

(Coffey, 2006; Nuutila and Salanterä, 2006). Throughout the first year, parents struggle to accept the child's diagnosis, care, and uncertainty of the future (Coffey, 2006). Optimal support at the time of diagnosis and initial discharge home can be encouraged by providing explicit and uncomplicated information to parents in an empathic way (Nuutila and Salanterä, 2006); assessing the family's daily routine, living conditions, background knowledge, skills and abilities, and coping behaviors; and evaluating the family's understanding of the information. It is also necessary to reassess parents' needs for information and support on a routine basis (Nuutila and Salanterä, 2006).

Other critical times include the exacerbation of the child's physical symptoms, which increases parental care. These crises often involve medical intervention and rehospitalization. Frequently, the child does not return to his or her precrisis level of functioning, and parents and family must adapt to new care needs and schedules. Instability may also follow transition points on the illness trajectory. Supporting parents, respecting their stress and emotions, and acknowledging their role as team members in the care of their child are important aspects of nursing care (Coffey, 2006; Nuutila and Salanterä, 2006; Panicker, 2013).

Impact of the Child's Chronic Illness

Each member in the family of a child with a chronic or complex illness is affected by the experience (Goudie, Narcisse, Hall, et al, 2014; Kuo, Cohen, Agrawal, 2011; Sullivan-Bolyai, Sadler, Knafl, et al, 2003). The effects on the parents and their responses may be so intense that they directly influence the other members' reactions and the child's own coping.

Parents

In addition to the stress of grieving for the loss of hope for a perfect child, parents are affected by whether or not they receive positive feedback from interactions with their child. Many parents feel satisfaction and fulfillment from the parenting role. For others, parenting may be a series of unrewarding experiences that contribute to feelings of inadequacy and failure (Box 17-3). These responses may be most evident in parents who are responsible for