

Pediatric Chronic Diseases—Stealing Childhood

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IT IS EASY TO ROMANTICIZE CHILDHOOD, ESPECIALLY IN THE middle of summer. Memories of lazy days at the beach, playing baseball or double Dutch with friends, catching lightning bugs in a jar and hopefully remembering to let them go, and having no concerns about bills to pay or time pressures or health problems. Perhaps childhood still is that way for some children, but for those with a chronic illness, life can be complicated and difficult. A child with asthma may need to take daily medication, an obese youngster may endure taunts or stares, a child with cancer may be hospitalized for extended periods of time, and concerns about bills and time and health are very real, at least for their parents.

This theme issue of *JAMA* is devoted to the very real problem of chronic diseases in infants, children, and young adults. It is a huge topic, not only in terms of the disorders encompassed but also in the impact on children, families, and society. Consequently, only a few aspects can be covered in this issue.

Perhaps the most surprising finding is that there is no clear definition of chronic health conditions in childhood. The Systematic Review by van der Lee and colleagues¹ involving 64 articles found 4 frequently used concepts, which varied in their reliance on types of conditions, duration of disease, impact on daily activities, and requirements for services. The main distinction was between definitions based on a list of diagnoses vs those based on functional limitations resulting from various conditions. The prevalence rates in these studies ranged from 0.22% to 44%, depending on factors such as how the definitions were operationalized, who provided the information for the study, the type of data gathered, and the year of the study.

The prevalence of chronic conditions in children is also addressed in a Commentary by Perrin and colleagues.² The authors note that the prevalence of these ailments as a group has increased over the last decades. However, most of this expansion reflects increases in the incidence of a few conditions—obesity, asthma, and attention-deficit/hyperactivity disorder—and is greater for minority and poor children. The reasons for the increase range from social

changes to perinatal factors, from diet and physical activity to environmental exposures.

Although we may not have a firm grasp on the prevalence of pediatric chronic illnesses overall, 2 studies in this issue provide new data to advance current understanding of 2 specific diseases: diabetes and cerebral palsy. The incidence of diabetes in adults has increased during the last 2 decades; however, the incidence in youth has been rarely investigated. The SEARCH for Diabetes in Youth Study³ involved a population-based ascertainment of new cases of physician-diagnosed diabetes mellitus in 2002 and 2003 among children and young adults younger than 20 years in 10 locations. With 2435 youth identified, the incidence of diabetes was 24.3 per 100 000 person-years. Among children younger than 10 years, most had type 1 diabetes; among older children, type 1 diabetes was also the most common, but type 2 diabetes became common especially among minority adolescents. The highest rates of diabetes (17.0 to 49.4 per 100 000 person-years) were found in minority adolescents. The authors estimate that 15 000 youth are newly diagnosed with type 1 diabetes and 3700 with type 2 diabetes in the United States annually. With few other studies available and available studies using different definitions and methods, it is difficult to compare rates between studies. It appears that the rates of diabetes in youth are increasing, but only continued surveillance will provide a clear answer.

Robertson and colleagues⁴ examined changes in the prevalence of cerebral palsy in extremely premature infants over 30 years in Edmonton, Alberta, Canada. Of 858 survivors at age 2 years, 122 (14.2%) had cerebral palsy. Cerebral palsy prevalence increased from 1974 to 1994, peaking at 131 per 1000 live births in 1992-1994, and then declined to 19 per 1000 live births in 2001-2003. The trends were similar for gestational age groups of 20 to 25 weeks and 26 to 27 weeks, and importantly paralleled trends in survival. The changes did not appear to be affected by changes in other factors, such as multiple births or cesarean deliveries. These results provide some insights into the etiology of cerebral palsy and suggest that neonatologists have had some success in preventing cerebral palsy during the last 10 years.

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Physicians have also observed success with another chronic disease—childhood cancer. Although survival rates for many pediatric cancers have improved, some dramatically, many survivors are developing late treatment-related complications. The study by Geenen and colleagues⁵ documents these adverse events in children treated for cancer in the Netherlands between 1966 and 1996, and followed up for at least 5 years. With almost complete follow-up (94.3%), the authors present physician-confirmed data on 1284 survivors. Almost 75% of survivors had at least 1 adverse event, such as orthopedic disorders, second tumors, and obesity. Forty percent had a least 1 severe or life-threatening event. Survivors of bone tumors and those children who received radiotherapy alone had the highest burden of adverse events. For children who have already endured cancer, the high prevalence of subsequent adverse events is disheartening and begs for further improvements in treatment.

Like adverse events for childhood cancer, treatment of another chronic condition of childhood—obesity—has been discouraging. Pediatric obesity has become an epidemic and has major ramifications for the long-term health of children as they age, especially in the rates of adult obesity and cardiovascular disease. Only a few weight loss interventions have been successful in children, and none have targeted minority youth, who are at greatest risk. Savoye and colleagues⁶ report the results of a randomized controlled trial of the Yale Bright Bodies Weight Management Program, a family-based, intensive-lifestyle intervention aimed at inner-city minority children. During 1 year, 174 overweight children aged 8 to 16 years received the program or usual diet and exercise counseling. The intervention group had essentially no change in body weight (0.3 kg from baseline to 12 months vs a 7.7-kg increase in body weight among controls), as well as improvements in body mass index (−1.7 vs 1.6), body fat, and insulin sensitivity. Although the success of the program may prove cost-effective in the long term, its expense and intensity may limit wide application.

Two other articles in this issue address some of the effects on a child having a chronic illness. Children with cancer or other serious disorders can spend a great deal of time in the hospital. A Commentary by Pao and colleagues⁷ examines the impact of “growing up in the hospital.” The effect on a child’s cognitive, emotional, and social development can be profound. The authors call for modifications to the hospital environment and clinical approach.

Certainly the least desirable outcome of a chronic illness is the death of a child. Feudtner and colleagues⁸ found that when children with chronic conditions die, they are increasingly dying at home. In a retrospective national case series between 1989 and 2003, the proportion of children with chronic disease dying at home increased from 10.1% to 18.2%, with larger increases for deaths occurring beyond infancy. The odds of dying at home were less among

black and Hispanic individuals than among white individuals. The authors speculate that these shifts may represent improvements in medical management of pediatric chronic conditions, advances in medical technology in the home setting, or changes in attitudes regarding end-of-life care.

This theme issue of *JAMA* leaves a mixed impression regarding the state of chronic conditions in children. Although the prevalence of some disorders is decreasing and the treatment of others is improving, the overall trend is for increases in chronic diseases of children. This will have substantial repercussions for future adult health. As Perrin et al² point out, “Rapid increases in childhood chronic conditions will lead to large numbers of younger adults with chronic illness and disabilities, dependent on public programs and expenditures, and experiencing lower quality of life, poorer social interactions, and less community participation.”

Understanding the causes of childhood chronic conditions is paramount. The good news is that one such effort is under way. The National Children’s Study⁹ has been called the most important study of children’s health and environment in the United States and likened to the Framingham study¹⁰ for cardiovascular diseases. It has been in the planning stages since 2000 and is beginning recruitment this year. Approximately 100 000 children will be tracked from before birth until age 21 years to examine the effects of environmental influences on health and development. Priority areas include many of the chronic diseases discussed in this issue. With data from this and other studies, hopefully progress will be made in preventing pediatric chronic illnesses so that all children can have carefree days throughout their childhood.

Financial Disclosures: None reported.

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