

many authors have described the rise in prevalence that has come about because of advances in medical care (Burns, Casey, Lyle, et al, 2010; Council on Children with Disabilities, 2005; Simon, Berry, and Feudtner, et al, 2010), accurate estimates of the numbers of affected families are not known (Carnevale, Rehm, Kirk, et al, 2008). However, the impact of chronic and complex illness in children is wide ranging. The family experiences significant challenges necessitated by the child's care requirements (Goudie, Narcisse, Hall, et al, 2014; Kratz, Uding, Trahms, et al, 2009; Kuo, Cohen, Agrawal, et al, 2011; MacDonald and Callery, 2008). A child's activity level and developmental opportunities can be affected. Days can be lost from school. Children with complex chronic conditions may be at increased risk for behavior or emotional problems. Parents may lose days from work, experience financial strain, and be challenged both emotionally and physically as they cope with care of the child.

TABLE 17-1
Chronic Conditions of Childhood

Specialty	Examples of Chronic Conditions
Cardiology	Complex congenital heart disease, congestive heart failure, cardiac dysrhythmias, Kawasaki disease, rheumatic fever, hyperlipidemia
Endocrinology	Diabetes, congenital adrenal hyperplasia, Cushing syndrome
Gastroenterology	Short bowel syndrome, biliary atresia, inflammatory bowel disease, hepatitis, cirrhosis, peptic ulcer disease, celiac disease
Hematology	Sickle cell anemia, thalassemia, aplastic anemia, hereditary anemias, hemophilia
Immunology	Immune deficiency, human immunodeficiency virus, Wiskott-Aldrich syndrome, severe combined immunodeficiency disease
Nephrology	Prune belly syndrome, renal disease
Neurology	Cerebral palsy, ataxia telangiectasia, muscular dystrophy, seizure disorder, spina bifida, traumatic brain injury
Oncology	Brain tumor, leukemia, lymphoma, solid tumors, bone tumors, rare tumors
Pulmonology	Asthma, chronic lung disease, cystic fibrosis, tuberculosis
Rheumatology	Systemic lupus erythematosus, juvenile rheumatoid arthritis, dermatomyositis

Siblings are also affected by having a “different” brother or sister, and they may simultaneously feel guilt, anger, or jealousy toward their ill sibling. Clinicians need to know that siblings of children with chronic illnesses are at risk for negative psychological effects (Hartling, Milne, Tjosvold, et al, 2014). Parents need encouragement and assistance with understanding the reactions of siblings to having a chronically ill family member (e.g., behavioral regression,