

Scope of the Problem

Advances in medical and nursing care, such as the increasing viability of extremely preterm infants, the portability of life-sustaining technology (e.g., total parental nutrition, ventilatory support), and life-extending treatments for children with conditions that previously would have led to an early death (e.g., malignancies, genetic conditions), have led to an exponential rise in the prevalence of children with complex and chronic diseases (Burke and Alverson, 2010; Simon, Berry, Feudtner, et al, 2010).

These children have complex conditions involving several organ systems and require multiple specialists, technologic supports, and community services to assist them to function to their healthiest potential. The complex, high level of skill required to meet their daily health care needs and the continuous nature and potential volatility of their conditions sets this group apart from the broader population of children with special health care needs (Cohen, Kuo, Agrawal, et al, 2011; Simon, Berry, Feudtner, et al, 2010; Kuo, Cohen, Agrawal, et al, 2011). A range of terms, such as *complex chronic condition*, *medically complex*, *technology dependent*, and *multiply handicapped*, have been used to describe this vulnerable population of children (Carnevale, Rehm, Kirk, et al, 2008; Cohen, Friedman, Nicholas, et al, 2008; Cohen, Kuo, Agrawal, et al, 2011; Feudtner, Feinstein, Zhong, et al, 2014). Frequent and prolonged hospitalizations; complex and multisystem health and developmental needs; and reliance on technology and care that cross hospital, clinic, and home settings are the key characteristics that all of these terms seek to signify about the children they are used to represent (Berry, Hall, Hall, et al, 2013; Cohen, Kuo, Agrawal, et al, 2011; Feudtner, Feinstein, Zhong, et al, 2014).

The nature and severity of childhood chronic and complex conditions is widely heterogeneous. Table 17-1 is a non-exhaustive sampling of conditions organized by specialty. However, these children and families are similar in the vulnerability that they experience due to the health and developmental consequences of these diagnoses on the child, such as ongoing functional impairment, neurodevelopmental disability, dependence on medical technology, and the need for ongoing skilled, supportive care from health care providers and family members. Although