

decisions that are best for the family and child at the time the decision is made (Kon, 2010).

Box 17-1

Facilitating Shared Decision Making

- Continually assess the impact of the child's illness and treatment on the family.
- Provide honest, accurate information regarding the trajectory of the disease, anticipated complications, and prognostic information.
- Discuss what the family desires for the child's quality of life.
- Avoid personal opinion or judgment of the family's questions and decisions.
- Be aware of nurses' personal and cultural assumptions and the ways these assumptions impact communication, decision making, and judgment.

Normalization

Normalization refers to the efforts family members make to create a normal family life, their perceptions of the consequences of these efforts, and the meanings they attribute to their management efforts (Knafl, Darney, Gallo, et al, 2010). For chronically ill children, such efforts may include attending school, pursuing hobbies and recreational interests, and achieving employment and a level of independence. For their families, it may entail adapting the family routine to accommodate the ill or disabled child's health and physical needs (Kratz, Uding, Trahms, et al 2009; Kuo, Cohen, Agrawal, et al, 2011).

Children with chronic and complex conditions and their families face numerous challenges in achieving normalization. Families move between the “normal” of living with the experience of chronic childhood illness and the “normal” of the healthy outside world; they often redefine “normal” based on their particular experiences,