Palliative care: nursing roles and considerations for improvements

March 2018
Facilitator: Margaret Fitch
Toronto Canada
Plan for session

- Review key concepts of palliative care
- Highlight nursing standards, roles and competencies in palliative care/end-of-life care
- Discuss what you think will be similar or different in Thailand
Hospice palliative care (CHPCA)

- Aims to relieve suffering and improve quality of living and dying
- Strives to help individuals and families
  - Address physical psychological social spiritual and practical issues and their associated expectations needs hopes and fears
  - Prepare for and manage self-determined life closure and the dying process
  - Cope with loss and grief during the illness and bereavement experiences
- Aims to treat all active issues and prevent new issues from occurring
- Promotes opportunities for meaningful and valuable experiences, personal and spiritual growth, and self actualization
Who needs palliative care?

- Who is a palliative care patient?
Hospice palliative care

- Is appropriate for any person and/or family living with or at risk of developing a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.

- May complement and enhance disease-modifying therapy or it may become the total focus of care.
Guiding principles

- Patient/family centered
- Ethical
- High quality
- Safe and effective
- Accessible
- Adequately resources
- Collaborative
- Advocacy-based
- Evidence-informed and knowledge-based
- Team based/circle of care
Bow tie model

Disease Management

PAIN AND SYMPTOM MANAGEMENT

REHABILITATION
SURVIVORSHIP
Palliative Care

HOSPICE PALLIATIVE CARE UNIT END-OF-LIFE-CARE

BEREAVEMENT

Where is palliative care provided
Hospice palliative care

Australian Population-based Palliative Approach Model

Groups

C

B

A

Needs

Complex

Intermediate

Primary care

Patient movement between levels

Exhibit 1. Original Australian model for population-based palliative approach (See Palliative Care Australia 2005, p.13)
Elements of an Effective Palliative Care Model

- A public health approach that integrates care into national health systems to increase accessibility and sustainability for individuals with life threatening illness across the lifespan.

- Specialist and generalist palliative care provision in all settings across the continuum of care recognizing that palliative care is the responsibility of all health and social care professional regardless of care setting.

- An interdisciplinary approach to address the needs of patients and their families.
Specialist palliative care services

- Composed of health care professional from various disciplines including medicine, nursing and allied health and pastoral care who have specialist palliative care training/education
- Provide direct care and or consultation services in the tertiary, secondary and/or primary care settings
- Provide leadership, research, quality initiatives, training, mentorship and supervision to support the delivery of generalist palliative care by other health professionals
Transitions

- Palliative care patients receive sub-optimal care if appropriate models of care are not in place to facilitate transitions between care settings (community, aged care, hospital, children’s and adult’s services)

- Transitional care models need to ensure that patient and caregivers...can access timely support when status changes or preferences for care changes

- Patient and caregivers may lack knowledge of available services and how to access them...may need help in navigating the transitions
Home based palliative care models

- Support provision of palliative and end of life care to people living in the community (private residence and/or residential aged care facilities)
- Requires involvement of local communities and consideration of mechanisms to provide ongoing support, training and health care professional remuneration
- Key characteristics include:
  - Advanced symptom management and support,
  - Communication and co-ordination
  - A focus on partnering and building palliative care capacity
  - Clarifying goals of care through advanced care planning
- Palliative care principles can be integrated into existing home-based care models to extend services and enhance sustainability
Acute care models

- May consist of specialist consultative services, inpatient palliative care units/beds and/or advanced practice nurse models
- Consultative services provided by hospital teams improve symptom control and quality of life alleviate emotional burdens and improve care giver and patient satisfaction; reduce hospital costs
- Need to be augmented by general practitioner teams and networked to community support services
- Specialist consultative service models focus on:
  - Discussion about prognosis and goals of care
  - Symptom management
  - Pursuing documentation of advanced directives
  - Discussion about foregoing specific treatment
  - Family and patient support
  - Discharge planning
Nursing home models of palliative care

- Older people admitted to a nursing home increasingly have multiple comorbidities.
- Embedding palliative care into nursing homes has proven to be challenging and requires multiple changes at all levels of the system.
- This population is more likely to have poor symptom control, unnecessary hospitalizations, and sub-optimal communication, inadequate advance care planning and families who are dissatisfied with end of life care; less apt to be referred to specialist palliative care services.
- Generalist palliative care model (augmented by specialist services) is recommended for nursing homes.
Hospice palliative care (nurses are in all locations...)

- General practice...
- Specialized units...
- Specialized (inter-professional) teams
- Acute care settings
- Home care and community settings
- Long term care/nursing home settings
Nurses in palliative care

- **Generalists**
  - palliative care is part of their practice/caring for various patient populations

- **Specialists**
  - palliative care is all of their practice/direct care

- **Advanced practice nurses**
  - palliative care expertise, leadership through research and education
Nurse role in palliative care

- advocate for and support persons in their experience of living-dying.
- provide comprehensive, coordinated, compassionate and holistic care.
- attends to pain and symptom management and provides psychosocial, grief and bereavement support.
- includes all areas of practice: clinical, education, administration, research and advocacy.
Dimensions of Nursing in Palliative Care

**Valuing** – believing in the intrinsic value of others, the value of life and that death is a natural process.

**Connecting** – establishing a therapeutic connection (relationship) with the person and their family through making, sustaining and closing the relationship.

**Empowering** – providing care in a manner that is empowering for the person and family.

**Doing for** – providing care based on best practice in pain and symptom management, coordination of care and advocacy.

**Finding meaning** – helping the person and family find meaning in their life and their experience of illness.
Standard: Quality of Living-Dying

- The PC nurse focuses on the quality of the experience of the person who is living with and dying from a life-limiting illness, as well as the experience of the family.

- The PC nurse practices with respect for the personal meanings, specific needs and hopes of the person who is living in the last phase of his/her life and his/her family.
Standard: Comfort

- The PC nurse utilizes a knowledge-based, systematic, holistic and evolving approach to address symptoms and issues specific to the living-dying experience.
The PC nurse provides care throughout multiple illness trajectories of life-limiting illnesses, which may occur over a short period of time (sudden death) or may be a longer process (exacerbations of chronic illness or recurrences of cancer). The PC nurse supports the individual and his/her family through these transitions, the dying process and throughout the grief and bereavement processes.

The PC nurse assists persons and families to access and navigate the health-care system.
The PC nurse practices in accordance with legislation, policies, guidelines and tools pertaining to assessment, information sharing, decision-making, advance care planning, pronouncement of death, after death care, and grief and bereavement support.
Standard: Leadership

- The PC nurse advocates for and promotes high quality and safe palliative care.
- The PC nurse advances HPC nursing through the generation and application of knowledge and research.
- The PC nurse is an essential team member of the inter-professional team and establishes collegial partnerships and contributes to the professional development of students, peers, colleagues and others through consultation, education, leadership and mentorship.
- The PC nurse communicates and advances the distinct contribution of nursing to the inter-professional team.
Standard: Personal and Professional Growth

- The PC nurse recognizes the privileges and challenges of working with persons who are living-dying and their families.
- The PC nurse understands his/her own personal experience in response to suffering and death.
- The PC nurse recognizes his/her personal needs and practices self-care while experiencing multiple losses during the care of persons who are dying and their families.
Caring for people in the final hours is an important and scared aspect of nursing practice.

Care at the end of life must be about whole person care.

It is about the art and science of nursing.
10 core competencies in palliative care - global core competencies for clinical practice in palliative care that are important for all practitioners, irrespective of discipline

- apply the core constituents of palliative care in the setting where patients and families are based
- enhance physical comfort throughout patients’ disease trajectories
- meet patients' psychological needs
- meet patients' social needs
- meet patients' spiritual needs
10 core competencies in palliative care - global core competencies for clinical practice in palliative care that are important for all practitioners, irrespective of discipline

- respond to the needs of family carers in relation to short, medium and long-term patient care goals
- respond to the challenges of clinical and ethical decision-making in palliative care
- practice comprehensive care co-ordination and interdisciplinary teamwork across all settings where palliative care is offered
- develop interpersonal and communication skills appropriate to palliative care
- practice self-awareness and undergo continuing professional development.
Generalist Nurse competencies in cancer control:
- Professional and Ethical Practice
- Holistic Approaches to Care and Integration of Knowledge
- Interpersonal Relationships
- Organization and Management of care
- Personal & Professional Development

Clinical Nurse Specialist competencies in cancer control:
- Clinical Focus
- Patient Client Advocacy
- Education & Training
- Audit & Research
- Consultancy

Advanced nurse practitioners competencies in cancer control:
- Autonomy in Clinical Practice
- Expert Practice
- Professional and clinical leadership
- Research
Nurse Competencies for Palliative Care
Canada - 2010

1. Care of the Person and Family
2. Pain Assessment and Management
3. Symptom Assessment and Management
4. Last Days/Hours/Imminent Death Care
5. Loss, Grief and Bereavement Support
6. Inter-professional /Collaborative Practice
7. Education
8. Ethics and Legal Issues
9. Professional Development and Advocacy
10. Professional Growth and Self-Care
11. Research and Evaluation
12. Advocacy
Process of providing hospice palliative care

- a therapeutic relationship (circle of care) between those who provide care and those who receive it, which evolves with time as familiarity, trust and confidence are established
- a therapeutic process that evolves through a series of therapeutic encounters
- the continued affirmation of the person’s and family’s values and choices
- the understanding that only therapies with a potential for benefit and acceptable risk or burden will be offered
Essential steps of a therapeutic encounter

- Assessment
- Information sharing
- Decision-making
- Care planning
- Care delivery
- Confirmation
Assessment

- History of active and potential issues, opportunities for growth, associated expectations, needs, hopes, fears.
- Examine with assessment scales, physical examination, laboratory, radiology, procedures.
Needs and Examples of Patients with Life-Threatening Illness

**Psychological**
- self-worth
- body image
- coping
- dying

**Social**
- family
- relationships
- school, work

**Spiritual**
- meaning of life
- suffering
- pain
- legacy
- meaning of death

**Informational**
- disease
- procedures
- coping skills
- symptoms
- services
- dying process
- end-of-life decision making

**Physical**
- pain
- fatigue
- vomiting
- nausea
- last hours

**Emotional**
- anger
- despair
- fear
- hopelessness
- grief

**Practical**
- finances
- childcare
- housekeeping
- legal
Information sharing

- Confidentiality limits
- Desire and readiness to information
- Process for sharing information
- Translation
- Reactions to information
- Understanding
- Desire for additional information
Decision-making

- Capacity
- Goals of care
- Issue prioritization
- Therapeutic options with potential for benefit, risk, burden
- Treatment choices, consent
- Requests for withholding, withdrawing therapy, therapy with no potential for benefit, hastened death
- Surrogate decision-making
- Advance directives
- Conflict resolution
Care planning

- Setting of care
- Process to negotiate and develop plan of care that
  - Addresses issues and opportunities, delivers chosen therapies,
  - Includes plan for:
    - Dependents
    - Back-up coverage
    - Respite care
    - Emergencies
    - Discharge planning
    - Bereavement care
Care delivery

- Care team *(composition, leadership, confirmation facilitation, education, training, support)*
- Consultation
- Setting of care
- Essential services
- Patient family extended network support
- Therapy delivery *(process, storage, handling, disposal, infection control)*
- Errors
Confirmation

- Understanding
- Satisfaction
- Complexity
- Stress
- Concerns, other issues questions
- Ability to participate in the plan of care
Focus on measurement of palliative care end of life care

- What will drive change?
- What is helpful for benchmarking purposes?
- What can be captured in terms of data? What ought to be captured?
- Where can we begin?
Top 10 measures for nursing in palliative/end-of-life care (nursing sensitive outcomes)
Measure 1

- **NAME:**
  - hospice and palliative care – comprehensive assessment

- **Definition:**
  - Percentage of patients for whom a comprehensive assessment was completed
Measure 2

- **NAME:**
  - Screening for physical symptoms

- **Definition:**
  - Percentage of seriously ill patients receiving palliative care in an acute hospital setting >1 day or patients enrolled in a hospice >7 days who had a screening for physical symptoms (pain, dyspnea, nausea, and constipation) completed
Measure 3

NAME:
- Pain treatment (any)

Definition:
- Percentage of seriously ill patients receiving specialty palliative care in an acute hospital setting >1 day or patients enrolled in a hospice >7 days who screened positive for moderate to severe pain on admission, and the percent receiving medication or nonmedication, within 24 hours of screening
Measure 4

NAME:
- Dyspnea Screening and Management

Definition:
- Percentage of patients with advanced chronic or serious life-threatening illnesses that are screened for dyspnea, for those who are diagnosed with moderate or severe dyspnea, a documented plan of care to manage dyspnea exists
Measure 5

- **NAME:**
  - Discussion of emotional or psychological needs

- **Definition:**
  - Percentage of seriously ill patients receiving specialty palliative care in an acute hospital setting >1 day or patients enrolled in a hospice >7 days with chart documentation of a discussion regarding emotional or psychological needs
Measure 6

- **NAME:**
  - Discussion of spiritual/religious concerns

- **Definition:**
  - Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual and religious concerns or documentation that the patient or caregiver did not want to discuss these issues
Measure 7

- **NAME:**
  - Documentation of surrogate

- **Definition:**
  - Percentage of seriously ill patients receiving specialty palliative care in an acute hospital setting >1 day or enrolled in a hospice >7 days with the name and contact information for the patient’s surrogate decision-maker in the chart or documentation that there is no surrogate
Measure 8

- **NAME:**
  - Treatment preferences

- **Definition:**
  - Percentage of seriously ill patients receiving specialty palliative care in an acute care hospital setting >1 day or enrolled in a hospice for >7 days with chart documentation of preferences for life-sustaining treatments
Measure 9

- **NAME:**
  - Care consistency with documented care preferences

- **Definition:**
  - If a vulnerable elder has documented treatment preferences to withhold or withdraw life-sustaining treatment (e.g., a do-not-resuscitate order, no tube-feeding, no hospital transfer), then these treatment preferences should be followed
Measure 10

- **NAME:**
  - Global measure

- **Definition:**
  - Patient and/or family assessments of the quality of care is a key part of measuring quality for any setting caring for palliative or hospice patients
Other areas where nurses can have an impact...
Major Challenges

- **Awareness** (and understanding) about palliative and end of life care
  - A minority are aware of term/about half know about services
- **Access** to quality palliative/end of life care
  - 16-30% of those dying with disease have access to PEOLC services
- **Integration** of palliative/end of life care
  - Palliative care services across the experience of illness (bow-tie model)
- **Education** of caregivers
  - Professional, volunteers, family members/friends
Shift the culture

- Loss and death are part of life
- Death denying society/fear of death
- Single-minded focus on cure

- Fostering a culture where all people live well until the end of their days (coalition QEOL)

- In all parts of health care system, we must start the conversation about how loss dying and death are part of life.
- Education is key: Educate and support health care providers to help them overcome their fear of loss, dying and death.
Starting the Conversation: Speak Up

- **Resources and toolkit** for health care professionals and individuals...planning for your care in the future

Example:

*Who would speak for you if you couldn’t speak for yourself?* (short video)
Starting the conversation…

- What does good quality of life mean to you?
- How important is it to you to remain independent?
- Do you value making your own decisions?
- Are you concerned about letting another adult make medical decisions for you if you are unable? What worries you most?
- Are there any medical treatments you would surely want when facing the end of life? Any treatments you might refuse?
- When thinking about serious illness, what are you afraid of?
- What role do you want your family to have in making decisions about your health care?
- If your family wants to protect you from receiving information, should the medical team honor these wishes?
- What does “dying with dignity” mean to you?
- What does “dying a good death” mean to you?
Examples of public posters

“I didn’t expect him to die so soon...

...I got the feeling the doctors weren’t entirely honest with us about his condition. My husband resisted talking about dying and after 40 years of marriage I feel he let me down by not opening up and I guess I let him down for not knowing how to talk about some of the things that I needed to discuss. It would have been nice closure if things had been different in the end. I can never get that time back.

It’s about conversations. It’s about decisions. It’s how we care for each other.

5 steps to the perfect gift

You’re critically injured or ill and can’t communicate. Who will speak for you and make decisions about your care? This holiday season, take these five steps – and give your family and loved ones the gift of knowledge and peace of mind:

1. THINK about what’s important to you
2. LEARN about different medical procedures and what they can or can’t do
3. DECIDE on a substitute decision maker – someone who is willing and able to speak for you if you can’t speak for yourself
4. TALK about your wishes with your loved ones
5. RECORD your substitute decision maker and communicate your wishes

Learn more: www.advancecareplanning.ca

Visit: www.speakup.ca
Canadian Virtual Hospice

- Ask a professional
- Support and information

Recent additions:
- Caregiving videos
- Indigenous Voices
- Living my culture
- Dealing with loss
## Indicator Framework
(provides a guide to select indicators)

### Quality Dimensions

<table>
<thead>
<tr>
<th>domains/goals</th>
<th>structure</th>
<th>process</th>
<th>outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safe</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>effective</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Person Centred</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Equitable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>efficient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continuity</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Dialogue and Discussion