Palliative Care For Older Adults in the Community

Nurses Leading the Way

Carol O. Long, PhD, RN, FPCN
Capstone Healthcare Group
Co-Director, Palliative Care for Advanced Dementia - Beatitudes Campus
Adjunct Faculty, Arizona State University College of Nursing and Healthcare Innovation
Phoenix, Arizona, USA

The World is on the cusp of profound demographic, social, and financial change with increasing numbers of older people who have complex, chronic diseases...

- How do we assure that:
  - Everybody (older adults) has access to excellent palliative care?
  - There are trained staff/caregivers?
  - Palliative care practice is evidence-based?
- What are the challenges, opportunities and future for palliative care and what role do nurses play?
What is Palliative Care?

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”


Palliative Care Worldwide

4-part typology depicting palliative care development across the globe (n = 234)

1. No known activity, N=75 (32%)
2. Capacity-building activity, N=23 (10%)
3. Localized hospice-palliative care provision – isolated, N=74 (31.6%); and generalized, N=17 (7.3%)
4. Integrated into mainstream medicine – preliminary, N = 25 (10.7%); and advanced integration, N=20 (8.5%) - Singapore and U.S.

Palliative Care Barriers → Needs (1)

- Rapidly aging population
- Shift to non-communicable diseases as the cause of death in older adults – chronic illness with long disease trajectories
- Capacity-building is inadequate:
  - Limited resources
  - Logistical barriers
  - Rules and regulations
- Societal norms:
  - Failure to acknowledge limits of medicine
  - Denial of death


Palliative Care Barriers → Needs (2)

Singapore

Life Expectancy

<table>
<thead>
<tr>
<th>Year</th>
<th>Male</th>
<th>Female</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>1960</td>
<td>61.7</td>
<td>65.7</td>
<td>63.7</td>
</tr>
<tr>
<td>1970</td>
<td>65.4</td>
<td>70.2</td>
<td>67.7</td>
</tr>
<tr>
<td>1980</td>
<td>68.9</td>
<td>74.2</td>
<td>71.5</td>
</tr>
<tr>
<td>1990</td>
<td>71.9</td>
<td>76.9</td>
<td>74.3</td>
</tr>
<tr>
<td>2000</td>
<td>76.1</td>
<td>80.1</td>
<td>78.1</td>
</tr>
<tr>
<td>2010</td>
<td>79.5</td>
<td>84.9</td>
<td>82.1</td>
</tr>
</tbody>
</table>

http://www.worldlifeexpectancy.com

Causes of Death

<table>
<thead>
<tr>
<th>Top 10</th>
<th>Cause</th>
<th>Rate*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Coronary Heart</td>
<td>82.39</td>
</tr>
<tr>
<td>2</td>
<td>Flu/Pneumonia</td>
<td>73</td>
</tr>
<tr>
<td>3</td>
<td>Stroke</td>
<td>33.75</td>
</tr>
<tr>
<td>4</td>
<td>Lung Cancers</td>
<td>27.53</td>
</tr>
<tr>
<td>5</td>
<td>Colon-Rectal Cancer</td>
<td>18.08</td>
</tr>
<tr>
<td>6</td>
<td>Breast Cancer</td>
<td>16.91</td>
</tr>
<tr>
<td>7</td>
<td>Liver Cancer</td>
<td>11.33</td>
</tr>
<tr>
<td>8</td>
<td>Diabetes Mellitus</td>
<td>10.85</td>
</tr>
<tr>
<td>9</td>
<td>Lung Disease</td>
<td>9.91</td>
</tr>
<tr>
<td>10</td>
<td>Kidney Disease</td>
<td>8.79</td>
</tr>
</tbody>
</table>

*Age-adjusted Rate=#/100,000
Palliative Care Barriers → Needs (3)

- Palliative care strategies are not widely known
  - Infrastructure and policies to support palliative care is lacking
  - Medical conditions warranting palliative care
  - Limited / developing
    - Palliative care training
    - Research and utilization
  - Recognition of quality of life: physical, psychological, social and spiritual needs


Palliative Care is gaining ground...

- Research is advancing: outcomes (quality), access and cost
- Education is evolving
- Practice is becoming more defined
  - Competencies
  - Certification: physician, social work, nursing
  - Standards of care and practice / consensus guidelines
  - Changing regulations

Numerous advantages, benefits, changes and challenges...
Session Objectives:

1. Provide an overview of palliative care, highlighting current efforts in U.S. - research, education, and practice
2. Review current benefits and challenges
3. Examine ways nurses can ‘lead the way’ in providing excellent palliative care in the community for older adults

Palliative Care in the U.S.

- Major studies suggest that Americans prefer to die at home (SUPPORT, 1995; IOM, 1997; Last Acts, 2002)
  - Hospital 35.3%
  - Nursing Home 27.9%
  - Other (includes hospice) 8%
  - Emergency Room 2%
  - Home 23.7%
- Site of death by age (2007)
  - Nursing Home 33% ages 75+
  - 42% ages 85+

National Center for Health Statistics, 2011
Conceptual Shift in Palliative Care

Old

Life Prolonging Care

Medicare Hospice Benefit

New

Life Prolonging Care

Hospice Care

Palliative Care

Death

Patient-Centered Care… What Do Patients with Serious Illness Want?

Study of 126 patients in 3 groups (dialysis, HIV, long-term care) – 5 themes:

1. Provide good pain and symptom control
2. Avoid inappropriate prolongation of the dying process
3. Achieve a sense of control
4. Relieve burdens on family
5. Strengthen relationships with loved ones

Patient-Centered Care…
What Do Family Caregivers Want?

Study of 475 family members 1-2 years after bereavement:

- Loved one’s wishes honored
- Inclusion in decision processes, honest information
- Support/assistance at home, privacy
- Practical help (transportation, medicines, equipment)
- Personal care needs (bathing, feeding, toileting)
- 24/7 access to care
- To be listened to
- To be remembered and contacted after the death


Why Palliative Care? Quality.

Defined as care that is:

1. Beneficial – equal or better survival
2. Patient and family-centered – service dyad
3. Efficient – cost-savings; care in most appropriate settings
4. Timely – reduces readmissions
5. Safe – improves inter-disciplinary care coordination
6. Equitable – benefits everyone; everyone wants comfort!
7. Better outcomes – less pain and burdensome symptoms, less suffering

Center to Advance Palliative Care [http://www.capc.org](http://www.capc.org)
National Quality Forum [www.qualityforum.org](http://www.qualityforum.org)
Institute for Healthcare Improvement [www.ihi.org](http://www.ihi.org)
Smith & Cassel. (2011). The Future of Palliative Care, Conversations in Palliative Care. HPNA.
Palliative Care Research

Research is a driving force for change in practice

- Center to Advance Palliative Care (CAPC) and Research Center
- National Consensus Project for Quality Palliative Care (2013)
- National Institute of Nursing Research

Palliative Care in Patients with Lung Cancer

- Randomization of 151 adults (age 65 ± 9) newly diagnosed with metastatic non-small cell lung cancer
  - Palliative care (PC) with standard oncological care
  - Standard oncological care alone
- Patients assigned to the PC had...
  - Better quality of life (Fact-L) 98.0 vs. 91.5 (p = 0.03)
  - Fewer depressive symptoms 16% vs. 38% (p = 0.01)
  - Longer median survival rates 11.6 months vs. 8.9 months (p = 0.02)

Palliative Care in Patients with Advanced Cancer

- 322 patients with advanced cancer (e.g., GI, Lung) randomized to
  - Usual care group (no palliative care)
  - ENABLE—Educate, Nurture, Advise, Before Life Ends intervention
- Those who received the intervention had:
  - Survival 14 months vs. 8 months ($p = 0.14$)
  - Lower symptom intensity ($p = 0.06$)
  - Lower depressed mood ($p = 0.02$)
- Those patients who died during the study but received the intervention had:
  - Higher quality of life ($p = 0.02$)
  - Lower depressed mood ($p = 0.03$)


Dementia in the U.S.

- Approximately 8% of people older than age 65 have a dementia
- Approximately 50% of people over age 85 have a dementia
- As many as 5.4 million people in the United States are living with Alzheimer’s Disease
- Alzheimer’s and related dementia triple healthcare costs for Americans age 65 and older
- Alzheimer’s is the 6th leading cause of death for individuals 65 and over
- 70% live at home in early – mid stage – 90% live in nursing home in late stage

The Burden of Dementia...

- Financial and emotional costs to families and family caregivers
  - >90% have a family caregiver (>70% are women)
  - 20-40% of caregivers report depression
  - Caregivers reporting emotional strain have a 1.5 fold increased risk of death
- Years of slowly progressive dependency
- Loss of work, family network, social supports, health, and savings
- Untreated physical symptoms and burdensome iatrogenic interventions

Clinical Course of Advanced Dementia

- CASCADE: Prospective study of 323 nursing home residents with advanced dementia from 22 nursing homes over 18 months
  - Overall mortality rate of 53%
  - 41% developed pneumonia; 6 month mortality of 47%
  - 53% had a febrile episode; 6 month mortality of 45%
  - 86% an eating problem; 6 month mortality of 39%
  - 39% in pain

Burdensome Interventions in Nursing Home Residents

- Over last 18 months of life...
  - 34% treated with IV therapies
  - 17% hospitalized
  - 10% taken to the emergency department
  - 8% were tube-fed
  - 22% referred to hospice
- 96% of proxies stated that comfort should be the primary goal


The New York Times

December 31, 2010
The Vanishing Mind Giving Alzheimer’s Patients Their Way, Even Chocolate – by Pam Bellock

**Featured Palliative Care for Advanced Dementia at Beatitudes Campus**

Comfort care that is holistic in nature and includes interventions which address symptom control, psychological needs of patients and families, quality of life, dignity, safety, respect for personhood, and an emphasis on the use of intact patient abilities and manipulation of the environment (Kovach, Wilson & Noonan, 1996)

http://www.nytimes.com/2011/01/01/health/01care.html
Palliative Care Nursing Education

- Undergraduate: palliative care is part of nursing curricula
- Graduate:
  - Hartford Institute for Geriatric Nursing “Try This” series
  - Palliative care sub-specialty in graduate programs
- Continuing Education: End of Life Nursing Education Consortium (ELNEC)- Geriatric and new APRN curriculum
- Competencies for the Generalist Hospice and Palliative Nurse (2010)


BSN Nursing Competencies for End-of-Life

- Precepts underlying hospice/palliative care are essential principles for all end-of-life care
- Such precepts include the assumptions that individuals live until the moment of death
  - Care until death may be offered by a variety of professionals; and that such care is coordinated, sensitive to diversity
  - Attends to the physical, psychological, social, and spiritual concerns of the patient and the patient’s family. These precepts provide guidance to the development of the educational preparation of nurses

Certification and Credentialing

- Certification from Hospice and Palliative Nurses Association
- Registered and Licensed Practical Nurses
- Advance Practice Registered Nurse
- Certified Nursing Assistant
- Evidence supports certification

Schmal, B. (2012). The vital role of professional certification. JHPN, 14, 177-181

Scope and Standards of Practice

- Hospice and Palliative Nursing (2007)
  - Hospice and Palliative Nurses Association (HPNA)
- Gerontological Nursing Practice (2010)
  - American Nurses Association (ANA)
- BOTH target nursing process and practice standards across healthcare settings
Extending Palliative Care Across Community Settings

- Early identification of services
- Expand the concept of healing
- Target older adults with life-threatening conditions
- Anticipate comfort needs, healthcare decisions, maximize quality of life
- Becoming educated

“Death is not the ultimate tragedy in life....

The ultimate tragedy is depersonalization--dying in an alien and sterile environment, separated from the spiritual nourishment that comes from being able to reach out to a loving hand, separated from a desire to experience things that made life worth living, separated from hope.”

- Norman Cousins, 1979

Palliative care across community settings brings hope and comfort that supports quality of life near the end of life.
Where is Palliative Care Nursing?

Palliative care should be everywhere and for everybody! Palliative care should be in...
- Acute care / hospitals
- Clinic settings
- Home Health Care
- Long-term Care
- Day Care
- Senior Settings / Congregate Housing

This is our community!

Nurses “Lead the Way”

Palliative Care Nursing Roles in the Community
Nurses ‘Lead the Way’ in Excellent Palliative Care

- Understands living and dying as natural process with various factors influencing the trajectory of illness
- Really ‘knows’ an older adult as a person and not a disease; person-centered and person-directed
- Thinks and practices holistically: Quality of life incorporates physical, psychological, social, and spiritual aspects of care along the continuum from wellness through end-of-life (Ferrell, 1990)
- Uses palliative care principles that are relevant and applicable within and across settings by maximizing resources and meeting the needs of the older adult
- Executes community-based practice principles from health through death

Nurses ‘Lead the Way’ in Excellent Palliative Care

- Maintains currency of knowledge and practice standards to respond to changing needs: is a critical-thinker
- Advocates for the person: abides by ethical principles, focuses on empowerment, and constantly evaluates the results
- Is resourceful
- Uses best evidence that comes from research
- Incorporates essential competencies into curriculum and practice
Nurses ‘Lead the Way’ in Excellent Palliative Care

- Knows the team and maximizes collaborative efforts – move from multidisciplinary to interdisciplinary models of practice
- Develops coalitions, consortiums or other connections to improve networks that foster collaborative practice in the care of older adults
- Summary: Nurses can and need to lead the way in excellent palliative care across health care settings for older adults!

Summary: Could this be the Future?

1. All patients and families will know to request and receive palliative care when facing a serious or life-limiting illness – regardless of setting
2. All healthcare professionals will have the knowledge and skills to provide palliative care
3. All healthcare institutions will be able to support and deliver high quality palliative care
4. Palliative care is no longer the ‘orphan’ service...it will be incorporated into the healthcare system
5. Nurses can and will ‘lead the way to’ successful palliative care that is community-focused
“Life is pleasant. Death is peaceful. It's the transition that's troublesome.”

Isaac Asimov

U.S. Science Fiction Novelist and Scholar (1920 - 1992)

“You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die.”

Dame Cicely Saunders
Founder of St. Christopher’s Hospice
London, England

Thank you!