to 29 per 100,000. In the early 1980s, 60% of children with CF were expected to survive to the age of 20. More recently, children with CF have been shown to survive a median of 37 years. Health outcomes for children with CF are related to their socioeconomic characteristics; for children with CF in families with an annual income lower than $20,000, a 44% increased risk of death has been shown compared with children in families with an income of $50,000 or higher. In another study, patients with CF who had Medicaid coverage had poorer lung function and required more hospitalizations for pulmonary exacerbations than more socioeconomically advantaged children.

Depression

The point prevalence of major depression in adolescents between the years 1987 and 1994 ranged from 2600 to 4300 per 100,000, and the 30-day prevalence was 5800 per 100,000; the lifetime prevalence for adolescents and young adults was 7500 to 40,000 per 100,000. Higher rates of depression have been reported for Hispanic white adolescents than for non-Hispanic white adolescents. Results of 2 other studies indicated that fewer black children with depression symptoms use mental health services than white children.

Diabetes Mellitus

The prevalence of DM (types 1 and 2 combined) for children and youth aged 0 to 18 years increased from 183 per 100,000 in 1998 to 218 per 100,000 in 2002. In 2005, the DM prevalence in children and young adults aged 0 to 20 years was reported as 220 per 100,000. From 1999 to 2002 the DM prevalence in adolescents aged 12 to 19 was 355 (type 1) and 145 (type 2) per 100,000.

Results of a 2007 study revealed that for 15- to 19-year-olds, the incidence (per 100,000 person-years) of DM type 1 was 15.1 (95% CI: 13.2–17.1) for non-Hispanic white youth compared with 12.1 (95% CI: 9.1–16.4) for Hispanic youth and 11.1 (95% CI: 8.1–15.1) for black youth. The situation was reversed for 15- to 19-year-olds with DM type 2; the rate was 5.6 (95% CI: 4.5–6.9) for white youth, 17.0 (95% CI: 13.3–21.8) for Hispanic youth, and 19.4 (95% CI: 15.3–24.5) for black youth. DM type 1 rates were shown to be lower in Asian/Pacific Islanders (6.8 [95% CI: 4.0–11.5]) and American Indians (4.8 [95% CI: 1.7–13.2]); however, rates of DM type 2 have been much higher (22.7 [95% CI: 16.9–30.4] in Asian/Pacific Islanders and 49.4 [95% CI: 35.6–68.5] in American Indians). Black and Hispanic children with DM type 1 had poorer glycemic control, and blacks survived less often compared with non-Hispanic whites.
Down Syndrome
The prevalence of Down syndrome in the United States from 1989 to 1996 was ~120 per 100 000 live births compared with 140 per 100 000 in the 1980s. State-based prevalence estimates have ranged from 87 to 158 per 100 000. Variation in prenatal diagnosis and pregnancy-termination rates may help explain these differences.

National birth defects monitoring has suggested that the Down syndrome birth prevalence is higher in Hispanic children and lower in black than in non-Hispanic white children. The CDC reported that the mean age of death for white patients with Down syndrome is 50 years compared with 25 years in black patients.

HIV/AIDS
The CDC has reported 9443 cumulative cases of AIDS among children younger than 13 years from the beginning of the epidemic in the mid-1980s through 2004. Mother-to-child transmission was the infection mode in 93% of cases. Among children younger than 13 years with HIV, non-Hispanic white children represented only 17% of cases; in contrast, 23% were Hispanic and 60% were non-Hispanic black. Asian Pacific Islander and Native American children accounted for <1% of HIV cases.

Since the beginning of the HIV epidemic, 40 059 youth aged 13 to 24 years have been infected with HIV. Each year, ~2500 adolescents and young adults are newly diagnosed with HIV/AIDS. As of 2005, nearly 20 000 people aged 13 to 24 years were living with HIV/AIDS. In 2006, the rate of new HIV infections per 100 000 for ages 13 to 29 years was 18.1 in white males, 123.3 in black males, 4.9 in white females, and 53.6 in non-Hispanic black females.

Sickle Cell Anemia
The birth prevalence of SCA reportedly ranges from 8.9 to 22.5 per 100 000 live births, which is comparable with the 1984 rate of 28 per 100 000 live births. Rates of survival to the age of 20 years has increased from 79% of children born before 1975 to 89% of children born after 1975. Gortmaker and Sappenfield estimated that the rate of survival to the age of 20 in 1984 was 90%. Rural patients with SCA have reported more limitations in physical functioning than urban patients.

Spina Bifida
After folic-acid fortification, neural-tube defect (including spina bifida) birth prevalence decreased from 24.9–37.8 to 20.1–30.5 per 100 000 live births. Prevalence also decreased when fetal deaths and elective terminations for prenatally determined spina bifida were included in prevalence rates. Mexico-born women in the United States have a two-fold higher risk of neural-tube defect–affected pregnancies, possibly because of unfortified diets. In the early 1980s, ~50% of children with spina bifida survived to the age of 20, compared with 80% to 85% today.

Traumatic Brain Injury
The TBI prevalence rate for children who require hospitalization has been reported as 63 per 100 000 children aged 0 to 14 years to 70 per 100 000 children aged 0 to 17 years. The prevalence of TBI in children who require an emergency department visit has been reported to be much higher: 57 to 69 per 100 000 children aged 0 to 14 years. TBI incidence in children who require ongoing health services related to the injury after hospital discharge was 5 per 100 000 in 1984. Long-term survival (to the age of 50 year) rates of children aged 17 with TBI were estimated to be 50% (severe impairment) to 95% (no or mild impairment). According to a 2005 study, black children experience more TBI-related hospitalizations and have a higher TBI-related mortality rate than white children.

DISCUSSION
This report highlights the importance of improving health care and outcomes for CYSHCN across racial, ethnic, and social groups and demonstrates the critical need for ongoing, candid epidemiology research within the framework of health-disparities investigation for CYSHCN. The low incidence and prevalence of certain rare childhood chronic illnesses may increase the challenge of identifying racial and ethnic variations in prevalence, access to care, and outcomes, but health disparities in children with acute leukemia, CF, and TBI have become more obvious after the creation of national registries and databases with health information on many children. Maintaining aggregated national demographic and health-outcomes data on CYSHCN who have rare illnesses is critical for identifying and understanding their health disparities, especially among Asian Americans, Native Americans, children from multiracial families, and members of many other racial/ethnic subgroups that are typically understudied. Studies described in this report have shown that many of the general health disparities experienced by minority children may increase the likelihood that those with a chronic illness or disability will experience condition-related health disparities. For example, just as life expectancy is higher for white than black infants and children, it is also higher for white children with acute leukemia, asthma, DM type I, Down syndrome, and TBI than for black children. Black children are more
likely to be born prematurely and at a lower birth weight, which possibly explains their higher rates of neurodevelopmental disabilities, including ADHD and CP. Higher asthma prevalence is related to diet quality, which may be substandard in poorer neighborhoods. Identifying and labeling disease-specific disparities is a small step toward developing a national plan to achieve child health equity. Results of previous studies have suggested that the earlier disabilities are identified, the more appropriate the response from the family, professionals, and the community. Furthermore, disease-specific health-disparity information may attract attention from clinicians who routinely care for children with the disease and contribute to the development of intervention strategies to reduce these disparities.

Any approach to disparity prevention for CYSHCN must take into account the multiplicity of contributing causes. For example, a black child with Down syndrome might benefit from a medical home that offers continuous, coordinated, family- and community-based comprehensive care delivered in a culturally appropriate manner and helps to overcome health care access barriers for that child. Understanding that the child has a risk of decreased life expectancy might prompt the medical home clinicians to enhance the child’s Down syndrome health care maintenance, screening, and preventive care. In addition, medical home clinicians, especially those with cross-cultural training, are likely to spend more time learning about the family’s cultural beliefs, approaches to disability, understanding, and expectations. Such clinicians are more likely to provide parents with educational materials in the appropriate language and with appropriate cultural understanding. They may also be more likely to identify and address the socioeconomic and cultural barriers (such as transportation obstacles, inconvenient hours for health care visits, or cultural beliefs and community customs) that influence the child’s health and well-being.

This report illuminates the serious and persistent problem of health inequity in CYSHCN and provides a stimulus to develop strategies that will help to overcome socioeconomic, racial, and ethnic disparities among children with chronic health conditions. In the Opening Doors Project, we found that this information helped focus our efforts, particularly with respect to increasing access and cultural understanding and removing language barriers.

CONCLUSIONS
Chronic health conditions, treatment, and outcomes are not evenly distributed among US children; in general, children of racial or ethnic minorities have greater health burden and experience poorer outcomes than white children. The results of this review indicate that we have a long way to go to ensure that all children, regardless of race or ethnicity, have comparable health burdens and receive the best health and developmental services available.

ACKNOWLEDGMENTS
This work was supported by National Institute on Disability and Rehabilitation Research grant H133B060012 and the HSC Foundation (Washington, DC).

We thank James Perrin, MD, Naomi Sacks, MA, Veronica Palmer-Segal, BA, Berna Kahrama, MS, Amy Yang, and Morgan Crossman for help with the background analysis for this article.

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