

discussion of pain assessment and management.

Box 17-8

Ethical Principle of Double Effect

An action that has one good (intended) and one bad (unintended but foreseeable) effect is permissible if the following conditions are met:

- The action itself must be good or indifferent. Only the good consequences of the action must be sincerely intended.
- The good effect must not be produced by the bad effect.
- There must be a compelling or proportionate reason for permitting the foreseeable bad effect to occur.

Parents' and Siblings' Need for Education and Support

Parents are the primary caregivers when the child is at home, and nurses providing care to the child and family need to teach the family about the medications being given to the child, how to administer medications, and the use of non-pharmacologic techniques. This empowers parents and provides a sense of control over the child's comfort and well-being, reducing their fear that their child will be in pain or suffering as he or she is dying. Additionally, better bereavement outcomes (e.g., adaptive coping, family cohesion, and less anxiety, stress, and depression) have been reported by parents who were actively involved in the care of their child (Goodenough, Drew, Higgins, et al, 2004; Lauer, Mulhern, Schell, et al, 1989). The grief work of fathers in particular seems to be facilitated when their child dies in the home setting. This finding may be related to the increased opportunity of working fathers to provide care to and spend time with their child at home versus the hospital setting.

Siblings may feel isolated and displaced during the time that their brother or sister is dying. Parents devote the majority of their time to the care and comfort of the dying child, causing siblings to feel left out of the parent–sick child relationship. Siblings may become resentful of their sick sibling and begin to feel guilty or