Health Literacy & Palliative Care: Nurse Training

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Importance of Nursing

• Nurses are the frontline of care across disease and settings
• Nurses spend a significant amount of time with family caregivers, providing education and support
• Nurses are centrally involved in patient and family decision-making
• Nurses promote communication among team members, patients, and family
The End-of-Life Nursing Education Consortium

• Began in 2000 with funding from Robert Wood Johnson Foundation
• Almost 170 national courses to date, curriculum in:
  - Core
  - Pediatrics
  - Geriatrics
  - Critical Care
  - Advanced Practice Registered Nurses (APRN)
  - Doctor of Nursing Practice (DNP)
  - International
• Trained over **19,800 trainers in all 50 states** (including District of Columbia) and **86 countries**

ELNEC website: [www.aacn.nche.edu/elnec](http://www.aacn.nche.edu/elnec)
Health Literacy in Palliative Nursing

• Health literacy concerns involve more than just access to palliative care
  – Complex medical words and abbreviations are used to describe medications, medical treatments, procedures, and disease processes with patients/families

• Health literacy impacts quality of care
  – Patients with low health literacy have poor knowledge of medications, impeding medication adherence
Health Literacy in Palliative Nursing

• Health literacy also includes “oral literacy”
  – Oral literacy is composed of speaking and listening skills
  – Lower aural (listening) skills complicate the ability to understand and recall complex oral information and impede medication management

• Analysis of recorded talk revealed:
  – As the grade level of caregiver/hospice team talk increased, caregiver anxiety increased
  – With increased anxiety, caregivers had greater difficulty understanding pain medication

Funding: (R01NR011472, Parker Oliver) Wittenberg-Lyles, et al., 2013a
• Health literacy also involves communication with family caregivers
  – Analyzed video-recorded care planning discussions between hospice team and caregivers revealed:
    • Team members used 6 times as many medical words compared to caregivers
    • Majority of medical words were drug names
    • \( \frac{3}{4} \) of medical words were not explained to caregivers
    • Caregivers provided little response, indicating lack of understanding

Funding: (R01NR011472, Parker Oliver) Wittenberg-Lyles et al, 2013b
Health Literacy in Palliative Nursing

• According to the US National Library of Medicine, the appropriate level of educational health information should range between 6th-7th grade reading level

• Nurse training is needed to develop this communication skill
• Communication (clinical narrative practice)
• Orientation & Options
• Mindful Communication
• Family Caregivers
• Openings
• Relating
• Team

Preferred COMFORT™ SM Reference
• **Orientation**
  – Describing the big picture of a diagnosis
  – Summarizing the disease path

• **Options**
  – Sharing options for treatment and care
    • Explain options that have been provided to patient/family
    • Tailor the format and modality of information presentation
    • Use plain language
Plain Language Planner© (PLP)

- The Plain Language Planner for Palliative Care© is one of the communication tools available in the curriculum.
- It was developed to translate common medications and symptoms into plain language at the 6th grade-level based on five readability indexes.

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Plain Language Explanation</th>
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<tbody>
<tr>
<td>AMITRIPTYLINE (Elavil)</td>
<td>Nerve pain can feel like “tingling”, “burning” or “electrical” zaps.</td>
</tr>
<tr>
<td>DEXAMETHASONE (Baycadron)</td>
<td>This can help with a queasy stomach, and also creates an appetite.</td>
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The PLP includes the following Plain Language Essentials:

• **Active Voice**
  – Example: “use your inhaler” (active)
  – Example: “once an inhaler is used” (passive)

• **Second Person**
  – Use “you” instead of “the patient” or “a person”

• **Limit jargon, define new words**
  – Consider what is medical jargon and what is lay language

• **Speak in short sentences (15 words or less)**
  – Limit the information you provide at one time
Research on the PLP

• Compared the plain language characteristics of explanations before and after the PLP was introduced and utilized by nurses
  – 234 written responses were collected from 155 nurses
  – A comparison of before and after responses:
    • Higher frequencies of plain language after educational session on PLP
    • Greatest improvement occurred in the use of jargon
    • 10% increase in use of active voice

Wittenberg et al., In Press
Trained 30 Interprofessional Hospital-based Palliative Care Teams in January 2015

Four courses offered as part of a new professional training program for oncology nurses funded by NCI to improve patient-centered communication across the cancer trajectory.
Health Literacy Resources

• Plain Language Planner for Palliative Care ©
  - Available as pocket guide
  - Available on Health Communication iOS App
  - Download at Palliative Care Communication Institute website: www.pccinstitute.com
Health Literacy Resources

• Textbook of Palliative Care Communication
  Oxford University Press, 2015
  – Cultural Humility
  – Health literacy and Communication
  – Written Communication
  – Health Disparities
  – Information in Symptom Management
Summary

Plain language is situated to be a productive solution to addressing the challenges of health literacy, especially symptom management, in palliative nursing.
References