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# Evolving Notions of Childhood Chronic Illness

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IN THIS ISSUE OF JAMA, VAN CLEAVE AND COLLEAGUES<sup>1</sup> present an analysis of 3 cohorts of children spanning 1988 to 2006 included in the National Longitudinal Survey of Youth (NLSY). The authors report that the prevalence of several categories of chronic illness in childhood is increasing and that these conditions arise, continue, or resolve in a highly dynamic fashion. Both findings have important implications and raise a number of significant questions.

The more than doubling in prevalence of chronic conditions reported by the authors is consistent with an increasing body of evidence documenting a historic shift in the epidemiology of child health—from acute to chronic illnesses—that began at least 50 years ago.<sup>2-4</sup> Indeed, while mortality rates, hospitalizations for common acute conditions and injuries, and school absence days due to illness were declining, the prevalence of chronic conditions severe enough to cause some level of activity limitation more than doubled between the 1960s and the 1980s.<sup>5</sup> Results from the report by Van Cleave et al suggest the upward trend in prevalence of chronic conditions has continued through the 1990s and into the first decade of this century.

Making sense of these findings is not an easy task.<sup>4</sup> Access to and improvements in the delivery of specialized care have resulted in a growing number of survivors of complex congenital disorders, prematurity, and cancer whose survival was almost unimaginable a few decades ago. Better access to care and better tools to diagnose chronic conditions, particularly emotional and behavioral conditions, may also contribute to the upward trend in prevalence. Concepts of health and disease and definitions of what constitutes a childhood chronic illness have also changed.<sup>6</sup> The narrow focus on physical defects during the “crippled children” era of the 1930s through 1960s evolved to include developmental disabilities and other physical conditions in the 1970s through 1980s, with the terminology shifting to “handicapped children.”

In 1998, the federal Maternal and Child Health Bureau reset the parameters and repositioned the delivery system infrastructure for children with chronic illness by promulgating an expansive definition of children with special health care needs that incorporated physical, developmental, emotional, and behavioral conditions.<sup>7</sup> When these broader concepts and definitions were operationalized in new national surveys of chil-

dren's health, no longer were 5% to 8% of children designated as chronically ill and disabled, but 16% to 18% were now classified as having special needs due to chronic conditions.<sup>8</sup> While some have claimed that diagnostic or conceptual creep is at play, it seems more likely that these new definitions are responding to the changing realities of childhood and to the changing epidemiology of childhood chronic disease.

Increasing rates of obesity appear to be driving the overall trend in prevalence described by Van Cleave et al,<sup>1</sup> but significant increases were noted for all physical health conditions, with lesser increases for asthma and fairly minimal changes in the reported rates of learning and behavioral problems. Although the obesity trend and its antecedents have been well described, the increasing rate of asthma and other physical ailments is less well understood. It is somewhat surprising that the learning and behavioral problem category did not show a greater increase in prevalence, given data from other cross-sectional surveys suggesting attention-deficit/hyperactivity disorder (ADHD) and other mental disorders are also increasing.<sup>9</sup>

The authors also report large dynamic changes in how conditions manifest and resolve. Are these dynamic changes in onset, duration, and resolution real? The NLSY identified chronic conditions by questioning the child's parent whether the child had an activity-limiting physical, mental, or emotional health condition that required regular health care. Mothers were then asked to identify the condition and provide an estimate of its duration. Conditions were recorded verbatim and coded by the interviewer. It is easy to suspect the reliability of the short sequence of questions and the ability of parents to report consistently over time. Consequently, some of the within-cohort dynamics are likely artifacts of the inherent inconsistencies in parental reports from one reporting interval to the next.

Even though some of the findings may be due at least in part to measurement error, there are sound reasons from a developmental perspective to expect that conditions in childhood should be dynamic. Other studies have documented developmental fluctuations in conditions like asthma, which can have an episodic and relapsing course and can be influenced by the onset of puberty or stressful transitions or changes in family environments.<sup>10</sup> As the authors suggest, less severe conditions,

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and those most responsive to appropriate health care, are more likely to demonstrate a resolving course for some proportion of children affected. It is also important to understand whether disparities in remission rates reflect disparities in access to effective treatments for children from different strata of society.

Child advocates and pediatric clinicians have long argued that children are not little adults and that the definition, conceptualization, and measurement of what constitutes a chronic condition differ as well. They contend that a child's developmental vulnerability; dependence on adults for caregivers; and the different types, prevalence, and patterns of chronic disease are indicative not only of different patterns of risk but also of the need for a more sensitive and developmentally attuned health care system. Although a significant proportion of chronic disease in adults and elderly individuals is a result of degenerative disorders and the cumulative effects of risks, stresses, and other exposures that gradually affect different body systems, traditionally more severe childhood chronic conditions were often the result of congenital abnormalities, neonatal exposures, or impairments that resulted from unintentional injuries.

The epidemiologic shift, signified by the increasing number of children with obesity, ADHD, asthma, and other less severe chronic conditions, seems to be associated with a shift in the social ecology of childhood. This changing ecology includes exposures to higher levels of toxic stress, increasing rates of absent parents, more sedentary and less active lifestyles, more television and multimedia use, and the ingestion of high-caloric and high-fat diets. A combination of developmental plasticity and developmental reserves can enable children to be functionally resilient under optimal circumstances. Yet the same adverse childhood experiences that can contribute to the onset of childhood illness can also affect stress-sensitive physiologic systems (nervous, endocrine/metabolic, immune), predisposing the same individuals to develop age-related diseases as adults.<sup>11</sup> This suggests that well-designed prevention strategies initiated in childhood could be a "two-for," preventing childhood chronic conditions as well as the adult chronic conditions that are likely to emerge in years to come.

It is also worth considering whether the evolving social ecology of childhood has created common and shared exposures that might explain why asthma, obesity, and other mental and behavioral conditions are increasingly prevalent. Recent studies have suggested that the prevalence of obesity is associated with both ADHD and asthma.<sup>12</sup> Could this be due to common early childhood risks that are triggering development of aberrant physiologic pathways? There is some evidence that high levels of early childhood stress may influence the development of neural pathways in the frontal cortex and hypothalamus, leading to poor executive function and impulse control and dysfunctional leptin response.<sup>13</sup> Could this be a reason children from lower social classes, who are more likely to experience toxic stress, are also more likely to manifest obesity, ADHD, asthma, and other increasingly prevalent chronic conditions?<sup>14,15</sup>

Addressing these and other questions will require high-quality longitudinal data that permit tracing how health develops in

childhood. Current longitudinal surveys, including the NLSY, collect minimal health data and even less information on the possible antecedents of health problems, complicating interpretation of findings such as those reported by Van Cleave et al.<sup>1</sup> The soon-to-be-implemented National Children's Study<sup>16</sup> could go a long way toward better describing the dynamics of childhood chronic conditions and the risk and protective factors that influence their emergence, duration, and resolution.

The obesity epidemic seemed to develop at a time when many indicators suggested that children's health was generally improving. The data presented by Van Cleave et al<sup>1</sup> suggest that the prevalence of other chronic health conditions is also increasing among US children and that obesity is not the only clinical time bomb ticking away in children. There is an urgent need to better understand why this is the case and what can be done about it. Addressing the increasing incidence and prevalence of chronic conditions in children will ultimately require major reforms in the child health system.<sup>17</sup> The child health system needs to do a better job preventing childhood chronic illness. The possibilities for such changes are substantial, as are the implications of not acting.

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