A Primer in Palliative Care

Wendy Anderson, MD MS
Associate Professor, Schools of Medicine & Nursing
Attending Physician, Palliative Care Service
Co-Director, Palliative Care Education Program

Innovations in Geriatric Nursing Care Conference
June 6, 2016
Acknowledgement

DorAnne Donesky, PhD, ANP-BC
Associate Adjunct Professor
Department of Physiological Nursing

Founder and Co-Director, Palliative Care Minor and Interprofessional Continuing Education Program
Objectives

- Define palliative care, including primary and consultative models
- Field status update, including areas of need
- Describe key roles for nurses in the ongoing expansion of palliative care, including project examples
- Provide resources for further development
## Confidence: Palliative Care Tasks

<table>
<thead>
<tr>
<th></th>
<th>Not Confident</th>
<th>Somewhat Confident</th>
<th>Confident</th>
<th>Very Confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ensure that patients receive palliative care when needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Describe palliative care to a patient family</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicate the value of palliative care to a physician</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Confidence: Palliative Care Tasks

<table>
<thead>
<tr>
<th>Task</th>
<th>Not Confident</th>
<th>Somewhat Confident</th>
<th>Confident</th>
<th>Very Confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ensure that patients receive palliative care when needed</td>
<td>13%</td>
<td>41%</td>
<td>37%</td>
<td>10%</td>
</tr>
<tr>
<td>Describe palliative care to a patient family</td>
<td>8%</td>
<td>34%</td>
<td>45%</td>
<td>13%</td>
</tr>
<tr>
<td>Communicate the value of palliative care to a physician</td>
<td>10%</td>
<td>35%</td>
<td>42%</td>
<td>14%</td>
</tr>
</tbody>
</table>

Anderson et al, J Pain Symptom Manage 2016
What is Palliative Care?

-www.getpalliativecare.org
National Need for Palliative Care

- High intensity care not in accord with most patient’s wishes
  - 9 in 10 prefer to feel better vs. live longer
  - 1 in 2 die in hospital, 1 in 5 in ICU

- Poor pain control, support, care coordination:
  - 1 in 4 patients – inadequate treatment of pain
  - 1 in 3 patients – inadequate communication, discharge counseling and follow-up care
  - 1 in 3 families – insufficient emotional support
    - Prevalent PTSD, complicated grief

Lynn & Adamson RAND Health 2003
Martin et al Health Affairs 2012
Dartmouth Atlas of Healthcare
Angus et al Crit Care Med 2004
Stanton & Rutherford AHRQ 2005
The Triple Aim for Serious Illness

- Unwanted interventions
- Family distress
- Quality of life
- Survival
- Satisfaction

Patient and family health

Palliative Care

Experience of care

Resource utilization

- Costs
- Net Margin
- ICU Beds
Timing of Palliative Care

- Diagnosis of life-threatening condition or debilitating illness or injury
- Disease modifying treatment
- Palliative care
- Disease progression
- Comfort care
- Hospice
- Bereavement
- Biological death
Growth in Hospital Palliative Care

Dumanovsky et al, J Pain Symptom Manage 2015
Areas of Need: Small, for Profit

https://reportcard.capc.org/
Hospital 39% sufficiency

Community 29% sufficiency

http://www.chcf.org/publications/2015/02/palliative-care-data
### Primary Palliative care

- Provided by all of patient’s clinicians
- Basic management of pain and symptoms
- Emotional support of patient and family
- Basic discussions about:
  - Prognosis
  - Goals of treatment
  - Suffering
  - Code status

### Specialty Palliative care

- Provided by interdisciplinary team of specialists
- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
- Support & coaching of frontline clinicians

---

Quill & Abernethy NEJM 2013
The Special Role of the Nurse

- Intimacy from nurse’s physical role in care:
  - Restoring dignity & worth
  - Compassionate, human presence with suffering
  - Responding to emotions: sadness, fear, helplessness, hopelessness
  - Helping patients & families regain sense of control
# The 4C’s: Key Roles for Nurses

<table>
<thead>
<tr>
<th>Key Roles for Nurses in Communication about Prognosis, Goals of Care, and Palliative Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Convening</strong></td>
</tr>
</tbody>
</table>
| **Checking**                | • Identify family needs for information  
                               | • Ensure that clinicians clearly convey information that families want  
                               | • Ensure that clinicians understand family perspectives |
| **Caring**                  | Identify emotions and respond to feelings |
| **Continuing**              | Follow up after discussions to clarify and reinforce information and provide support |

Krimshtein et al, J Palliat Med 2011
ICU Palliative Care Nursing

- Help bedside nurses gain palliative care skills and integrate them into practice
- Trained hospital palliative care advance practice nurses and nurse educators to provide this education
IMPACT-ICU

Project Components

**Stakeholder Engagement**
- Informed ICU Clinicians & leadership of project
- Addressed concerns
- ICU nurse survey

**Communication Workshop**
- 8-hour long small group workshop
- Role-play: Palliative care communication
- Reflection session: burnout & distress
- Led by palliative care teams & nurses

**Rounding in Target ICUs**
- Advance practice nurses and educators
- Mentor bedside nurses to assess and address palliative care needs
- Provide support at bedside
**Nurse-Patient (Family) Conversation:**
- Elicit patient & family goals and needs
- Elicit understanding of prognosis
- Provide emotional support

**Family Conference:**
- Ensure key topics are discussed
- Ensure patient & family understands information
- Provide emotional support

**Nurse-Physician Conversation:**
- Elicit physician perspective on prognosis and goals
- Present patient, family, nurse perspectives
- Develop plan to address patient & family needs
What is Your Comfort Zone?

Telling vs. Asking
Talking vs. Listening
Giving information vs. Responding to emotion
Skills Practice: “A Toolkit”

Table 3. The NURSE Tool Guides the Practitioner In Verbal Expressions of Empathy

<table>
<thead>
<tr>
<th>Skill</th>
<th>Theme</th>
<th>Example phrase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Naming</td>
<td>State your observation of the patient’s emotion</td>
<td>“I can see you and your husband are concerned about your current condition.”</td>
</tr>
<tr>
<td>Understanding</td>
<td>Legitimize the patient’s emotion</td>
<td>“I can imagine this news may be shocking.”</td>
</tr>
<tr>
<td>Respecting</td>
<td>Praise or acknowledge the patient’s work</td>
<td>“I am so impressed with your work.”</td>
</tr>
<tr>
<td>Supporting</td>
<td>Let the patient know she is not alone</td>
<td></td>
</tr>
<tr>
<td>Exploring</td>
<td>Ask the patient</td>
<td></td>
</tr>
<tr>
<td>Exploring</td>
<td>Ask the patient</td>
<td></td>
</tr>
</tbody>
</table>

Table 1. The Ask-Tell-Ask Strategy: Sample Phrases and Rationales

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Example phrase for AP</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ask</td>
<td>“I am hearing that you have a lot of questions that seem to be about your prognosis. I am happy to answer your questions. What worries you the most?”</td>
<td>Disclosure of specific prognostic information that the patient wishes to know, fosters trust and the therapeutic relationship.</td>
</tr>
<tr>
<td>Tell</td>
<td>The AP discloses the prognostic information that the patient wishes to know at this particular time.</td>
<td>This question helps to clarify the patient's understanding and need for information.</td>
</tr>
<tr>
<td>Ask</td>
<td>“Did my response help answer your question?”</td>
<td>This question helps to clarify the patient's understanding and need for information.</td>
</tr>
</tbody>
</table>

Svarovsky, J Adv Pract Oncol 2013
Palliative care advanced practice nurses and educators

Goal: 2 x month

Focus:
- Primary palliative care assessment
- Plan to address needs
- Support of the nurse
Results: Workshop

- 428 ICU bedside nurses completed workshop
- All 15 skills rated higher after workshop, p<0.01

- Elicit a family’s understanding of a patient’s goals of care.
- Identify and respond to a family member’s expressions of emotional distress.
- Communicate the value of a palliative care consultation to a physician.
- Use self-care practices to prevent burnout and compassion fatigue.

% of ICU Bedside Nurses Who Reported “Excellent” or “Very Good” Level of Skill
Results: Bedside Rounding

Identified palliative care needs (82% of patients): symptoms (51%), family distress (50%), communication (52%)

<table>
<thead>
<tr>
<th>Support Provided by APNs &amp; Educators</th>
<th>% (n=605)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supported nurse</td>
<td>60 (365)</td>
</tr>
<tr>
<td>Family support and communication</td>
<td>49 (293)</td>
</tr>
<tr>
<td>Bedside nurse’s role in palliative care</td>
<td>38 (232)</td>
</tr>
<tr>
<td>Assessing symptoms</td>
<td>36 (216)</td>
</tr>
</tbody>
</table>
Impacts: Themes from Project Leaders

- Increased scope of practice for bedside nurses
- Community and peer support among ICU nurses
- Improved quality of interdisciplinary communication
- Closer relationship between ICU bedside nurses, palliative care nurses and team
- Synergy with other ICU palliative care improvement efforts
UCSF Palliative Care Education

Palliative Care Education Program

UCSF School of Nursing

Palliative Care Minor
NP & CNS Students

Interprofessional Continuing Education
Clinicians in Practice

TeamTalk
Clinicians in training
Continuing Interprofessional Education in Palliative Care: A Longitudinal Learning Experience

Winter - Spring 2017

Palliative care is an interprofessional specialty focused on quality of life for seriously ill patients and their families. It is holistic and person-focused, and improves patient and family health and satisfaction. To meet the palliative care educational needs of practicing clinicians, we developed an advanced interprofessional training program. This 2 quarter-long learning experience teaches:

- Pain and Symptom Management: Including assessing and creating multimodal management plans
- Communication Skills Training: To navigate discussions of serious illness, including prognosis, goals of care, family meetings
- Psychosocial, Spiritual, and Cultural Issues
- Interprofessional Teamwork: Understand roles of different disciplines and enhance cross-disciplinary collaboration
- Ethical Issues in Palliative and End-of-Life Care
- Self-Care: Techniques to foster resilience
- Models of Integrating Palliative Care: An array of settings across the continuum of care

Components & Schedule
- Winter 2017: N203—Palliative and End-of-Life Care Across the Continuum
  Tuesdays 10 am – 1 pm, January - mid-March, 2017
- Spring 2017: N203A—Advanced Communication in Palliative Care
  Wednesdays, 1-3 pm, April - early June, 2017
- Interprofessional Communication Training Sessions
- Mentorship and Consultation with Program Directors

Program Directors

DorAnne Donesky, PhD, ANP-BC
Associate Adjunct Professor
UCSF School of Nursing
Dr. Donesky co-directs the Adult-Gerontology Clinical Nurse Specialist program in the School of Nursing. Her areas of expertise include quality of life for patients with advanced pulmonary disease and communication skills training.

wendy.anderson@ucsf.edu

Wendy Anderson MD, MS
Associate Professor
UCSF School of Medicine
Dr. Anderson leads a program of research, education, and quality improvement with the goal of improving care for seriously ill hospitalized patients. Her projects focus on palliative care in the ICU and interprofessional communication.

Cost & Registration
- Open to nurses, physicians, social workers, therapists, chaplains, pharmacists and other practicing clinicians
- Applications will be available in September 2016
- Course fees will include continuing education credits
- Contact: DorAnne Donesky, PhD, ANP-BC at doranne.donesky@ucsf.edu
Resources

- End-of-Life Nursing Education Consortium (ELNEC)
- VitalTalk Website, App, Online & In Person Trainings: http://vitaltalk.org/
- Center to Advance Palliative Care, OnLine Trainings: https://www.capc.org/providers/courses/
- Palliative Care Certificates: Washington, Colorado
- CSU OnLine: https://csupalliativecare.org/
Contact

Wendy.Anderson@ucsf.edu

DorAnne.Donesky@ucsf.edu