



## Mini-Symposium: Pulmonary Complications Paediatric Systemic Disorders

## Healthcare Inequalities in Paediatric Respiratory Diseases

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## EDUCATIONAL AIMS

- To recognise the impact of health outcome disparities in respiratory disease
- To understand the role of socioeconomic status (SES), environmental and molecular causes of differential health outcomes
- To identify opportunities to reduce health care disparities in practice

## ARTICLE INFO

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## SUMMARY

Identifying that health inequalities exist is not enough; nor does the knowledge that a patient has a high-risk genotype or comes from a higher risk socioeconomic background does not, by itself, help the patient. To thoroughly examine the origins of health disparities, a broad view of environmental and molecular influences must be included. As these factors are identified, it is important to focus on interventions that can change outcomes for patients. Tools for education, community involvement, literacy, and environmental safety need to be developed, tested and disseminated. The basic science of health disparities must move forward in a coordinated fashion by structuring research that is an integrated effort between basic sciences, clinical medicine and include all traditionally underserved communities. Only through these collaborations can we hope to eliminate health inequalities in the future.

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## INTRODUCTION

Health care inequalities exist across all of medicine. This is of paramount importance to paediatric pulmonary medicine due to the heavy burden of respiratory disease among children. This writing aims towards examining the risks associated with factors, including socioeconomic status, health care literacy, environmental influences, cultural barriers, and race and ethnicity and those biological aspects that also influence outcomes. By approaching health disparities in an integrated, multi-factorial way, targeted interventions can be developed to improve outcomes for children suffering from pulmonary diseases.

This article reviews the literature on health outcome disparities as these relate to preterm birth/chronic lung disease of infancy, asthma and cystic fibrosis (CF). In chronic lung disease of infancy (prematurity) health inequality affects not only the paediatric patient but also underscores how inequalities in maternal health impact the health of the child. Asthma is an example of a heterogeneous multi-factorial genetic disease that has multiple factors affecting outcomes and no single aetiology. Although CF is a classic Mendelian disease caused by a single gene defect, a wide

range of outcomes exists largely independent of that defect. An appraisal of these diseases in various populations can help understand what factors affect outcomes and thereby provide a framework for further interventional studies.

*Socioeconomics and Beyond*

Lower socioeconomic status is often the most influential risk factor for poor health outcomes in acute and chronic disease. However, it is important to move beyond merely identifying it as a risk factor and rather, understand what qualities related to poverty exacerbate illness.

Different factors associated with SES impact health in different ways; for example, family income affects financial resources and maternal education influences disease self-management abilities. Much of the information on these parameters may not have even been collected in secondary data sources, which leads to the use of proxy measures, such as insurance status and median income by geographic location. As a result, these gross proxy measures are broad conclusions, which may overlook crucial underlying factors that worsen outcomes and exacerbate the difficulties in identifying easily manipulable factors.

Beyond the physical environment in which patients live are other environmental factors that influence their health status, such as family income, cultural influences, healthcare access, literacy,

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and community interactions, which, in turn, affect immunisation rates, emergency room utilisation, and the incidence of cancer and obesity.<sup>1</sup> How these environmental factors interact with molecular factors, such as genetic variability and predispositions and inflammatory profiles is key to developing a truly comprehensive approach to health disparities. It is evident from current research that outcome inequalities are multi-factorial and involve the simultaneous interaction of many influences: external and internal, unchangeable and controllable.

#### *The Scope of Disparity*

The National Vital Statistics Report from the Centers for Disease Control and Prevention (CDC) in the United States informed that in 2008, 12.3% of all births were premature births. These births have an annual social cost estimated to be at least \$26 billion dollars, according to the Society of Maternal and Fetal Medicine. Globally, it is estimated that 9.6% (12.9 million) of all births were preterm in 2005. This burden is not distributed equally among regions with approximately 85% (10.9 million) of preterm births concentrated in Africa and Asia. Latin America and the Caribbean accounted for 0.9 million preterm births and Europe and North America followed with each having approximately 0.5 million preterm births.<sup>2</sup> These infants often develop pulmonary complications of prematurity and are at increased risk for respiratory conditions beyond the neonatal period. By first addressing preterm births by encouraging adequate prenatal care, the morbidity associated with chronic lung disease of prematurity can be indirectly reduced.

According to the World Health Organization 300 million people worldwide suffer from asthma with a global prevalence of 1% to 18%. Scotland, Jersey, Guernsey and Wales have the highest prevalence of asthma among children at over 30%. However, asthma case fatality rates are highest in China, Russia, Uzbekistan, Albania and South Africa.<sup>3</sup> In the US, the CDC reports that 9.6% (7.1 million) of children have asthma. Children living in below the poverty threshold are more likely to have ever been diagnosed with asthma (18%) or to still have asthma (14%) than children in families that were not below the poverty threshold (13% and 8%). In North America, hospitalisation rates for minorities are 150% higher than for white children. Non-Hispanic white children are less likely to have been diagnosed with asthma (12%) compared to non-Hispanic black children (22%) or compared to Hispanic children (13%).<sup>4</sup>

In comparison to 12.9 million preterm births and 300 million people worldwide with asthma, CF affects approximately 70,000 people worldwide, 30,000 of those in the United States. About 1 in every 2,000–3,000 children born in the US and the European Union are affected with CF. Although CF affects a much smaller population; it is associated with substantial morbidity and mortality. A monogenic autosomal recessive disease, the severity of CF is partially correlated with the severity of the cystic fibrosis transmembrane conductance regulator (CFTR) defect; however, there is marked variability in health outcomes of CF patients with the same CFTR mutations. These outcome differences have been attributed to environmental and genetic variability.<sup>5</sup> Previous research has shown that low SES and also Hispanic ethnicity (even when independent of SES) are both associated with worse lung function and a steeper rate of pulmonary decline.<sup>6</sup> According to the 2009 CF Foundation Patient Registry, the number of minority patients with CF is increasing and is over 10% of the US CF population. With the adoption of CF newborn screening and the rapidly changing demographics in the US, the number of Hispanic and African American patients with CF is predicted to increase proportionally. Given the increased rate of poverty in these populations paired with the independent risk associated with

ethnicity it is important to understand the impact of SES and culture on cystic fibrosis, as well as genetic variation.

#### *Access to Care and Utilization of Health Services*

Race-stratified models have shown that disparities in preterm births occur as a result of inadequate prenatal care, as the result of lack of access or utilisation.<sup>7</sup> Differential use of health care resources not only includes the neonatal period but also extends beyond it. Regional differences in perinatal mortality in the Netherlands were attributed to differences in health care delivery.<sup>8</sup> Neonatal intensive care unit admissions have been shown to vary according to socioeconomic group with the lowest socioeconomic quintile having the most admissions.<sup>9</sup> Controlling for medical complications, the use of accepted respiratory medications after NICU discharge differs between racial and ethnic groups with African American infants being 4 times more likely to receive oral beta-agonists than non-African American infants and Hispanic infants receiving less inhaled medications than white, non-Hispanic children.<sup>10</sup> African American infants and low SES infants received RSV prophylaxis less often in extremely low birth weight neonates in the first year of life than other racial or ethnic groups.<sup>11</sup> The cause for these differential practices is unknown; however is an area amenable to intervention. Standardising discharge protocols, assuring that evidence-based medicine is followed regardless of race/ethnicity or SES would be the first step in eliminating disparities at this level.

For children with asthma, a medical home provides support, treatment, and teaching critical for adequate control. The use of an urgent care model for asthma negatively affects outcomes. Lacking an asthma care specialist or an asthma action plan has been associated with a higher rate of acute asthma exacerbations.<sup>12</sup> In the US, African American and Hispanic children with asthma are hospitalised more often than white children, and they more frequently utilise emergency departments.<sup>13</sup> These last-resort, emergency facilities often become the primary means of obtaining medical attention for a child's asthma symptoms for those from lower-income families. An Italian study showed that children from disadvantaged backgrounds were hospitalised more frequently and did not make regular use of spirometry.<sup>14</sup> Race/ethnicity correlates with the overuse of urgent care, even after adjusting for insurance, symptom severity, and socioeconomic factors. Providing a medical home for paediatric patients with asthma is an important step to improving asthma care.

It is important to note that access to treatment includes more than access to a medical professional; a patient or family's ability to obtain prescribed treatment is an important component of self-management. This financial burden may cause low-income families to choose between medications and other basic living needs, leading to gaps in medical management. Access to healthcare services may also be limited in obtaining appropriate testing and diagnostics in a timely manner. Assessment and testing for allergic triggers and the implementation of environmental control measures occur less often in low and middle income households and also among minority children.<sup>15</sup>

In diseases such as asthma, access to quality care is key component in health outcomes. Conversely, in CF it is estimated that over 85% of US CF patients are seen at Cystic Fibrosis Foundation accredited CF care centers, which standardises the use of the best practices, thus minimising variability in care. Given the high standard of care for CF, early diagnosis is key to improved outcomes. Although the possibility of CF is universally investigated across the US, newborn screen protocols differ by state – in addition to accuracy, logistics, and cost. Depending on the diagnostic methodology chosen, false negatives may disproportionately affect the minority population and result in a health

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