Background

- Palliative care for children begins at diagnosis (WHO, 2013).
- Indiana’s infant mortality rate (2009) was 7.8%; majority diagnoses required NICU admissions (March of Dimes, 2013).
- Of all neonatal deaths in the NICU, 74% to 83% are preceded by withdrawal of medical treatment (Lewis, 2012).

Review of the Literature

- Search: The databases searched using the key terms and inclusion criteria were JBI, National Guideline Clearinghouse, Cochrane, CINAHL, MEDLINE (EBSCO), PubMed, ProQuest Nursing & Allied Health Source, hand search, reference lists, professional websites.
- Key terms used: palliative care, end-of-life, moral distress, barrier, nurse, newborn nurse, and neonatal nurse.
- Inclusion criteria: subjects were nurses working in NICU, English print, published 2003-2013, setting in NICU, moral distress or perceived barriers to palliative care measured.
- Results: CINAHL 4; PubMed 9; all other sources 0.

Synthesis of the Evidence

- Articles: 1 level I (EBP clinical guideline based on IR); 2 level IV (quasi-experimental); 5 level VI (descriptive); 4 level VII (EBP guidelines based on LR/expert opinions, narrative review, expert opinion).
- Outcomes measured: nurses’ perceived barriers to palliative care, moral distress, causes of moral distress, nurses’ comfort with palliative care, and recommendations for neonatal palliative care.
- Quality: low to high; guidelines without rigorous design and poor research design for some descriptive studies; quasi-experimental had strong designs.

PICTOT

In neonatal nurses working in the neonatal intensive care unit (NICU), how does establishing a palliative care protocol including nursing education regarding palliative care and a patient care team as compared to the present palliative care protocol affect nurses’ perceived barriers to palliative care and moral distress within three months?

Decision to Change Practice

Evidence supports the following recommendations:
- Nursing educational sessions about neonatal palliative care (Diak, Wolff, Bos, Haney, & Dichter, 2012; Rogers, Baligi, & Gomez, 2008; Zhang & Lane, 2013).
- Formation of care team consists of nurses, physicians, nurse practitioners, social worker, chaplain, pediatrician, lactation consultant, and hospice representative (Gale & Brooks, 2006; NANN, 2010).
- Introduction of neonatal palliative care protocol consisting of 6 phases: pre-resolution, introduction to palliative care, initiation to palliative care, dying process, death, and bereavement (De Lisle-Porter & Podruchny, 2010; Gale & Brooks, 2006).

Implementation

- Sample: Nurses with greater than 6 months NICU experience. Pre-intervention participants (n=54); post-intervention participants (n=44).
- Setting: Level III NICU in northern Indiana.
- Theoretical Frameworks: Corley’s Moral Distress theory and Stetler model.
- Design: Pretest -posttest design.
- Intervention: Protocol included:
  - formation of a care team;
  - communication tool;
  - three educational sessions conducted and recorded;
  - participants’ completion of surveys pre- and post-intervention.

Evaluation

- Neonatal Palliative Care Attitude Scale (NiPCAS): Measures 16 potential barriers to palliative care using a Likert scale of 1 (strongly agree) to 5 (strongly disagree).
- Moral Distress Scale (MDS): Measures 21 potential causes of moral distress on Likert scale of 0 (never) to 4 (very frequently) for frequency of cause, 0 (none) to 4 (great extent) for intensity of distress, and moral distress which is the product of frequency and intensity.

Table 1: Barriers (Significant Findings)

<table>
<thead>
<tr>
<th>Concept</th>
<th>Mean Pre-SD(n)</th>
<th>Mean Post-SD(n)</th>
<th>t</th>
<th>df</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical staff support of palliative care</td>
<td>2.53 (0.63/43)</td>
<td>2.30 (0.46/43)</td>
<td>2.031</td>
<td>42</td>
<td>0.049</td>
</tr>
<tr>
<td>Physical environment for palliative care</td>
<td>4.27 (0.90/44)</td>
<td>3.91 (0.96/44)</td>
<td>3.216</td>
<td>43</td>
<td>0.002</td>
</tr>
<tr>
<td>Palliative care policies or guidelines</td>
<td>2.90 (1.21/42)</td>
<td>2.36 (0.66/42)</td>
<td>2.634</td>
<td>41</td>
<td>0.012</td>
</tr>
<tr>
<td>Option of palliative care given to families</td>
<td>2.88 (1.05/43)</td>
<td>2.51 (0.94/43)</td>
<td>2.075</td>
<td>42</td>
<td>0.044</td>
</tr>
<tr>
<td>Expression of opinions, values, and beliefs about palliative care</td>
<td>3.18 (0.79/44)</td>
<td>2.80 (0.70/44)</td>
<td>2.951</td>
<td>43</td>
<td>0.005</td>
</tr>
</tbody>
</table>

Conclusions

The establishment of the neonatal palliative care protocol significantly decreased nurses’ perceived barriers to palliative care. Nurses felt more positive about:
- medical staff’s supportiveness of palliative care;
- agency’s physical environment for palliative care;
- availability of palliative care policies or guidelines;
- palliative care options given to families;
- team members expression of opinions, values, and beliefs about palliative care.

The establishment of the neonatal palliative care protocol was associated with nurses’ perception of moral distress in the following ways:
- decrease frequency of nurses witnessing false hope given to families and working with unsafe providers were noted;
- decrease in moral distress caused by working with unsafe providers was noted.

Recommendations

- Strengths of the project:
  - high participation rate (70%) and low attrition rate (18.5%);
  - use of internal evidence such as previous clinical agency’s protocol, staff interviews, and video recording of education sessions.

- Recommendations if project was repeated:
  - longer implementation phase to include protocol utilization;
  - family outcomes in the analysis such as satisfaction scores.

- Implications for nursing:
  - include all available evidence to create quality palliative care protocols;
  - more rigorous research regarding neonatal palliative care;
  - include palliative care in nursing curricula and lifelong learning for nurses;
  - include culture, economics, ethics, law, politics, society, and technology in guidance of creating neonatal palliative care protocols.

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