



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

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Statement of the Problem

- Pediatric end-of-life (EOL) care differs from that of adults
- When a child is dying, they are typically referred to home-based hospices that mostly provide care to adults
- Hospice nurses often have limited knowledge about pediatric palliative and EOL care and may feel uncomfortable caring for a child at EOL

Background/Literature Review

- Home-based palliative and EOL care for children is needed, as this is often the parents' preferred setting for their child's care and death (Friedrichsdorf et al., 2015)
- Professional caregivers need education about pediatric EOL care, facilitating discussions, communication, pain and symptom management, and managing one's own grief (Price et al., 2017; McConnell & Porter, 2017; Vesel & Beveridge, 2018)

Purpose

Needs assessment to evaluate hospice nurses' comfort level and knowledge regarding caring for children at EOL

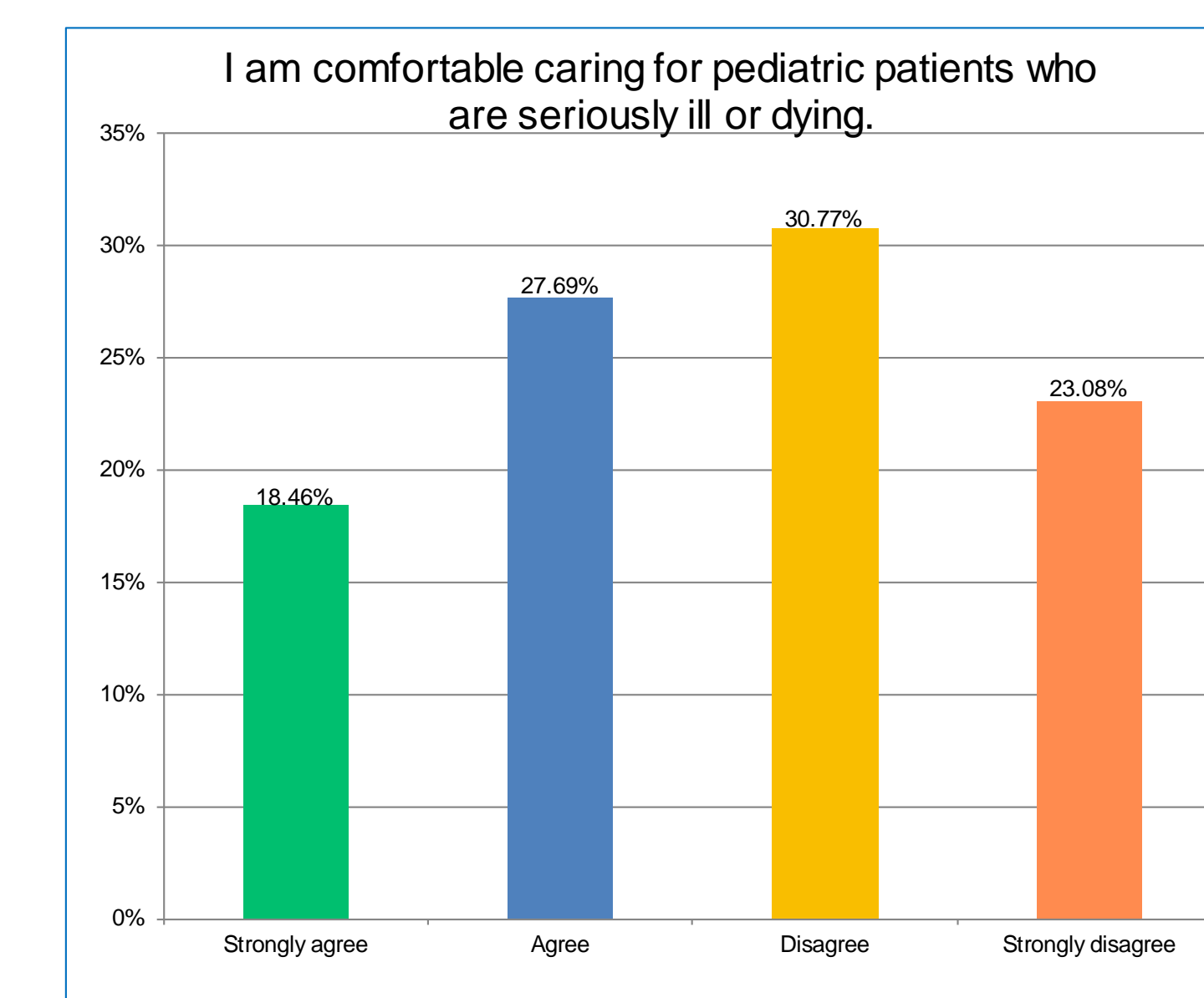
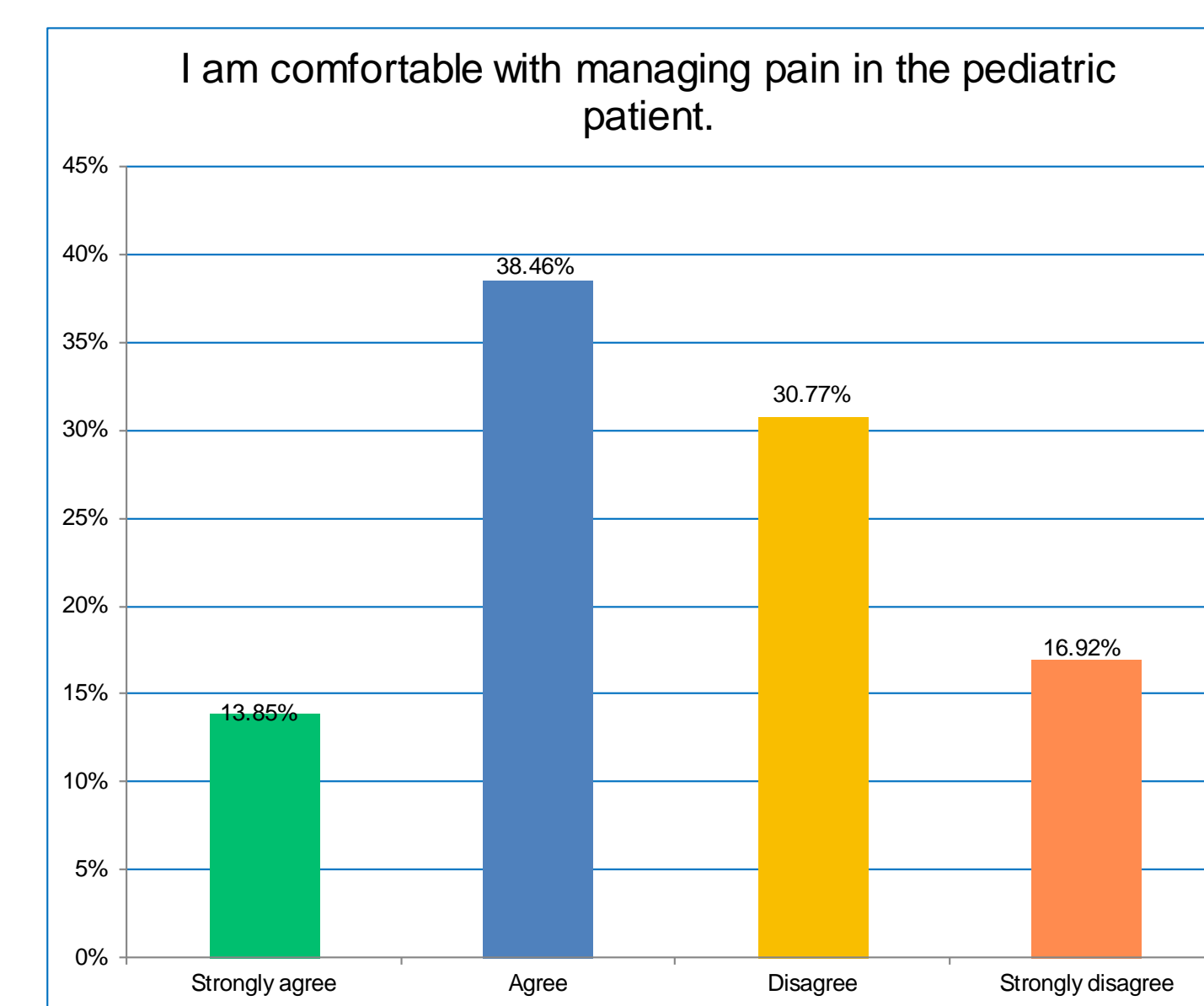
Methods

- Online Survey Monkey nursing survey distributed to 70 hospices in the San Francisco Bay Area
- Survey focused on comfort level, knowledge, and desire for further education on pediatric palliative and EOL care
- Results analyzed using descriptive statistics

Limitations

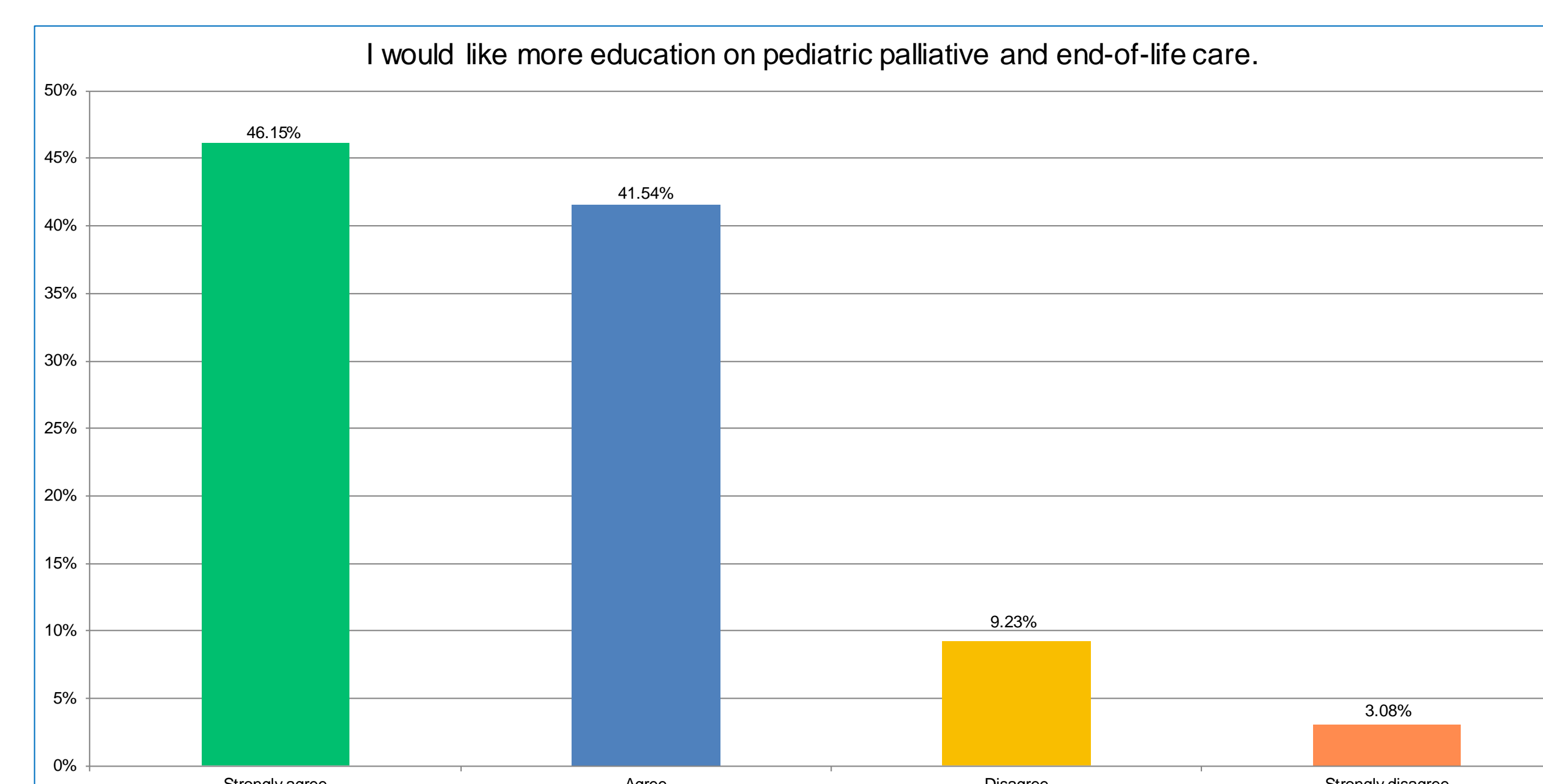
- Only surveyed nurses in the San Francisco Bay Area
- Responses from 10 pediatric nurses, 55 adult nurses; comparison between groups limited
- Anonymous survey; it is unknown which organizations participated and whether or not they accept pediatric patients

Findings and Analysis



San Francisco Bay Area Hospice Nurses (N=65)

- Average 6.8 years hospice experience
- 55 nurses (85%) care primarily for adults; 10 (15%) care primarily for pediatric patients
- Even distribution between nurses who strongly agree/agree and disagree/strongly disagree that they are knowledgeable about pain assessment in nonverbal/infants, knowledgeable about pediatric symptom management, comfortable with pediatric pain management, and comfortable administering pediatric EOL medications and providing EOL care
- 80% of nurses felt skilled with communication, identifying EOL changes, and managing self-care
- 60-66% felt knowledgeable about pain assessment in verbal children, comfortable facilitating discussions, and coping with personal grief
- 21 nurses (41%) were knowledgeable about non-pharmacological interventions based on development
- **57 nurses (88%) would like more education**
- 24 (37%) had recent additional pediatric palliative care education

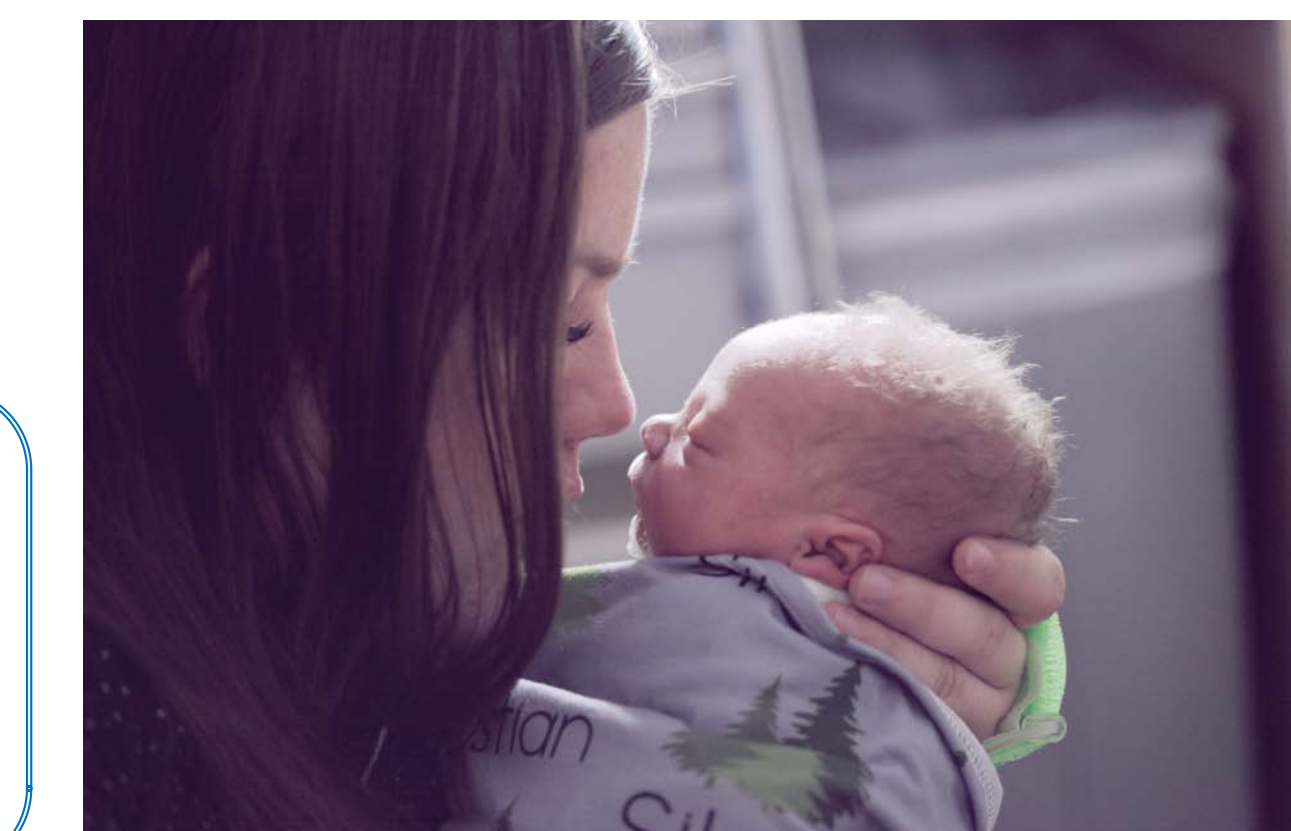


Qualitative Responses

"I don't feel confident or comfortable in caring for pediatric EOL/palliative patients."

"I think this is a very important part of the care continuum."

"Providing palliative nursing care to a pediatric patient frightens me."



"We should see more peds than we do. I suspect many die inpatient..."

"Who more than parents of dying children need our support??"

"I'm just not certain I could administer medications to a child who is dying, or be there to witness that death."

"I wish there was more available education and support to broaden our care to younger children and have adequately trained nurses on staff."

"I would be honored to provide pediatric hospice care, but our agency does not offer this."

"Some of my current skills translate to that population but many do not."

"I would love to have more education regarding peds EOL in the home."

Implications

- Survey results are mixed regarding knowledge and comfort with caring for dying children
- Hospice nurses would value further pediatric-specific education
- Participants who had received recent pediatric education felt they had the skills for self-care while caring for this population
- There are few pediatric-specific hospice organizations, it is critical that access be expanded through more pediatric training and availability of palliative and EOL care

Acknowledgements/References

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