

Palliative Care Standards & Models



Ian Anderson Continuing Education Program
in End-of-Life Care



End-of-Life Care

- 222,000 Canadians die each year
- 75% die in institutions
- 90% want to die at home – people over 65 are less likely to die at home
- 90% die of a protracted illness
- Each death affects the well-being of 5 other people



Current Reality

- Only 5% of Canadians receive integrated multidisciplinary palliative care
- Cancer patients (25% of deaths) account for 90% of people receiving palliative care
- Pain and symptoms poorly controlled
- Advance Care Planning not undertaken



End-of-Life Care Across the Country

- End-of life care varies from province to province AND from one institution to another
- Rural residents receive less services
- Drug plans vary
- Beds have been eliminated due to restructuring
- Few provinces have designated palliative care as a specific entity → no budget
- Caregivers assume most of the costs → Health problems
Stunted careers
Poverty

**Quality End-of-Life Care: The Right of Every Canadian, Standing
Senate Committee on Social Affairs, Science and Technology, June 2000**



Objectives

- Describe North American societal attitudes towards death and dying
- Describe current barriers to providing quality EOL care
- Describe current state of EOL care in Canada
- Define palliative care, its basic principles and standards
- Describe some of the physical, psychological and social and spiritual issues of dying patients and their families
- Describe the role of a multidisciplinary team in caring for dying patients and their families



How Canadians Died in the Past

- Early century, life expectancy = 50 years
- Death was quick: accidents or infection
- Sick were cared for at home with help of physicians
- Second half of 20th century, focus on technology
- Death-denying
- Value youth, productivity, independence
- De-value aging, family, interdependence, caring for each other



Medicine's Shift in Focus

- Aggressive fight against illness & death
- Prolong experience of living with a chronic illness
- Sometimes prolong life at incredible cost
- Life expectancy has increased to 76 years
- Many health care providers believe they have failed if the patients die
- Nevertheless, all of us will die



Quality of End-of-Life Care

The Patients' View:

FIVE Components of Quality End-of-Life Care

- 1) Adequate pain and symptom management
- 2) Avoiding inappropriate prolongation of dying
- 3) Achieving a sense of control
- 4) Relieving burden
- 5) Strengthening relationships with loved ones

Singer P.A., Martin D.K., Kelner M., Quality End-of-Life Care: Patient's Perspectives, *JAMA* 1999 281(2) 163-168



Caregiving

- Burden of care assumed by small number of family members, often women
- May lack skill and resources to provide such care
- Stress and burnout common
- No employment protection for leave to care for sick family member
- If able to take leave, still face financial burdens



Barriers to Good EOL Care

- Failure of government, professions and public to acknowledge its importance
- Fears of adverse effects result in poor pain & symptom control
- Discomfort in communicating bad news, prognosis
- Lack of skill in helping patients and families negotiate the goals of care
- Lack of understanding of right to refuse Rx
- Personal worries, fears and a lack of self confidence and knowledge lead to avoidance



EOL Care in Current Healthcare System

- Acute Care Hospitals lack funding, under provincial care plan, to maintain palliative care teams
- In long term facilities some costs are assumed by patients and families
- Remuneration for health care providers does not take into account time needed to provide quality EOL care



EOL Care in Current Healthcare System

- Home care is variable, fragmented and financed through different mechanisms
- People dying at home assume costs of medications & supplies
- Round the clock care rarely available
- Private health care plans may cover some of the gaps, otherwise have to use personal savings
- Some people are forced to seek admission to hospital or palliative care unit since they can't afford to die at home or in long term care



Hospice

- Additional source of support for people with life-threatening illness
- Accessed directly or through professional referral
- Most hospice care is provided through the home
- Few residential hospices
- In Ontario 20-30% of funding is from government, rest is from charitable donations



Hospice Programs

May include the following:

1. Emotional, spiritual & psychological support,
2. Collaboration and coordination with other agencies
3. Volunteers for personal and respite care
4. Financial and legal planning
5. Hospice services for children
6. Bereavement support



Hospice Care

- In 1996 — in Ontario alone — 7,800 people volunteered for hospice, providing 250,000 hours of in-home service
- Standards of care vary from province to province
- Consult hospice associations for information and a list of hospices in region



Physician Training

- No consistent amount or format for EOL education in medical schools
- Training to function as a member of a team — necessary for quality care — is very rare
- A few graduate programs have mandatory time in palliative care but teaching is variable
- New 1 year postgraduate training program, jointly accredited by CFPC & RCPSC but no funding for salaries
- Education is crucial for all team members but few training programs in universities/colleges



Research

- Disturbing lack in EOL care
 1. Need for data collection and surveillance of EOL situations,
 2. Effectiveness of interventions
 3. Analysis of geographic, demographic and culture on quality of EOL care
 4. Decision-making
 5. Cost-effectiveness



Standards of Palliative Care

- CPCA seeks standards of practice applicable to all settings & models
- Necessary to communicate & compare findings & experiences
- Does not imply uniformity
- Act as a foundation: need to develop specific standards to their setting and population

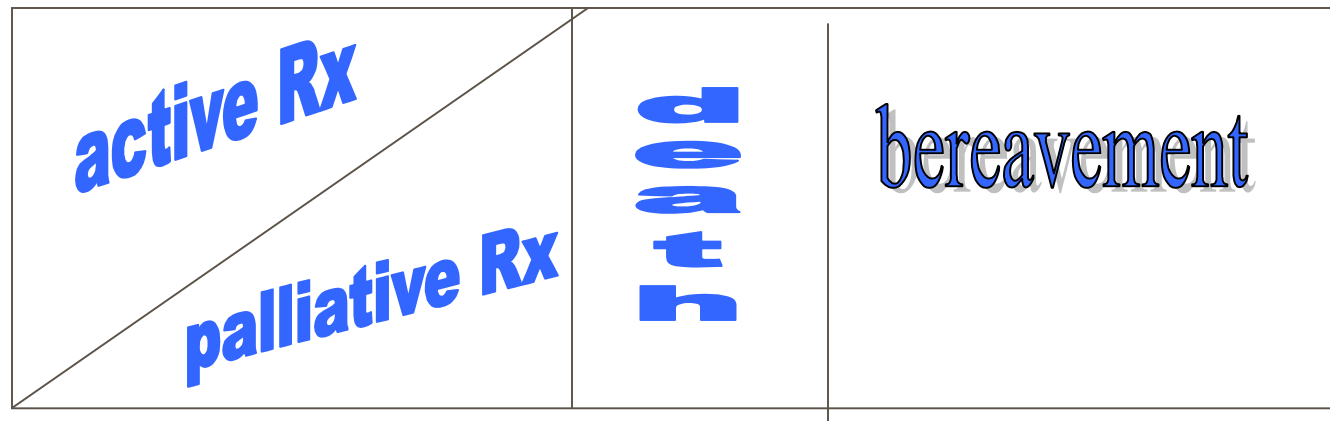
Models of Palliative Care

- 1960-70s

curative	palliative	
	active	terminal

Models of Palliative Care

- 1987, *Caring Together*, Health & Welfare Canada





Philosophy of Palliative Care

- Affirms life and regards death as a normal process
- Neither hastens nor postpones death
- Relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of care
- Offers a support system to help patients live
- Offers a support system to help the family cope

World Health Organization 1990



Towards Standards of Palliative Care

- Meet the needs — physical, psychological, emotional and spiritual — of the dying person and family
- Access: Equal, without discrimination
- Respect for Ethical Principles
- Right to information
- Right to choice/empowerment
- Patient and family = a Unit of Care

CPCA Standards Committee 1995



Towards Standards of Palliative Care

- Interdisciplinary team approach
- Continuity of care
- Community collaboration through partnership and mutual support
- Governance & administration
- Quality of Care: Standards of conduct & practice
- Program evaluation
- Education, information, research and advocacy

CPCA Standards Committee 1995