

Psychosocial Risks of Chronic Health Conditions in Childhood and Adolescence

Committee on Children With Disabilities and Committee on Psychosocial Aspects of Child and Family Health

Chronic health conditions affect many children and adolescents. These conditions are illnesses or impairments that are expected to last for an extended period of time and require medical attention and care that is above and beyond what would normally be expected for a child or adolescent of the same age, extensive hospitalization, or in-home health services.¹ These conditions include, among others, juvenile rheumatoid arthritis, asthma, cystic fibrosis, diabetes, spina bifida, hemophilia, seizure disorders, neuromuscular disease, acquired immunodeficiency syndrome, and congenital heart diseases. Although each specific condition may be relatively or extremely rare, when they are considered together, many children and adolescents are affected.

Health conditions may be characterized by their *duration* and their *severity*. Although these terms are often linked, they refer to different aspects of a health condition. A chronic condition is generally one that has lasted or is expected to last more than a defined period of time, usually 3 months or longer. Conditions vary widely in their onset, course, and duration.² Severity refers to the impact a condition has on a child's physical, intellectual, psychological, or social functioning.³ This impact may occur as a result of persistent symptoms, required treatments, limitations of activity or mobility, or interference with school, recreation, work, and family activities.

Current estimates are that between 10 and 20 million American children and adolescents have some type of chronic health condition or impairment. Most of these conditions are relatively mild and interfere little with the children's ability to participate in usual childhood activities.⁴ However, at least 10% of children with chronic conditions, ie, approximately 2% of those aged 0 to 21 years (1½ to 2 million children and adolescents nationwide), have a chronic condition severe enough to have an impact on their daily lives.

Recent medical and surgical advances have markedly decreased the mortality rates for children and adolescents with chronic conditions. While previously many of these individuals died in childhood or adolescence, current data suggest that at least 90%, even those with severe conditions, survive at least to

young adulthood.⁵ Given this change in survival, health care for these children and adolescents must be expanded to include more than management of their chronic condition and intercurrent acute illnesses. Pediatric care should also maximize children's functional abilities and sense of well-being, their health-related quality of life, and their development into healthy and productive adults.

PSYCHOLOGICAL RISKS OF CHRONIC CONDITIONS

Over the past two decades, much research has examined the psychological functioning of children and adolescents with various specific health conditions.⁶ Large, community-based studies^{7,8} and national surveys⁹ have assessed the risk of emotional, behavioral, and educational difficulties experienced by children and adolescents with a chronic health condition. Most of these studies have examined parents' ratings of behavioral and emotional status and have not identified specific psychological disturbances. These studies suggest that the majority of children and adolescents with chronic health conditions do not have identifiable mental health, behavioral, or educational difficulties. Children and their families are remarkably resilient in adapting to the additional stresses and challenges presented by a chronic health condition. Children, their siblings, and their parents often learn new coping strategies and show evidence of exceptional strength and mastery as a result. Nevertheless, these same studies show that children and adolescents with chronic conditions do have about twice the prevalence of psychological symptoms as compared to children without a chronic condition. Behavioral or emotional symptoms can be identified in approximately 10% of children overall and in about 20% of children with chronic health conditions.

It is not clear which specific characteristics of the child or adolescent, the family, and the health condition itself contribute most to resilience, to the stresses experienced, and to the risk of developing secondary emotional or behavioral difficulties. One might expect that the more severe the condition is, the greater the likelihood of psychological problems. Most studies show surprisingly little, if any, relationship between severity and problems with psychological adjustment.^{6,10,11} The risk of psychological adjustment problems seems to reflect more the presence of a chronic condition than its severity.¹² In general, the increased risk of psychological problems affects children and adolescents with all kinds of chronic con-

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ditions without great variation from one to another. There are characteristics of some conditions that do seem to be associated with higher rates of emotional or behavioral problems. For example, children who have chronic conditions that affect the central nervous system, especially seizure disorders,^{7,9} and children and adolescents who have an associated long-term physical disability may be at a higher risk for psychological problems than children with other chronic conditions.⁸ Dependence on others for daily activities may also contribute to their risk of psychosocial dysfunction. Specific health conditions may cause specific coping issues for children and adolescents, such as driving with epilepsy, issues involving sexuality for those with cystic fibrosis, or the social stigma of inflammatory bowel disease. However, children and adolescents with *any* type of chronic condition will have unique psychological stresses in addition to those faced by all children.

If neither the severity nor the type of condition adequately explains the risk of psychological problems, what family and child characteristics might predict this risk? Children's intelligence and temperament appear to contribute to their ability to adapt to the extra stresses of the illness.^{13,14} Parents' self-esteem, mental health, social support network, and beliefs about health care all have an impact on the success of children's adaptation,^{6,9,13,15} as does the cohesiveness, flexibility, and effectiveness of shared communication within the family. Current research efforts will likely identify additional factors associated with increased risks for psychological problems and factors that foster children's resilience. This information will provide pediatricians with more guidance regarding the prevention and identification of psychological difficulties when working with families whose children have chronic health conditions.

RECOMMENDATIONS FOR PEDIATRIC CARE

Primary care pediatricians have a central role in providing screening, preventive, and supportive services to children and adolescents with chronic health conditions and their families.

The usual pediatric model of assessing children's functioning in their family, in school, and with peers applies to those with a chronic health condition just as it does to all other children and adolescents. Pediatricians who take a comprehensive and family-based view of the broad clinical implications of childhood chronic conditions will recognize their critical role in diminishing the child's risk of psychological adjustment problems. Identifying children and families at risk for coping poorly with the stress of chronic health problems; assisting families to prevent psychological, social, and behavioral complications; and searching for early evidence of such problems should be part of regular pediatric care. Most of the stressful issues for families with children with chronic conditions can be anticipated and dealt with preventively through education and supportive counseling services provided appropriately by the pediatrician. It may be appropriate for some children and adolescents to be referred for mental health services.

Pediatricians should develop links with local schools and other agencies that provide support and services for children and families. Schools play a central role in the education and socialization of all children and often have resources that help with the prevention, identification, and management of psychosocial problems in their students, including those with health impairments.¹⁶ Because increasing numbers of children with chronic conditions are in school from the age of 3 years, schools are a key resource in their long-term management. They frequently provide major assistance to families and to pediatricians in diminishing the psychosocial risks of chronic conditions.

Pediatricians can also help families by ensuring well-coordinated medical care and efficient and effective communication with the many professional providers of care involved with the family. They can help to ensure that families have access to local supportive networks for parents and for children. Also, pediatricians should provide appropriate information about the individual's illness and its management, recreational opportunities, and mechanisms to assist with the financial strain associated with chronic health conditions.¹⁷

The prevention of psychosocial complications of childhood chronic illness will be met best by a family- and community-centered approach in which the pediatrician assesses the skills and needs of the child and family, participates in planning and implementing comprehensive intervention programs, and supports families in the complex task of raising children and adolescents with chronic conditions.¹⁷

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