Talking to Patients About 21st Century Palliative Care

Pippa Hawley
phawley@bccancer.bc.ca
Conflict Declaration

• I have no relationship with any commercial interests
• My program has carried out a survey study sponsored by Paladin labs
• All speaking honoraria I am offered are donated to the UBC Division of Palliative Care
Mitigation of Bias

• I am not aware of any biases to mitigate
Objectives

• To understand the current WHO definition of Palliative Care

• Be able to draw a simple model to illustrate how modern palliative care fits with cancer management

• Have a strategy for overcoming patient and family reluctance to accept palliative care
Historical Understanding

ACTIVE ("CURATIVE") TREATMENT

PALLIATIVE CARE
Focus of care

Therapy to modify disease

Hospice Palliative Care

Bereavement
Glacial Rate of Uptake

Cancer Treatment and Palliative Care are Not Mutually Exclusive

Current Care Model

Proposed Care Model

Temel, ASCO 2010, #7509  www.iom.edu
“Google Images” Example
“Google Images” Example
"Google Images” Example

a) SERIES

CURING  PALLIATION  DEATH  BEREAVEMENT

b) PARALLEL

CURING  PALLIATION  DEATH  BEREAVEMENT


c) INTEGRATIVE*

BEREAVEMENT  CURING  HEALING (including palliation)  CONTINUAL  DEATH  BEREAVEMENT

"Mindset of "Being With" and "Doing To"

DIAGNOSIS

t₀  time
WHO Definition [my italics]

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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.”

2013
Palliative Care......

.....is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications
Three Main Aims of Palliative Care

• To relieve physical and emotional suffering
• To improve patient-physician communication and decision-making
• To coordinate continuity of care across settings

So what’s so special about that? Isn’t that just good medical care?
Benefits of Specialist Palliative Care

- Reduction in symptom burden
- Improved patient and family satisfaction
- Improve physician satisfaction
- Reduced costs
  - All of these benefits have been seen in multiple studies, in multiple countries and multiple settings
  - No harms have been demonstrated, particularly no shortening of survival
  - The earlier in illness palliative care is provided, the greater the benefits (and cost savings)
  - If this was “usual care” then why would the benefits be found?
Not “Just Hand-Holding”
“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
• 5th edition since 1993
• 1,280 pages
• “Over 200 contributors and 100 chapters deal with all aspects of this rapidly developing specialty”
• This is only one of many
• **SO: WHO DOES PALLIATIVE CARE SERVE IN BC?**
Natural Deaths in BC 2013-14

31,318 deaths, 30.6% from cancer
89% of all adult deaths were from chronic conditions.

Palliative Group A:
Individuals who received one or more primary palliative service

Palliative Group B:
Individuals who received one or more intermediate palliative service

Palliative Group C:
Individuals who received one or more tertiary palliative service

Dedicated palliative care services*

*dedicated palliative services are hospital, hospice, community, or home-based care/consults provided by palliative care specialist teams from a funded palliative care program.
The Results

Only 60% Identified in System

Palliative Group C:
Individuals who received one or more tertiary palliative service

Palliative Group B:
Individuals who received one or more intermediate palliative service

Palliative Group A:
Individuals who received one or more primary palliative service

Palliative Group O:
Individuals who may benefit from a palliative approach, but received general health services

60% 40%

*Dedicated palliative care services are hospital, hospice, community, or home-based care/consults provided by palliative care specialist teams from a funded palliative care program.
Of those, 25% received specialist care.
BC Data Exercise; 2012 Decedents

Palliative Group C:
Individuals who received one or more tertiary palliative service

Palliative Group B:
Individuals who received one or more intermediate palliative service

Palliative Group A:
Individuals who received one or more primary palliative service

Palliative Group O:
Individuals who may benefit from a palliative approach, but received general health services

25% of 60% is 15%

*Dedicated palliative services are hospital, hospice, community, or home-based care/consults provided by palliative care specialist teams from a funded palliative care program.
Maybe That’s OK?

• There are no international standards with which to compare
• It is very difficult to determine meaningful palliative care quality indicators, e.g.
  – Contact with a specialist service 3 days before death, after a prolonged period suffering, does not indicate a good job was done
  – A death at home may be a wonderful experience or an appalling trauma
• Anecdotal evidence however suggests that many patients do not receive the palliative care they need
• At least now we have a baseline
• Now how do we do better?
THE PROVINCIAL
End-of-Life Care
Action Plan
FOR BRITISH COLUMBIA

Priorities and Actions
for Health System
and Service Redesign
Ministry of Health
March 2013
Barriers to Access

• Availability of services
  – Beds
  – Specialists
  – Nurses
  – Drugs, equipment etc...
• Reluctance to refer
  – Don’t know what/how, or don’t see any need
• Reluctance to be referred
  – Don’t know what/how, or don’t see any need
What We See......

Focus of care

Therapy to modify disease

Palliative

Bereavement
What Many of our Patients See

Focus of care

Therapy to modify disease

Hospice Palliative Care

Bereavement
Explaining Palliative Care

• Information comes from a variety of sources
  – News (TV, print and digital)
  – Movies
  – TV shows
  – Literature
  – Social media
• Friends and family
• Health care professionals
“Yes, you do have the right to die with dignity. But, until then, anything goes.”
It’s not Disease Management OR Palliative Care, you can have both. I can’t draw this........
The Bowtie Model of 21st Century Palliative Care

Disease Management

Cure
Symptom Management and Supportive Care
Control

Survivorship
Hospice

Palliative Care
“Palliative Care is for Living Well”
“We need to look after the disease and the rest of you”

Expectation: cure

Disease Management

Palliative Care

Cure
Resection of breast tumour

Adjuvant chemoradiation

Pain & Symptom Management

Nutrition

Information

Counselling

Tamoxifen

Physio and Exercise

Survivorship

Control

Hospice

Expectation: cure
"We will always be part of your care team"
This is Where You Are…

Disease Management

Cure

Control

Symptom Management and Supportive Care

Survivorship

Hospice

Palliative Care
This is Where You Are...

Disease Management

Cure

Symptom Management and Supportive Care

Survivorship

Hospice

Control

Palliative Care

Control

Cure
This is Where You Are...

Disease Management

Disease Management

Cure

Symptom Management and Supportive Care

Survivorship

Palliative Care

Control

Hospice
“We can never be 100% certain what will happen”
Cycle Repeats

Disease Management

- Cure
- Control

Symptom Management and Supportive Care

- Survivorship
- Hospice

Palliative Care

Bereavement
Summary

• You should now be able to draw the Bow Tie model to illustrate how palliative care integrates with cancer management throughout the course of illness
• You should introduce the vocabulary of palliative care early in the course of illness
• Take every opportunity to educate before it’s personal