

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.”

World Health Organization. (2012). *WHO Definition of Palliative Care*. Available at <http://www.who.int/cancer/palliative/definition/en/>

Palliative Care Worldwide



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

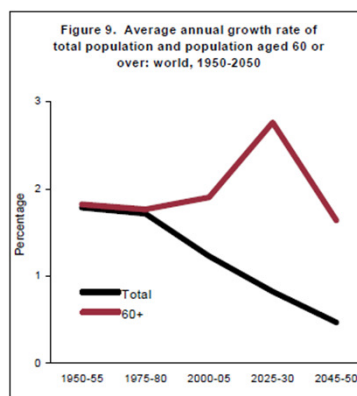


1. No known activity, N=75 (32%)
2. Capacity-building activity, N=23 (10%)
3. Localized hospice-palliative care provision – isolated, N=74 (31.6%); and generalized, N=17 (7.3%)
4. Integrated into mainstream medicine – preliminary, N = 25 (10.7%); and advanced integration, N=20 (8.5%) - **Singapore and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

World Palliative Care Alliance. (2011). *Mapping Levels of Palliative Care Development: A Global Update 2011*. Author.

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



United Nations. *World Population Ageing 2009*.

Palliative Care Barriers → Needs (2)

Singapore

Life Expectancy

Year	Male	Female	All
1960	61.7	65.7	63.7
1970	65.4	70.2	67.7
1980	68.9	74.2	71.5
1990	71.9	76.9	74.3
2000	76.1	80.1	78.1
2010	79.5	84.9	82.1

<http://www.worldlifeexpectancy.com>

Causes of Death

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

*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

Bruera, E. et al. (2004). *Palliative Care in the Developing World. Principles and Practice*. IAHP Press.
 Ferrell, B. (2010). Trends for the Future. In *Core Curriculum for the Generalist Hospice and Palliative Nurse*. HPNA
 Fletcher & Panke. (2012). Improving value in health care. *JHPN*, 14(7), 452-459.
 Open Society Foundations (n.d.). *Palliative Care as a Human Right*. Author.
 Smith & Cassel. (2011). The Future of Palliative Care. In *Conversations in Palliative Care*. HPNA.
 UN Human Rights Council: Access to Palliative Care: A Neglected Component of the Right to Health.
<http://www.inhhro.org>

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...

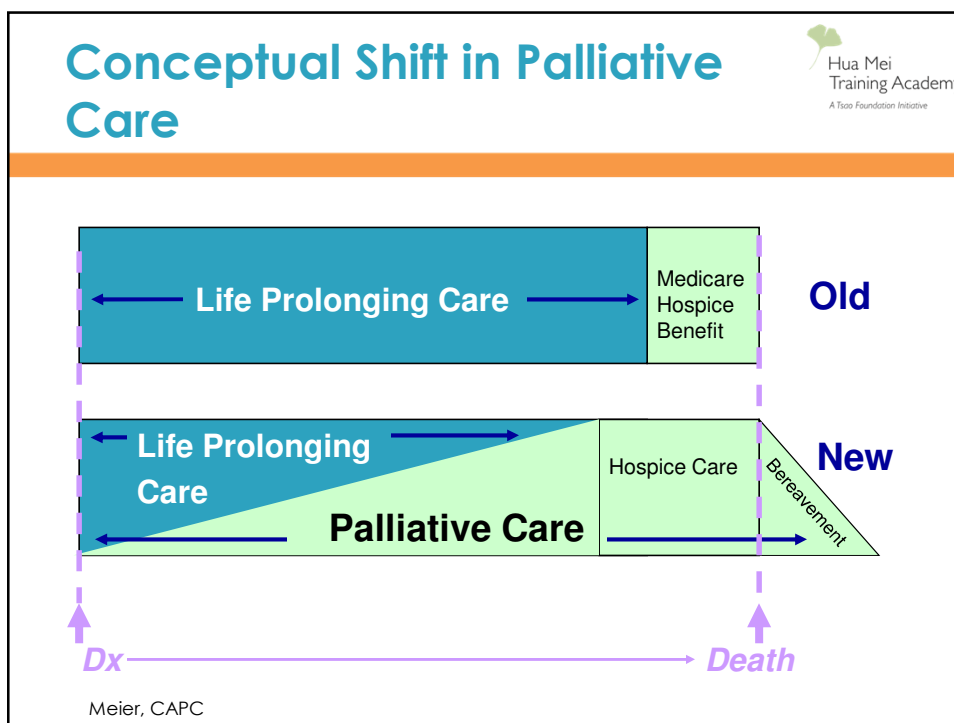
Session Objectives:

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)
- Site of death in U.S.(2007)
 - 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



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

Hua Mei Training Academy
A Tsao Foundation Initiative

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

Singer et al. (1999). Quality end of life care patients' perspectives. *JAMA*, 281(2),163-168.

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

Tolle et al., (1999). *Oregon Health Report Card*.

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>
 National Quality Forum www.qualityforum.org
 Institute for Healthcare Improvement www.ihl.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)
- Hospice and Palliative Nurses Association Research Agenda (2012-2015)
- 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 ($p = 0.02$)

Temel et al. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer, *NEJM*, 363, 733-42

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 ($p = 0.03$)

Bakitas et al. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized control trial. *JAMA*, 302, 741-749.

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

Alzheimer's Disease Facts and Figures. (2012). From www.alz.org

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

Mitchell, et al. (2009). The clinical course of advanced dementia. *NEJM*, 361, 529-1538.

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**



Mitchell, et al. (2009). The clinical course of advanced dementia. *NEJM*, 361, 529-1538.

The New York Times

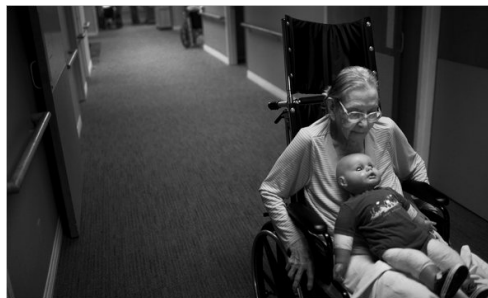


December 31, 2010

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 **ELNEC**
- Competencies for the Generalist Hospice and Palliative Nurse(2010)



ELNEC.(2012). *History, statewide effort and recommendations for the future. Advancing palliative nursing care.* Archstone Foundation.

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*



AACN (2000). *A peaceful death: BSN competencies.*

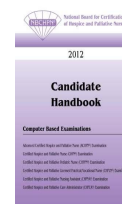
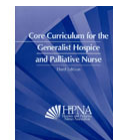
<http://www.aacn.nche.edu/elnecc/publications/peaceful-death>.

International Council of Nurses. (1997). *Basic Principles of Nursing Care.* Washington, DC: American Nurses Publishing

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

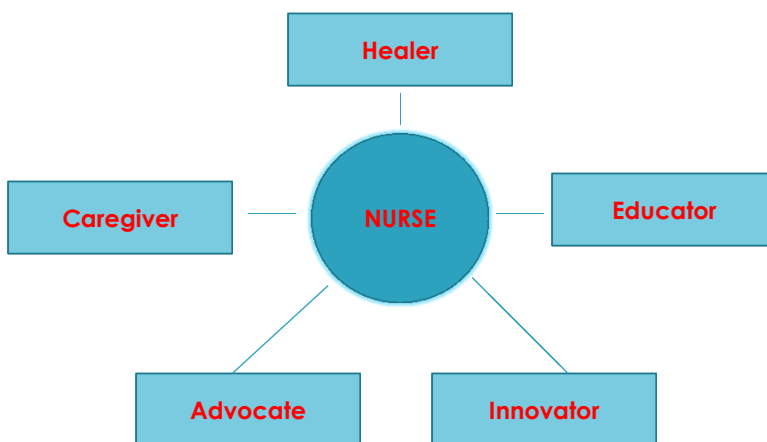
Day Care

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!