



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

Module 1

PALLIATIVE CARE – STANDARDS AND MODELS



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Case Scenario

Elizabeth Jones is a 44-year-old elementary school teacher. Six years ago she had a lumpectomy for breast cancer followed by adjuvant radiotherapy and chemotherapy. She was well for almost 4 years, when she developed a skin recurrence in her scar. This was treated with further surgery. About two months later, while at work, she had a grand mal seizure. A CT of her brain revealed at least 6 metastases to her brain. She had whole brain irradiation and was placed on dexamethasone, a powerful cortisone drug and anti-seizure medication. Further investigation revealed metastases in her liver, lung and peritoneum. She began chemotherapy but had no response to 3 different regimens. No further treatment is planned.

Elizabeth is referred to you for palliative care assessment and follow-up. You see her at home. Your first impressions of her are that of a very ill woman in quite a bit of distress and that she is quite cushinoid. She asks you if you have come to kill her.

Introduction²

- ❑ Over 220,000 Canadians die each year
- ❑ 75% of the deaths take place in hospitals and long term care facilities
- ❑ Each death potentially affects the well being of an average of five other people.
- ❑ It is estimated that only 5% of dying Canadians receive integrated and interdisciplinary palliative care.
- ❑ The standard of palliative care received by patients varies widely across the country.
- ❑ Rural residents have considerably less access to palliative care than the residents of large urban areas.
- ❑ About one quarter of the deaths in Canada are related to cancer, but cancer patients account for more than 90% of those receiving palliative care.
- ❑ Few provinces have designated palliative care as a core service with a specific budget.
- ❑ In many parts of the country, the number of inpatient palliative care beds has been cut as a result of health care restructuring.

Objectives

1. Describe North American societal attitudes toward death and dying.
2. Describe current blocks in providing better care for the dying.
3. Describe the current state of palliative care in Canada
4. Define palliative care, its basic principles and standards.
5. Describe some of the physical, psychological, social, and spiritual issues of dying patients and their families.
6. Describe the possible roles of the various team members in caring for dying patients and their families.

Content

I How Canadians Died In The Past¹

- ❑ In the early part of the twentieth century, average life expectancy was fifty years. People usually died quickly of infectious diseases or accidents.
- ❑ Medicine focused primarily on comfort and caring as few treatments were available to actually extend life.
- ❑ The sick were typically cared for at home with support from their physician, if one was available.

II Medicine's Shift In Focus¹

- The second half of the twentieth century became the age of science and technology. This caused a shift in the values of North American society on many levels.
- It has been suggested that we have become a “death-denying” society. We value youth, productivity and independence while devaluing aging, family and interdependent caring for one another.
- During this time, medicine has seen astonishing advances in many fields. We can now aggressively combat illness and death. We frequently attempt, and often succeed, at prolonging life no matter what the cost.
- With these advancements, the average life expectancy has increased to 76.
- The shift in focus has become so complete that death has become the enemy to be beaten at all costs. Many health care workers have come to believe that they have failed if they do not save their patients from death.
- Nevertheless, all of us will die.
- While we have learned to cure some illnesses, medicine has primarily managed to prolong the experience of living with chronic illness and the process of dying.

III How We Die¹

- Less than 10% of us will die of a sudden event such as a myocardial infarction or an accident (see figure 1).
- The rest of us (>90%) will die of a protracted life-threatening illness. Those who die of cancer will likely have a steady decline with a relatively short terminal phase (see Figure 2). Those who die of congestive heart failure, chronic lung disease or Alzheimer type dementia will likely experience a slow gradual decline marked by periodic crises and a sudden death (see Figure 3).

IV Place of Death¹

- 1949 – 50% of deaths were in institutions.
 - 1958 – 61% of deaths were in institutions.
 - 1980's to present – 75% of deaths were in institutions.
- } U.S. data
- In contrast, a 1996 American hospice survey indicated that 90% of respondents wanted to die at home.
 - Many people that currently die in hospital or long-term care facilities could be cared for at home if this was in keeping with their wishes.

V Caregiving¹

- ❑ Burden of care often falls on a small number of family members, often women, who may lack the skill and resources to provide that care.
- ❑ Caregiver burnout and stress is a frequent problem.
- ❑ Currently, there is no legislation in place to allow people to take a leave of absence from their jobs to care for sick family members without the threat of job loss. Those who are able to take a leave of absence from work often incur significant financial losses.

VI Barriers To Good End-of-Life Care¹

- ❑ Failure of public, government and health care personnel to acknowledge importance of end-of-life care.
- ❑ Fears of adverse effects have resulted in inadequate pain and symptom management.
- ❑ Discomfort with communicating bad news and prognosis has led to frequent misunderstandings.
- ❑ A lack of skill in assisting patients and families to negotiate clear goals of care and a lack of understanding of people's rights to decline treatment have led to the frequent use of futile interventions.
- ❑ Personal fears, worries and a lack of confidence and knowledge have led many physicians to avoid dealing with patients who are dying.

VII End-of-Life Care in the Current Health Care System²

- ❑ Physicians who provide palliative care are generally paid on a fee-for-service basis. Remuneration tends to be poor when one considers the amount of time required to properly care for these patients.
- ❑ Health Care remains focused on hospital care and many acute care hospitals lack the basic funding to maintain palliative care teams.
- ❑ Palliative care in hospitals is usually paid for by a provincial health plan, which typically covers professional care, medication, supplies and equipment while the person remains in hospital.
- ❑ In long-term care facilities residents may be required to pay for varying amounts of their care.
- ❑ Home care is variable, fragmented and financed through different mechanisms.
- ❑ Patients receiving home palliative care may have selected parts of their care covered by the provincial health plan. These plans do not always include the cost of medication, supplies, oxygen or equipment. Few provinces will cover the cost of around the clock care at home for more than a few days. Private insurance may cover some of these gaps in funding or people may use their personal savings.

- Some patients are forced to seek admission to hospital or palliative care unit since they cannot afford the cost of care at home or the costs in the long-term care facility.

VIII Hospice

- Hospices are an additional source of support and services to people with life threatening illnesses.
- Hospice may be accessed directly by the public or through professional referrals.
- Most hospice care is provided at home although there are a few freestanding residential hospices.
- In Ontario, 20-30% of hospice funding is from the government. The remainder is funded through charitable donations.
- A hospice program may include the following components: emotional support, collaboration and coordination with other agencies, volunteers for personal care and respite care, spiritual support, financial and legal planning, hospice services for children and bereavement support.
- In 1996 in Ontario, more than 7,800 people volunteered for hospice providing over 250,000 hours of in-home service.
- Standards for hospice care vary from province to province. Health care providers should consult their hospice associations for information and a list of hospices in their region.

IX Physician Training²

- Palliative care requires collaboration among service providers, is delivered across multiple settings, extends beyond cancer to chronic diseases and thus involves unique education and training challenges.
- At present, there is no consistency in whether undergraduate medical students receive palliative care training, or in what format. Training medical students to function as part of a team is rare.
- A few post-graduate programs have mandatory training in palliative care but teaching is highly variable.
- There is a new one-year post-graduate program of added competence in palliative care that is jointly accredited by the College of Family Physicians and the Royal College of Physicians and Surgeons. Unfortunately, there is no specific funding for residents salaries for this particular program.
- Appropriate training and education are crucial for all members of the interdisciplinary team. At the present time, few universities or colleges in Canada offer palliative care training programs.

X Research²

- There is a disturbing lack of research into end-of-life care.
- There is a pressing need for data collection and surveillance of various end-of-life situations as well as studies of the effectiveness and cost effectiveness of certain interventions, and analysis of demographic, geographic, cultural and other variables.

XI Standards of Practice³

- The Canadian Palliative Care Association ([CPCA](#)) continues to seek a national consensus on acceptable standards of practice applicable to all palliative care settings and program models.
- Standards are necessary so that we may communicate with each other and compare our experiences and findings.
- Standardization does not imply uniformity. The adoption of common national principles of practice provides a foundation for the provision of palliative care. Individual programs will then need to work with the model guidelines to define a standard of practice that is specific to their particular setting and patient population.

XII Definitions/Models of Palliative Care³

- 1960's-1970's. Earliest model of palliative care developed by Dame Cicely Saunders:

Curative	Palliative	
	Active	Terminal

- 1981 – Palliative Care Foundation, Toronto, Ontario:

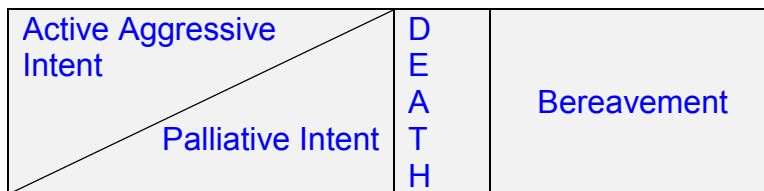
Palliative care is active compassionate care of the terminally ill at a time when their disease is no longer responsive to traditional treatment aimed at cure and prolongation of life and when the control of symptoms – physical and emotional – is paramount. It is multidisciplinary in its approach and encompasses the patient, the family, and the community in its scope.

- 1989 – Health and Welfare Canada:

Palliative care is a program of active compassionate care primarily directed towards improving the quality of life for the dying.

It is delivered by an interdisciplinary team that provides sensitive and skilled care to meet the physical, psychosocial and spiritual needs of both the patient and the family. The philosophy and principles of palliative care may apply to the patient populations other than the dying and the palliative care program may have a secondary role in addressing the needs of these groups.

Accompanying the definition was the diagram that follows, a modification of a diagram that first appeared in the *Caring Together* report from Health and Welfare Canada in 1987.



- 1990 – World Health Organization;

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment.

Palliative care:

- affirms life and regards death as a normal process
 - neither hastens nor postpones death
 - provides relief from pain and other distressing symptoms
 - integrates the psychological and spiritual aspects of care
 - offers a support system to help patients live as actively as possible until death
 - offers a support system to help the family cope during the patient's illness and in their own bereavement
- 1995 – Working Definition of the CPCA Standards Committee:

Palliative care, as a philosophy of care, is the combination of active and compassionate therapies intended to support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social and spiritual expectations and needs, while remaining sensitive to personal, cultural and religious values, beliefs

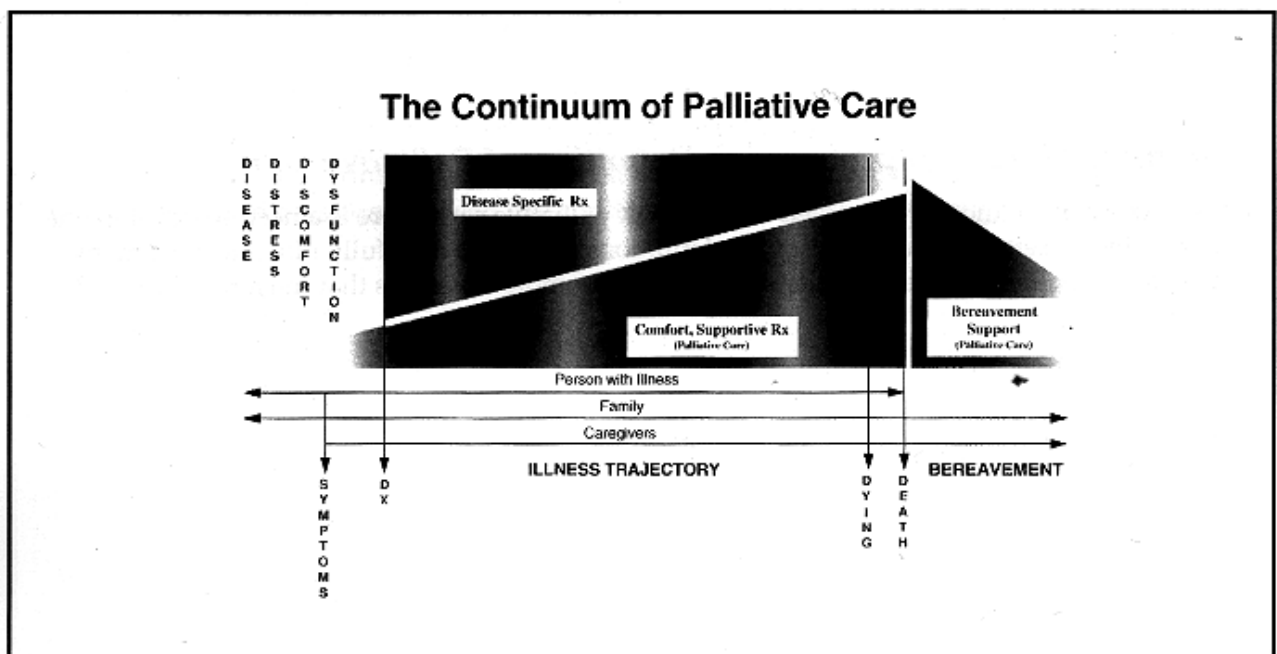
and practices. Palliative care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care.

Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family, caregivers and service providers. It should be available to the individual and his/her family at any time during the illness trajectory and bereavement.

While many service providers may be able to deliver some of the therapies that provide comfort and support, the services of a specialized palliative care program may be required as the degree of distress, discomfort and dysfunction increases.

Integral to effective palliative care is the provision of opportunity and support for the caregivers and service providers to work through their own emotions and grief related to the care they are providing.

This was initially developed by Frank D. Ferris, Palliative Medicine,
Mount Sinai Hospital, Toronto, 1994



XIII Suggested Philosophy Of Palliative Care³

- Every individual has the right to participate in informed discussions about the health care resource options that may help to optimize the quality of his/her life during the course of living with a life-threatening illness, especially when dying, and to choose the best possible options based on that information.
- Palliative care strives to meet the physical, psychological, social and spiritual needs of patients and families, with sensitivity to their personal, cultural and religious beliefs and practices, through patient-directed supportive interventions, whether or not the patient is receiving anti-disease therapy.
- Care should be delivered in a patient-focused, family centered environment.
- It is the patient's right to access information and services from an interdisciplinary team of appropriately trained professionals and volunteers, who receive continuing palliative care education and evaluation.

XIV Suggested Principles of Palliative Care³

<p>1. Meet Physical, Psychological, Social, and Spiritual Expectations/Needs Care is directed towards meeting the physical, psychological, social and spiritual expectations/needs of the patient and family with sensitivity to their personal, cultural and religious values, beliefs and practices.</p>
<p>2. Access Patients and families have timely access to information and the services provided by palliative care when they need and are prepared to accept them. Information and services are provided in a language that they can understand. Essential palliative care services are available 24 hours per day, 7 days per week.</p>
<p>3. Equal Availability without Discrimination</p>
<p>4. Ethics The ethical principles of autonomy, beneficence, non-maleficence, justice, truth telling and confidentiality are integrated into the provision of care and program development.</p>
<p>5. Right to Information It is the patient's right to be informed about his/her disease, potential treatments and outcomes, appropriate resources and options. It is the family's, caregiver's and service provider's right to be informed about the disease, potential treatments and outcomes, appropriate resources and options, respecting the patient's right to confidentiality.</p>
<p>6. Right to Choice/Empowerment Decisions are made by the patient and family in collaboration with the caregivers and service providers, respecting the level of participation desired by the patient and family. The patient's and family's choices for care, settings of care and information sharing are respected.</p>

<p>7. Unit of Care The unit of care is the patient and family.</p>
<p>8. Interdisciplinary Team Care is provided by an interdisciplinary team of caregivers and service providers working collaboratively with the patient and family.</p>
<p>9. Continuity of Care A coordinated, continuous plan of care that minimizes duplication is maintained across all settings of care from admission of the patient to bereavement support for the family.</p>
<p>10. Community Collaboration Through Partnerships and Mutual Support The palliative care needs of a community can only be met through the collaborative efforts of available services in partnership at patient care and programmatic levels.</p>
<p>11. Governance and Administration Governance and administration are essential to support the program and ensure accountability. Broad based governance includes community representatives, caregivers, service providers, patients and families.</p>
<p>12. Quality of Care Care is delivered by all service providers within professionally accepted standards of conduct and practice.</p>
<p>13. Program Evaluation Program evaluation is essential to the delivery of quality palliative care and to the maintenance of standards of conduct and practice.</p>
<p>14. Education, Information, Research and Advocacy for Palliative Care Education, information, research and advocacy for the development and maintenance of public policy, palliative care standards and resources are essential to improve the delivery of palliative care.</p>

XV A Conceptual Framework of Palliative Care

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San Diego Hospice
© 2001

SEE APPENDIX I

<http://www.cme.utoronto.ca/endoflife/FERRIS%20SQUARE.pdf>

References

1. Emanuel LL, von Gunten CF, Ferris FD, eds. The Education for Physicians on End-of-Life Care ([EPEC](#)) Curriculum. The EPEC Project, The Robert Wood Johnson Foundation, 1999.
2. [Quality End-of-Life Care: The Right of Every Canadian](#). Senate of Canada Report June 2000
3. Ferris FD, Cummings I, eds. Palliative Care: Towards a Consensus in Standardized Principles of Practice. The [Canadian Palliative Care Association](#) 1995.

Detailed Case Scenario

Elizabeth Jones is a 44-year-old elementary school teacher. Six years ago she had a lumpectomy for breast cancer followed by adjuvant radiotherapy and chemotherapy. She was well for almost 4 years, when she developed a skin recurrence in her scar. This was treated with further surgery. About two months later, while at work, she had a grand mal seizure. A CT of her brain revealed at least 6 metastases to her brain. She had whole brain irradiation and was placed on dexamethasone, a powerful cortisone drug and anti-seizure medication. Further investigation revealed metastases in her liver, lung and peritoneum. She began chemotherapy but had no response to 3 different regimens. No further treatment is planned.

Symptoms included some abdominal pain from a grossly enlarged liver, nausea, constipation, abdominal distension and increasing weakness. She also has had a number of panic attacks resulting in weekly trips to the emergency department.

Elizabeth is a single parent of two children. Jennifer is 14 and Alexandra is 19. Elizabeth has been divorced for 7 years from Mel who still involved with his children and their support. He has remarried and has 2 stepchildren. Elizabeth was engaged to be married to Frank but she called off the wedding when she developed brain metastases. Frank still visits her frequently. Alexandra is at university in a town about 150 km away. Jennifer is at home in high school but having problems with her school performance. Elizabeth has two sisters and one brother living near her. Her father died of cancer 2 years ago. Her mother, Madge, also lives nearby but has had little contact with her daughter since the divorce. Madge is a devout Catholic and does not believe in divorce. Elizabeth has not allowed any of her friends to visit her over the last four months.

Elizabeth is referred to you for palliative care assessment and follow-up. You see her at home. Your first impressions of her are that of a very ill woman in quite a bit of distress and that she is quite cushinoid. She asks you if you have come to kill her.

Current Medications: Tylenol #3-2 tabs q4h prn, Stemetil 10 mg q6h prn, colace 2 tabs bid and senokot 2 tabs hs prn

Directions for Facilitators

1. Distribute the case scenario. Allow the participants a couple of minutes to read the information or have one of the participants read the scenario.
2. Before diving into the case, spend some time discussing general issues around end-of-life care. Below are several possible discussion points.

A. Societal attitudes toward death and dying:

TIP: Ask participants to reflect on society's attitudes.

It is popularly said that North America is “death-denying”. Another view is that it is “death-avoidant”. We have tried through science to control nature. Death is included as a part of nature. We control/manage/defeat disease. We think we can do the same with death. Most people believe that you can fight death through treatment or you control death by choosing when to take your life (assisted suicide / euthanasia). The average person knows more about euthanasia than palliative care (e.g. on internet, in bookstores, “how to kill yourself”).

TIP: Ask participants to reflect on their own feelings regarding death and dying and on what they feel is important with respect to death with dignity.

What is death with dignity? Is it to be pain free and peaceful? Or is it the view of the euthanasia promoters? People are seldom afraid of death. They are more commonly afraid of the dying process, death extension, and prolonged suffering.

B. Current blocks in the care of the dying:

- ❑ Old paradigm of palliative care practice: that palliative care only begins after all other efforts have failed. Modern view of palliative care pictures active treatment and palliative care occurring together through the course of the disease.
- ❑ Values, beliefs, lack of knowledge / adjustment to new reality of dying, living in the presence of dying, no one practices dying
- ❑ Lack of education among professionals.
- ❑ Current structure of the health care system.
- ❑ Current level of home-care services available to palliative patients in your area.

C. Talking about death, dying, and palliative care with patients and families:

TIP: See [Communications Module](#).

Getting started – “I would like to speak with you about how to support you in your daily living, how to keep you at work, how to conserve energy and diminish pain.”

Once in – “What is it that is most important to you now? If we had to change one thing, outside of curing you of your illness, what would it be? How can we make the situation a little bit better?”

3. Have the participants brainstorm around the information given in the case. List the relevant issues on a flipchart.
4. Facilitate discussion of relevant issues. As it becomes apparent that there are gaps in the participants’ knowledge, list the issues that require further investigation. Do not provide answers to all their questions.
5. At the end of the session, assign each of the participants one or two of the learning issues for them to review on their own and report back to the group at the next session.

TIP: This case is intended as a general introduction to palliative care. Many of the issues raised here will be more thoroughly developed in other modules. Do not feel you have to cover everything in this one case.