

Death of the child

Parental Roles

Parenting a child with a complex chronic condition requires attending to the routine aspects of parenting with the added responsibility of performing complex technical care, symptom management, advocating for their child, and seeking and coordinating health and social services for their ill or disabled child (Kirk, Glendinning, and Callery, 2005). These added responsibilities must then be balanced with the needs of other family members, extended family and friends, and personal health and obligations to minimize consequences to the overall functioning of the family (Coffey, 2006).

Often one parent or partner remains at home to manage existing family responsibilities while the other remains with the ill child. The partner who is not included in the caregiving activities may feel neglected because all of the attention is directed toward the child and be resentful that he or she is not sufficiently informed to be competent in the care. Without active participation in the child's care, the parent has little appreciation of the time and energy involved in performing these activities. When this partner does attempt to participate, the other parent may criticize the less skillful efforts. As a result, communication and support for each other may be adversely affected.

The nurse can assist parents in avoiding role conflicts by providing anticipatory guidance early on. Teaching should address stressors often identified as having an impact on the marriage, including (1) the burden of care at home assumed by primarily one parent, (2) the financial burden, (3) the fear of the child dying, (4) pressure from relatives, (5) the hereditary nature of the disease (if applicable), and (6) fear of pregnancy. Other causes of tension may center on the inconveniences associated with care, such as long waits for an appointment, lack of parking near care facilities, or lack of overnight accommodations.

Mother–Father Differences

Mothers and fathers of a child with a complex condition often adjust and cope differently. Mothers are often the primary caregiver and are more likely than fathers to give up their jobs to care for