

Providing End-of-Life Care to Children: A Needs Assessment of Hospice Nurses

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Problem Statement: Children have unique end-of-life (EOL) needs, and it is difficult to find pediatric-specific hospice support. Adult hospice nurses often feel uncomfortable and have limited knowledge about pediatric EOL care.

Background/Literature Review: Literature supports the need for home-based EOL care for children. It also demonstrates the need for nurses to receive pediatric EOL education, specifically regarding facilitating discussions, communication, pain and symptom management, and managing personal grief.

Purpose: The purpose of this needs assessment is to evaluate hospice nurses' perceived comfort level and knowledge regarding caring for dying children.

Methods: An online survey was sent to 70 hospices in the San Francisco Bay Area to be forwarded to nursing staff. Survey questions focused on comfort level, knowledge, and desire for further education on pediatric palliative and EOL care.

Findings: Sixty-five nurses completed the survey. Fifty-five nurses (85%) care primarily for adults, while 10 (15%) care primarily for pediatric patients. There is an even distribution between nurses who strongly agree/agree and those who disagree/strongly disagree that they are knowledgeable about pain assessment in nonverbal/infants and pediatric symptom management, and comfortable with managing pediatric pain, administering pediatric EOL medications, and providing EOL care. At least 80% of nurses believed they were skilled in communication, identifying EOL changes, and managing self-care. A slight majority (60-66%) were knowledgeable about pain assessment in verbal children, comfortable facilitating discussions, and comfortable coping with personal grief. Twenty-one nurses (41%) were knowledgeable about nonpharmacological interventions based on development. Fifty-seven nurses (88%) would like more education, while just 24 (37%) had recent additional pediatric palliative care education.

Implications: While survey results are mixed regarding knowledge and comfort with caring for dying children, hospice nurses, overall, would value further pediatric-specific education. Because there are currently few pediatric hospices, it is critical that pediatric palliative and EOL care be expanded.