Importance of Cultural Competence in Palliative and Hospice Care in the Underserved Population

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http://www.hpna.org
Objectives

• At the end of this session, participants should be able to:
  • Discuss the ways that culture influences both formal and informal community-based care for persons with serious illness.
  • Describe a community-campus partnership to improve the quality of home care for persons with complex and/or serious illness and their caregivers.
  • Identify resources available through HPNA to help improve the cultural competence among home care providers caring for persons with serious illness and their caregivers.
• Bridges to Healthy Transitions
  • WVU School of Nursing
  • Ethnography - Focus on socio-cultural contexts, processes, and meanings within cultural systems of formal care and informal care networks and rural health disparities.
    • Building Capacity for Rural Integrated Palliative Care (NIH)
    • Elder Transitions in Chronic and Advanced Illness (WV Community Voices)
    • Building Bridges to Integrated Palliative Care: A Lay/Interprofessional Education Collaborative
      • Home care, skilled nursing, medical homes
What is culture?

• Culture is multidimensional and the word implies an integrated pattern of human behavior that is inclusive of patterns of thought, communication, actions, beliefs, social interaction, values, and institutions of race, ethnic, religious, or social groups. (1)

• Culture shapes how an individuals and groups interpret and derive meaning of illness, suffering and death. (2)

• Cultural safety emphasizes the importance of understanding the unique perspectives of individuals within particular social and historical contexts. (3)

• Sociocultural dissonance between curative and palliative care
It might be time for palliative care....
Palliative Nursing is More than EOL Care

• Aims to relieve suffering and to support the best possible quality of life for patients with advanced chronic or life-threatening illnesses and their families.

• Palliative Care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering.

• Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information and choice.

National Quality Forum:  

National Consensus Project: http://www.nationalconsensusproject.org/
Integrated Palliative Care
Palliative Nursing and Culture

- Palliative nursing emphasizes person/family-centered care and demonstrates respect for cultural perspectives, preferences, and practices surrounding illness progression, decision-making, help seeking, family composition, caring, disability, death, dying, and bereavement.

- Tailored communication to person/family level of literacy, health literacy, financial literacy, and numeracy.

- Interpretive services
  - Use of family
  - Written materials

- Address cultural concerns and needs by maximizing cultural strengths, e.g. family, faith, etc.
RESEARCH FINDINGS
What percentage of your clients have more than one chronic illness? (n=221)
What percentage have symptoms that negatively impact quality of life? (n=221)

<table>
<thead>
<tr>
<th>Percentage Range</th>
<th>&gt; 1 CI</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-25%</td>
<td>1.1%</td>
<td>3.7%</td>
</tr>
<tr>
<td>26-50%</td>
<td>8.1%</td>
<td>11.8%</td>
</tr>
<tr>
<td>51-75%</td>
<td>34.4%</td>
<td>41.7%</td>
</tr>
<tr>
<td>76-100%</td>
<td>56.5%</td>
<td>43.3%</td>
</tr>
</tbody>
</table>
Top Symptoms Reported by Elders and Caregivers

Frequency of Report

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty Getting Around</td>
<td>83</td>
</tr>
<tr>
<td>Weakness</td>
<td>72</td>
</tr>
<tr>
<td>Pain</td>
<td>71</td>
</tr>
<tr>
<td>Short of Breath</td>
<td>64</td>
</tr>
<tr>
<td>Tired</td>
<td>59</td>
</tr>
<tr>
<td>Memory Loss</td>
<td>58</td>
</tr>
<tr>
<td>Depressed</td>
<td>58</td>
</tr>
</tbody>
</table>
Elder Survey: (n = 450)
Do elders have unmet palliative care needs?

<table>
<thead>
<tr>
<th>Strongly Agree/Agree</th>
<th>Neutral</th>
<th>Disagree/Strongly Disagree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elder/ Caregiver</td>
<td>54%</td>
<td>23%</td>
<td>15%</td>
</tr>
<tr>
<td>Agency</td>
<td>89%</td>
<td>5%</td>
<td>4%</td>
</tr>
</tbody>
</table>
How often do you not access services that might be helpful for the following reasons? (n=229)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Always/Frequently</th>
<th>Once and a while</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost</td>
<td>92</td>
<td>26</td>
</tr>
<tr>
<td>Independence/pride</td>
<td>72</td>
<td>33</td>
</tr>
<tr>
<td>Social conditions</td>
<td>22</td>
<td>32</td>
</tr>
<tr>
<td>Experience/reputation</td>
<td>40</td>
<td>37</td>
</tr>
<tr>
<td>Concerns confidentiality</td>
<td>31</td>
<td>40</td>
</tr>
<tr>
<td>Distance/transportation</td>
<td>52</td>
<td>39</td>
</tr>
<tr>
<td>Mistrust of outsiders</td>
<td>45</td>
<td>37</td>
</tr>
<tr>
<td>Do not know where to go</td>
<td>43</td>
<td>42</td>
</tr>
<tr>
<td>Filling out applications</td>
<td>41</td>
<td>30</td>
</tr>
<tr>
<td>Domestic abuse</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>Understanding services</td>
<td>46</td>
<td>47</td>
</tr>
</tbody>
</table>
Elder/Caregiver: How important are the following? (n = 229)
How often do you turn to the following for help?

<table>
<thead>
<tr>
<th></th>
<th>Monthly</th>
<th>Weekly</th>
<th>Daily</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child/Teen</td>
<td>5</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Grandchild</td>
<td>6</td>
<td>12</td>
<td>5</td>
</tr>
<tr>
<td>Adult child</td>
<td>9</td>
<td>14</td>
<td>20</td>
</tr>
<tr>
<td>Parent</td>
<td>4</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Grandparent</td>
<td>5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sibling</td>
<td>21</td>
<td>11</td>
<td>8</td>
</tr>
<tr>
<td>Friends</td>
<td>6</td>
<td>18</td>
<td>3</td>
</tr>
<tr>
<td>Neighbor</td>
<td>4</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Church</td>
<td>6</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>
Rural Cultural Themes

• Independence
  • “Give me something so I can help myself”

• Resourcefulness
  • Advocating for self and others

• Importance of kin and cultural scripts
  • “Do I have to die so my daughter can have a life?”
  • “If Aunt Bessie says it ain’t so, it ain’t so”

• Meaning of place and home

• Differing interpretations of illness and transitions
  • Terminology - “chronically ill”
  • Cascade of loss in identity, function, and social interaction over time.
Cultural Themes

• Differing interpretations of treatment options
  • “Meaning” of morphine

• Faith
  • “I put my faith in “Him” because Dr. xxxx is just a man with a degree.”

• Acceptance
  • “It is what it is but you can’t let it get you”

• Preferences
  • “Treat me like I’m human”

• Negative aspects of care
  • They didn’t come, they didn’t listen, they didn’t hear…
  • “There’s no soul in the deal”
Building Bridges to Integrated Palliative Care: A Lay/Interprofessional Education Collaborative

• Community partners – Home Health
  • Panhandle Home Health, Inc. Martinsburg, WV
    • Berkeley, Jefferson, and Morgan County
    • Strong commitment to quality and person/family centered care
    • Great collaborators and people

• Purpose
  • Improve quality of care through the integration of palliative care concepts into standard formal and informal care processes
  • Weaves together characteristics of effective care coordination, palliative care science, and Appalachian culture into an educational program and associated tools and resources for professionals and lay persons.
Processes

- An assessment of knowledge, beliefs, and attitudes about palliative care among formal care providers;
- A cultural assessment of organizations providing care and the community at large; and,
- An assessment of barriers and assets related to integrated palliative care from multiple perspectives, including patients and families.
- Incorporate findings into educational intervention and toolkits.
Outcome Measures

• Provider knowledge, attitudes, self-efficacy to provide palliative care, timely referral to hospice/palliative care; and,
• Patient/caregiver outcomes including symptom and caregiver burden, self-efficacy for managing chronic illness, emergency room and hospital admission rates, and self-reported quality of life.
• Data on symptom and caregiver burden, life course and health transitions, satisfaction with care, evaluation of the toolkit and resource guides, and quality of life will be collected, analyzed, and reported.
What’s in it for home health?

• Improved quality, health outcomes, satisfaction with care
• Person/family centered educational toolkits
  • Care preferences, goals, barriers, and other important information that impacts health outcomes
  • Introduction of palliative care concepts, non-pharmacological interventions to manage symptoms
  • Culturally congruent care through focus on person and family preferences, values, and goals
Summary

• Culture is multifaceted
• Cultural assessments are critical to quality nursing care
  • Ask about what is important and listen
  • Clarify language, meaning, and interpretation
  • Cultural relevance and missed opportunities in practice
• Sociocultural tensions and dissonance can arise
• Palliative nursing cultivates cultural self-awareness related to biases, values, and beliefs and how these shape interactions with colleagues and those persons they care for.
Resources

• Resources for Palliative Care and Cultural Competence
  • HPNA
  • Other
References

