Infusing Palliative Care into Your Organization

Carol Buller ARNP

Objectives

- Recognize changes in the population which will necessitate need for palliative care.
- Define palliative care.
- Discuss opportunities and barriers to delivering of palliative care in the elder care settings.
- Discuss advance care planning approaches.

Why we need palliative care

Death and Dying in America

Changes over the last century

- Early 1800s
- Early to mid 1900s
- Current experiences

Changes in aging

- Baby boomers reach retirement age this year
- Oldest Old fastest growing population group
- 25% of all deaths in US occur in NH
- 1 in 4 persons will die in a NH/AL
- By 2030 - 40% of all deaths in US will occur in NH
- Increasing rise in number of residents with dementia

What this means for aging services

- Increasing role in caring for persons with dementia and frailty
- Increasing role in caring for dying
- Residents who return from hospital "sicker and quicker"

How we die

- Degenerative or chronic disease
  - Coronary artery disease
  - Cerebral vascular disease
  - COPD
  - Diabetes
  - Alzheimer’s disease
  - Chronic kidney disease
Illness Trajectories - #1
Sudden death – unexpected cause
< 10% (MI, accident, etc.)

Illness Trajectories - #2
Steady decline – short terminal phase

Illness Trajectories - #3
Slow decline – periodic crisis - death

Illness Trajectories - #4
Lingering, Expected Death

Barriers to quality care at end of life
- Restorative and rehab model of care
  1987 Omnibus Reconciliation Act
  Attain or maintain “highest practical” physical mental & psychosocial well being
- Biomedicalization of Aging
  a medical problem to be fixed
  treatment is expression of care
- Reimbursement for rehab not palliative services

Cultural Confusion
- Death is inevitable for all permanent residents
- Weight loss, skin changes, progressive debility = poor quality of care
- Sx occur in the normal process of aging with decline to death
Outcome of current approach

- Failure to acknowledge limit of medicine
  - Futile care
  - Use of inappropriate and aggressive curative treatment
  - Prolonging the dying process
  - Contribute to physical & emotional suffering
- Denial of death
  - Prevents residents from accessing palliative care

Hospice

- Why do we like Hospice for our residents?
  - Focus on comfort
  - IDT approach
  - Help with care
  - Meds and equipment
  - Continuous care
- OR is it that we are no longer responsible or held accountable because the person is declining and dying?

Palliative Care

- Approach that improves QOL of patients & families
- For persons facing problems with life-threatening illness
- Prevention and relief of suffering
  - Early identification
  - Assessment
  - Treatment of pain, physical, psychosocial & spiritual needs
  - World Health Organization 2002

Principles of palliative care

- Provide relief from pain & other distressing sx
- Affirms life – sees dying as a natural process
- Intends neither to hasten or postpone death
- Integrates psychological & spiritual aspects of care
- Offers a support system to help people live actively as possible until death, and to families to help cope during illness & bereavement

Palliative care & Hospice Care

- Palliative care – control or alleviate sx
- Multidisciplinary services and care of whole person/family
- Hospice services
  - Life limiting illness – 6 months or less
  - Patient elects
  - Medicare, Medicaid, private insurance covered benefit
Palliative Care & LTC

- Good long term care is good palliative care.
- Good geriatric care is good palliative care.
- Good resident directed (centered) care is good palliative care.

Current approach

- Rehab and Restorative Treatment
- Palliative Care
- Hospice

Continuum of care

- Disease-Modifying Treatment
- Rehabilitation
- Restorative care
- Palliative Care
- Hospice Care
- Bereavement Support

Terminal Phase of Illness

Focus is on quality of life along the continuum

Predicting death

- Cancer – predictable dying trajectory
- Chronic conditions: COPD, CHF, Dementia
  - Not easy
  - Most NH residents die with multiple, chronic illness
  - Unpredictable dying trajectory
  - Last phase of life may last months to years

No limits to palliative care

- Palliative care essential to EOL care
- Not bound by end of life
- Both restorative and palliative care available on admission for all residents.
- Palliative care is complimentary
- Outcome: resident Quality of Life

Advance care planning

Family support and preparation
Is a palliative approach possible?

- Complimentary with resident centered care models
- Can be used with restorative models
- Used with hospice and EOL care

Where to begin?

- Adapt systems of care
  - What are you doing now that focuses on comfort and sx management?
  - What opportunities do you have?
- Team approach – interdisciplinary team
  - Core: medical director, nursing, social work
  - Team: rehab, dietary, individual care staff members
- Outcome goals
  - Increase opportunities for advance care planning
  - Improve pain recognition & management

Quality Improvement Process

- Evaluate & improve resident QOL
- Gather and use data to protect against regulatory enforcement of restorative care
  - IDT assessment and interventions based on
    - Resident and family choice & preferences
    - Goals of care
    - Burdens and benefits of treatments
    - Medical information
      - Diagnoses, current disease progression

Resources

- Hospice partners
- On line resources
- Center to Advance Palliative Care
  - Palliative care in LTC
  - References
  - Exemplars

Advance Care Planning

- During the first months after admission
- Care plan meetings
  - Review what is known about condition
  - Review advance directives
  - Discuss and prioritize the 3 major goals of care
    - Maximizing comfort
    - Maintaining function
    - Prolonging life

Advance Care Planning

- Talking with residents and families/DPOAHc about preferences for future care.
- Asking about goals and values.
- What are your hopes?
- What do you know about your health/condition?
- Future preferences & decisions for treatments
How to introduce ACP

- Talk about it
- Have you thought about...
  - “What would you do if you get worse?”
  - “Would you want to go to the hospital for treatment?”
  - “What was that hospital experience like for you?”
  - “What does “comfort” mean to you?”

Documenting the ACP conversation

- Advance Directive reviewed with
- Discussed life sustaining treatment decisions
  - CPR
  - Antibiotics
  - Medically Administered Fluids and Nutrition
  - Comfort feeding
- Resident preferences are for: (resident’s words)
- Resident/family request more information on:
- Health care provider notified of this discussion.

Transportable Physician Orders for Patient Preferences - TPOPP

- Document treatment preferences
  - CPR, intubation, mechanical ventilation
  - Other life-sustaining treatment preferences
  - Physician order set
  - Transportable orders across health care settings
  - Improves EMS ability to treat according to preferences

Pain management

- Many residents still suffer with daily pain without adequate pain management.
- What are we doing well?
- What opportunities do we have to improve on pain management?
  - Education
  - Assessment tools
  - Follow through
  - Use on non pharmacologic modalities

What about weights and wounds?

- Palliative care does not obviate the need for excellent assessments and proactive care.
- Recognize that weight loss and changes in skin occur as a normal manifestation of the process of dying.
- Treat the person not the number.

A story
Will any one remember me?

- What is it like to die in this facility?
- What could it be like to live and die in this place?
- Education
  - Core team: SW, DON, Hospice nurse, APN, chaplain
  - Care staff members
  - Nursing team
  - Residents/families

Palliative Care Team Meeting

- Triggers for palliative care review
- Look for reversible conditions
- Symptom management
- Discuss goals and preferences with resident/family
- Develop the palliative care plan
- Refer to Hospice if appropriate

Other Outcomes

- Memorial board
- Pocket cards of individualized comfort care plan
- Nutrition trays for families
- Bedside memorial
- Memorial pall – covering
- Score Card review with the direct care staff
- Yearly remembrance for staff & residents

It was a time of purpose

- Compassionate care extended to other residents
- More attention to pain management
- Considered an exemplary organization by are hospice teams and referral resources
- Staff satisfaction and retention

References