

Nursing Care of the Child and Family at the End of Life

Regardless of where the child is cared for during the terminal stage of illness, both the child and the family usually experience fear of (1) pain and suffering, (2) dying alone (child) or not being present when the child dies (parent), and (3) actual death. Nurses can help families by lessening their fears through attention to the care needs of the child and family.

Fear of Pain and Suffering

The presence of unrelieved pain in a terminally ill child can have detrimental effects on the quality of life experienced by the child and family. Parents feel that having their child in pain is unendurable and results in feelings of helplessness and a sense that they must be present and vigilant to get the necessary pain medications. Persistent pain also has an impact on the family as a whole. Nurses can alleviate the fear of pain and suffering by providing interventions aimed at treating the pain and symptoms associated with the terminal process in children.

Pain and Symptom Management

Pain control for children in the terminal stages of illness or injury must be given the highest priority. Despite ongoing efforts to educate physicians and nurses on pain management strategies in children, studies have reported that children continue to be under-medicated for their pain ([Wolfe, Grier, Klar, et al, 2000](#)). Nearly all children experience some amount of pain in the terminal phase of their illness. The current standard for treating children's pain follows the [World Health Organization's \(1996\)](#) analgesic stepladder, which promotes tailoring the pain interventions to the child's level of reported pain. Children's pain should be assessed frequently and medications adjusted as necessary. Pain medications should be given on a regular schedule, and extra doses for breakthrough pain should be available to maintain comfort. Opioid drugs such as morphine should be given for severe pain, and the dose should be increased as necessary to maintain optimal pain