

Young Children with Special Health Care Needs: Practice and Policy in the 21st Century

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- **A Noncategorical Approach to Chronic Illness in Family and Community: Diagnosing Asthma in Preschool Children**

Madeleine Ullman Shalowitz

- **Helping Children Succeed: What Does Genetics Have to Do With It?**

Marilyn C. Dumont-Driscoll

Ullman Shalowitz: A biomedical outcome will usually focus on disease, apply a treatment to that disease, and look at how the treatment affects the outcome. Asthma in the child occurs in the context of the child's temperament and unique experience of childhood; how he or she looks, feels, and behaves. Much information about children is from the parent's perspective, processed through the quality of that relationship, and influenced by the parents' own experiences of being parented with chronic illness, or exposure to someone else who was hospitalized or who died. Parents and children live within a larger ecological model of the family, community, and school.

In the face of stress and support, the family and its relationships vis-à-vis each other, the family, and community periodically shift in response to their environment. In a noncategorical model of pediatric chronic illness, everything else is not specific to the disease in question. The family exists in its larger context and in its relationships, whether there is a chronic illness or not, and regardless of which chronic illness it is. Disease-specific characteristics are important but, in fact, the larger context equally drives outcomes.

This framework will be applied to describe a noncategorical approach to chronic illness, focusing on asthma in school-aged children. Maternal life stress profiles will then be analyzed over time, and how those stresses relate to how sick the child is. Finally, maternal mental health will be related to having a child with asthma. The greatest increase in asthma prevalence over the course of the 1980s and 1990s was among children ages zero to 4, at 68 children per thousand. Since asthma is rarely diagnosed prior to 18 months of age, the incidence is mainly among children approaching 2 years of age, just as they begin preschool.

A study was recently completed among 5- to 12-year-olds in Chicago. A primary screening for asthma was conducted for every child in school, using a questionnaire sent home to the parents. The schools targeted were low income and racially heterogeneous, and were in transition zones at the borders of neighborhoods. The first question in a simple screen was whether a doctor or a nurse ever told the parent that their child had asthma, followed by four questions about respiratory symptoms. Ninety percent of the parents responded to the questionnaire that was sent home. The study sought to recruit families for a longitudinal project, and roughly half of them said that they would be interested. The ages of children in the survey are kindergarten through

grade six, with a mean age of about 10 years, evenly split between boys and girls. A quarter of the surveys were in Spanish; the survey is translated and validated in Spanish.

The schools thought that their numbers for asthma were about three percent, but the rates are much higher. The study found a higher prevalence of asthma than reported in the national statistics, but almost an equal number of children, 14%, at risk for asthma based on respiratory symptoms. Over a quarter of the children have respiratory symptoms that may or may not have been diagnosed. Also documented are the racial and ethnic disparities among children with asthma, even though they are all in low-income neighborhoods. The literature does not clearly delineate whether the excessive asthma is a low-income phenomenon or a race phenomenon; but the race disparity does persist, regardless of controlling for the neighborhood.

Among African-Americans, about 18% of the children had potential for asthma diagnosis, while Latinos and Whites were similar at 10%. The study also looked at life stress profiles based on life stresses over a 12-month period, looking at the relationship of those profiles to asthma symptoms and health care use. A variable was created that represented asthma morbidity by looking at clusters of people, including those who have experienced many symptoms, high levels of health care use, hospitalization, and high morbidity. This was validated against the clinical judgment of an asthma specialist using the children's medical records.

Alterations in physiological states are associated with a variety of health outcomes, including preterm labor, asthma onset, and metabolic syndrome, because of its association with diabetes, cardiovascular disease, and hypertension. Some data show that children who experience marital discord in their 1st year of life are more likely to develop asthma by age 3, and that early violence exposure is associated with an allergic profile in the first 3 years of life. In the study, 26% of respondents in these low-income, but not very poor, neighborhoods felt unsafe. There were also high rates of family members and friends of respondents dying within a 12-month period, representing the high amount of stress activity in people's lives.

Moderate to severe asthma morbidity was related to higher numbers of stressors at each time point studied. Of the children who were most ill, 60% of them were in the high stress profile. There is a statistically significant distribution of the high stress profile to the more significant asthma morbidity. Within this group, almost 60% of the children have moderate to severe asthma. Mothers of children with asthma also have high rates of depression symptoms, but these symptoms are generally high in low-income mothers, and asthma is common among low-income minorities. The literature also shows that having a child with asthma increases the risk of depression in the mother. Spanish-speaking Latinos seem to have more symptoms of depression, and mothers with less than a high school education also have higher rates of depression.

Factors associated with depression were nested to find which have the greatest effect. Looking at depression related to race, language, and education, 6% of the depression score is explained; but if life stress and the mother's physical health are added to the equation the number is boosted to almost 27%. If social support is added, the explanatory power is raised to 32%. It is by far the life stress in the family that influences depression, not the chronic illness. Thus by modeling the social context, having a child with diagnosed asthma neither increases nor decreases the number of symptoms of depression.

Living with high levels of life stress over time is associated with a greater likelihood of more severe asthma. Caregiver mental health is a reflection of life circumstances, stressors, and supports, but a child's diagnosis of asthma is not associated with a change in the parents' symptoms of depression. In terms of the implications for research and education, be aware of asthma underdiagnosis when a child has respiratory symptoms. Always consider life circumstances when a child is persistently ill. Children with special health care needs share many issues and circumstances that must be factored into a successful education plan and research design.

Dumont-Driscoll: Zerhouni has indicated five major challenges related to health in the United States, all of which affect children; including chronic illnesses and health disparities. Emerging diseases, such as Type II diabetes, are now seen in pediatric populations. Health expenditures are astronomical, and account for a large percentage of the gross national product.

While the United States is known to have the best medical care in terms of technology and resources, does it have the best health care? Health indicators show a sobering list of statistics compared to other countries on infant mortality, under-5 mortality, death rate for noninjuries, age-appropriate immunizations, and self-reported health conditions in teenagers.

A new paradigm for approaching disease and health is to include genetics. The goal is to intervene before symptoms emerge. The human genome project provides an opportunity to transform medicine in the next 20 years. Moving from curative to preemptive strategies will cut health care costs and prevent disease before it occurs. Rather than considering this approach with a eugenics view, it is important to ask what the benefit is of the human genome project and how to maximize the health of children.

There are 25,000 genes in the body, and 6 billion base pairs. What does this mean in terms of pediatric morbidity and mortality? Certain diseases that affect children, such as hearing and vision defects, asthma, behavioral issues, obesity, and diabetes all have a strong genetic component. Rather than considering genetics as a paradigm that involves single gene defects, it is important to recognize the interplay between a child's genetic makeup and environmental factors, combining the macro- and micro-levels. There are individual differences dependent upon exposure, experiences, genetic predisposition, and susceptibility, as well as the protection that may come from a child's genetic makeup.

As one example, obesity indicates a significant problem that is often not identified as genetic; but genetics can help explain not only the etiology, but also significant consequences that may have been ignored previously. Obesity has now been classified as an epidemic, with numbers doubling among children aged 6 to 11 years, and tripling among children aged 12 to 19 years. A study on Prader-Willi syndrome sheds light on the relationship between genetics, obesity, and their effects. Prader-Willi syndrome is a genetic condition caused by the absence of chromosomal material from chromosome 15. These children begin their lives with little muscle tone, and parents are unable to feed them. They also have significant mental retardation and developmental delay. Some time between 2 and 5 years of age, these children suddenly develop voracious appetites. Prader-Willi has always been recognized as a neurocognitive syndrome, as have several other genetic syndromes. The study found that children with Prader-Willi syndrome are

significantly lower than control siblings in terms of early morbid obesity and general intellectual ability. However, the other worrisome finding is that the nonsyndrome children who developed morbid obesity below 5 years of age, when matched with control siblings, were not doing well intellectually. Neuroimaging studies done from MRIs show significant white matter lesions among the obese children; but none of these lesions were seen in the children with normal weights.

How significant is obesity as it increases in our population, particularly for children in Early Head Start or Head Start programs? Every single known genetic syndrome of obesity has associated with it mental retardation or significant developmental delay. Are children who become obese or significantly overweight at a young age at increased risk for developmental delay or other cognitive deficits? Could there be a toxic effect that is related to elevated neurotransmitters or hormones?

The brain is still developing and myelinating until age 5 or even until the early teenage years, so it is sensitive compared to an adult who has the same exposure and becomes overweight at an older age. The additional point that perhaps leaves some concern is that some children with Prader-Willi syndrome diagnosed as early as 3 days old, who have had strict control of their diet, never become obese. The cognitive scores of these children are significantly higher than the children with abnormal weight gain. Is there a genetic basis in certain cases, with reason to think that obesity potentially has disastrous impact on children? The extent to which a society protects its children reflects the magnitude of its investment in its future, and such a failure to protect cannot be condoned.

Simpson: Research and policy issues for children's special health care needs was presented. At the national level, there is need for advocating policy change to promote quality of care for all children. A large focus is on health care disparities and making sure that all children benefit from the potential and promise that health care can provide.

Shalowitz emphasized that the biomedical model of care for children is limited. Less than 10% of eventual health status is attributable to medical care; health behaviors, social determinants, and factors outside the direct control of the health care system are more important. Not all children in America experience education or health care in the same way. In this country, geography is destiny. There have been interesting studies on the roles of residential segregation and health disparities on infant mortality, particularly in the African-American community.

Another point is that disparity is complex, with issues of inequality and relative deprivation. A British study shows that perceptions of one's status in society relative to others may have more of an impact on stress and outcome. If one is poor, but everyone around is poor as well, there is less of a potential impact on health status. Technological medical innovations over the past 20 years have also led to advances in children's health care needs. As the health care system gets better at taking care of chronic illnesses, disparity and access to an efficacious system will grow.

The new genetics are critical, and the field is realizing that the issue is no longer nature versus nurture; it is how nature interacts with nurture throughout the life span. Issues around health and genetics, challenges the system to consider the return on investment. With asthma, for example,

taking better care of children in the ambulatory setting, with asthma care, family management, and self-management, results in children hospitalized less often. However, hospitals are paid on a fee-for-service model, so they lose money if they build good disease management programs. A better understanding of the business case is challenging for the health care system.

There is a helpful framework for research and policy on children's special health care needs in the 21st century. There is potential to receive high quality health care, but this potential drops depending on a host of preconditions, including income, race, ethnicity, and English language proficiency. One out of seven children with special health care needs was without health insurance at some point in the preceding 12 months. For Hispanic children, the rate of uninsured during the previous 12 months is 26 percent, with nearly 50% of Hispanic respondents stating that their coverage is inadequate. Discontinuous health insurance has an enormous impact on whether or not families seek care. One third of parents of children with special health care needs do not believe that they have adequate insurance to cover their needs, and they often pay out-of-pocket for certain services that are either not covered by their plan or not fully covered.

A consistent source of primary care is critical for children with special health care needs. A strong evidence base is necessary to build good clinical content. A national survey of children with special health care needs in 2001 showed that 54% of these children have medical homes. Nearly 20% of the children in this survey had difficulty getting a referral for specialty care, and nearly 16% had one or more unmet needs for specific healthcare services. Again, Hispanics experience higher barrier rates.

The Deficit Reduction Act of 2005 offers the most significant change to Medicaid since its inception in the 1960s, potentially affecting the nature of Medicaid coverage for children everywhere. The State Children's Health Insurance Program (SCHIP) was a major victory for child advocates in 1997, and which is up for reauthorization in 2007. More of Medicaid and SCHIP are being delivered through managed care plans, through the private sector. The move towards consumer-directed health care, where people get a fixed benefit and decide how to spend it, is challenging.

Finally, the Title V block grant provides services for children's special health care needs. Funding for this program has not kept up with inflation and has decreased, raising concern about whether children's special health care needs will be adequately accessed in the future. It raises the issues of whether the children will be eligible, enrolled, and able to afford the services in their health plans, and of which services will be covered.

A new Institute of Medicine study has begun to define high clinical value services that should be covered by consumer directed health care. However, there is little evidence for much of what children need, and use of an evidence standard misses many issues that affect children. What are the future research issues around access, outreach, and eligibility? Children are not easily transitioned to the adult health care system, which is becoming a larger issue as children with special health care needs and chronic illnesses live longer.

The Institute of Medicine also reports on quality of care, with defined dimensions of safety, effectiveness, timeliness, patient or family centeredness, efficiency, and equity. Large gaps

persist between the care people should receive and the care they do receive, whether it is preventive, acute, or chronic care. This is true for all types of health insurance. In the beginning, it was assumed that managed care was the problem, but it is not. There are problems throughout the care system for all age groups. The best benchmark is that 74% of services for children's special health care needs are organized so that families can use them easily; but most performance is in the 50th or 60th percentile.

Looking forward to the future, policy and research need to address many key issues; including evidence-based practice and how to measure and improve quality of care for children. When talking with health care policy makers about health care for children, the response is that children only cost \$63 billion, compared to the Medicare system. Therefore it is important to link this early investment and continuous investment throughout childhood in health care to broader social outcomes, such as educational achievement and economic productivity.

Pascoe: Health literacy is linked to decision making and parent behavior related to child health. Is health literacy a barrier to care; is it a policy issue?

Simpson: Absolutely. A 2004 Institute of Medicine report estimated that over 90 million Americans are not health literate. Health literacy is the ability to read and understand health instructions and numbers. In one survey, only 57% of adults said they understood their doctor's instructions, and these were American-born, English-speaking respondents. For chronically ill children on multiple medications, the cognitive burden of understanding complex clinical instructions and the trade-offs it entails are even further challenged by families who are health illiterate.

Pascoe: What is the challenge for families living in rural settings?

Simpson: There are access issues in rural settings, as well as quality of care issues, particularly for complex, chronically ill children. Telehealth options are helping providers isolated in their communities to care for these children so families can stay grounded where they are. The field is no longer called "telemedicine," but rather "telehealth" to reflect its different dimensions.