# Talking to Patients About 21<sup>st</sup> Century Palliative Care

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#### **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

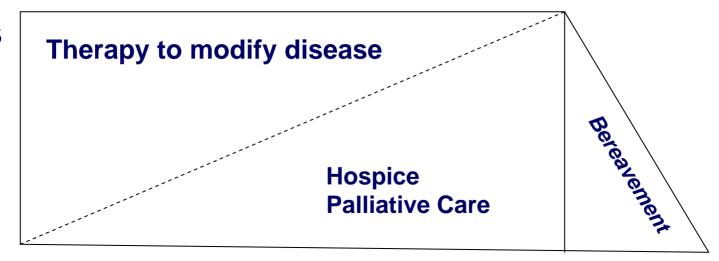
- To understand the <u>current</u> WHO definition of Palliative Care
- Be able to draw a simple model to illustrate how modern palliative care fits with cancer management
- Have a strategy for overcoming patient and family reluctance to accept palliative care

# Historical Understanding

ACTIVE ("CURATIVE")
TREATMENT

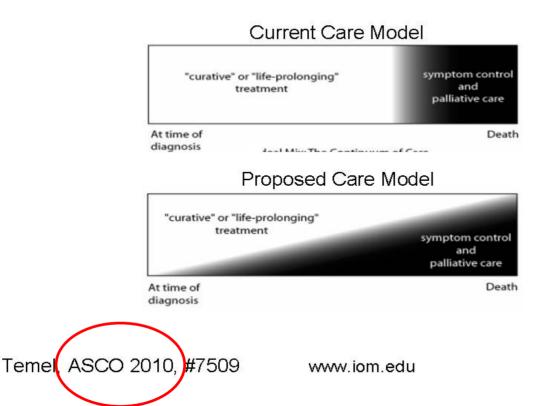
PALLIATIVE CARE

Focus of care

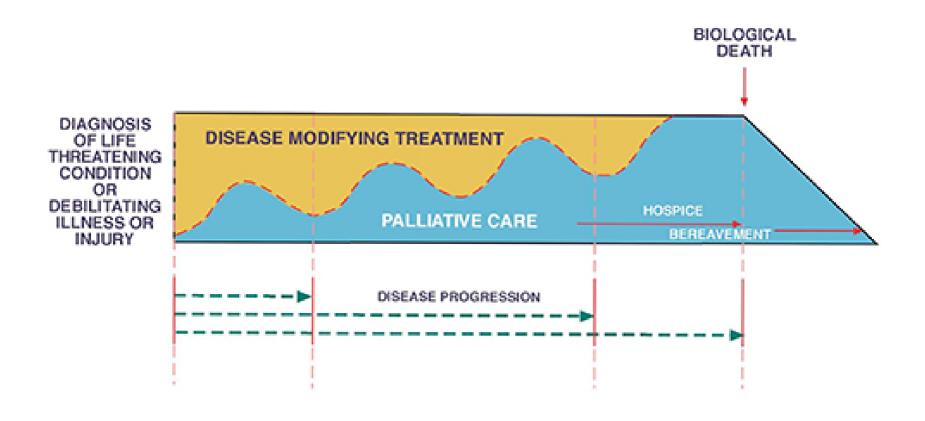


### Glacial Rate of Uptake

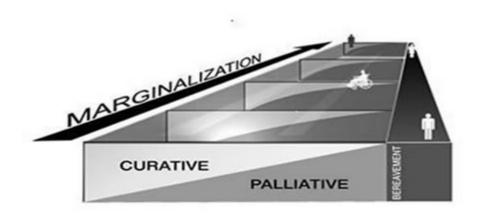
# Cancer Treatment and Palliative Care are Not Mutually Exclusive



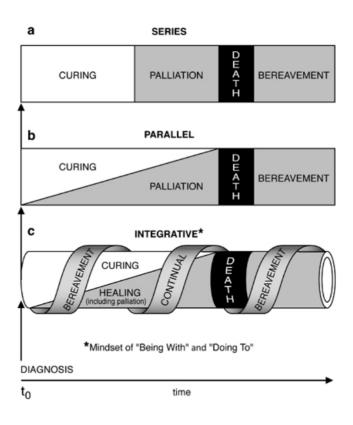
### "Google Images" Example



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## "Google Images" Example



### 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 lifethreatening 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."

#### 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

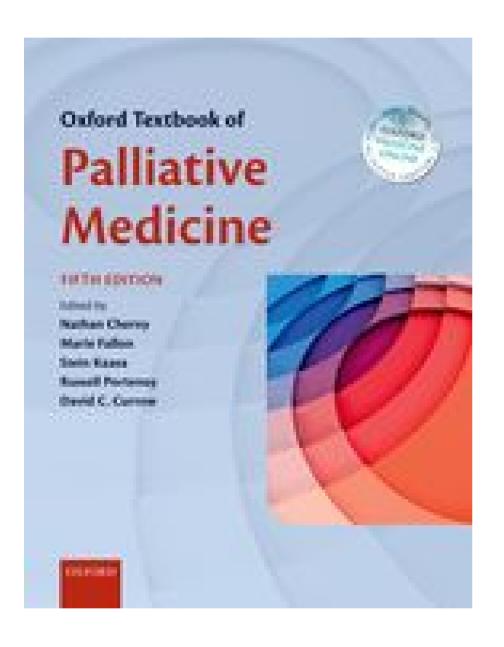
- Reduction in symptom burden
- Improved patient and family satisfaction
- Improve physician satisfaction
- Reduced costs
  - All of these benefits have been seen in multiple studies, in multiple countries and multiple settings
  - No harms have been demonstrated, particularly no shortening of survival
  - 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"





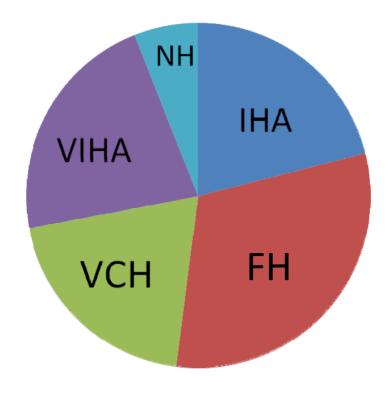
"There's no easy way I can tell you this, so I'm sending you to someone who can."



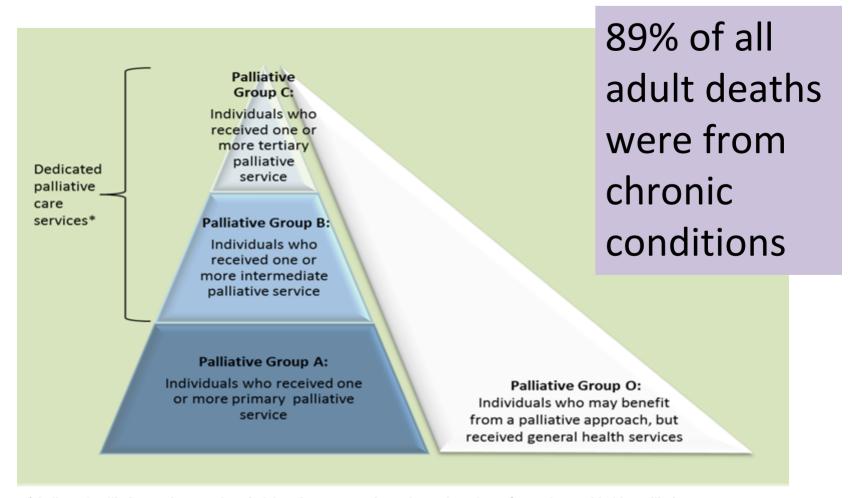
- 5<sup>th</sup> edition since 1993
- 1,280 pages
- "Over 200
   contributors and 100
   chapters deal with all
   aspects of this rapidly
   developing specialty"
- This is only one of many
- SO: WHO DOES
   PALLIATIVE CARE
   SERVE IN BC?

#### Natural Deaths in BC 2013-14

31,318 deaths, 30.6% from cancer

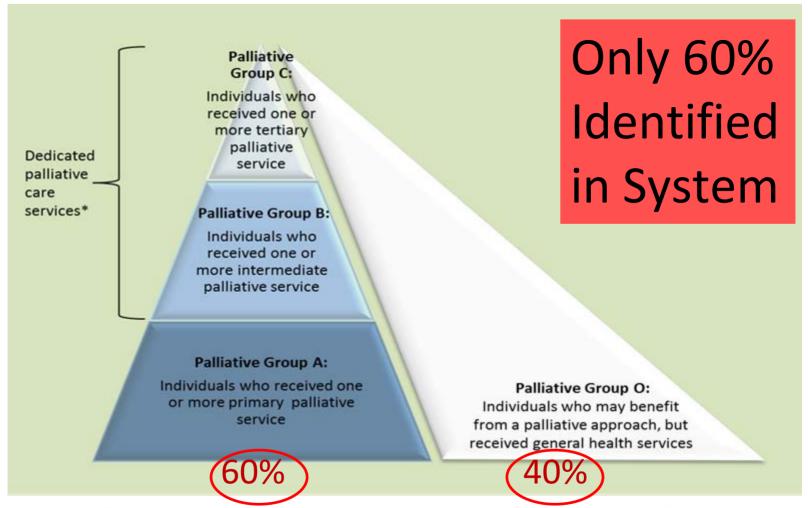


#### BC Data Exercise; 2012 Decedents

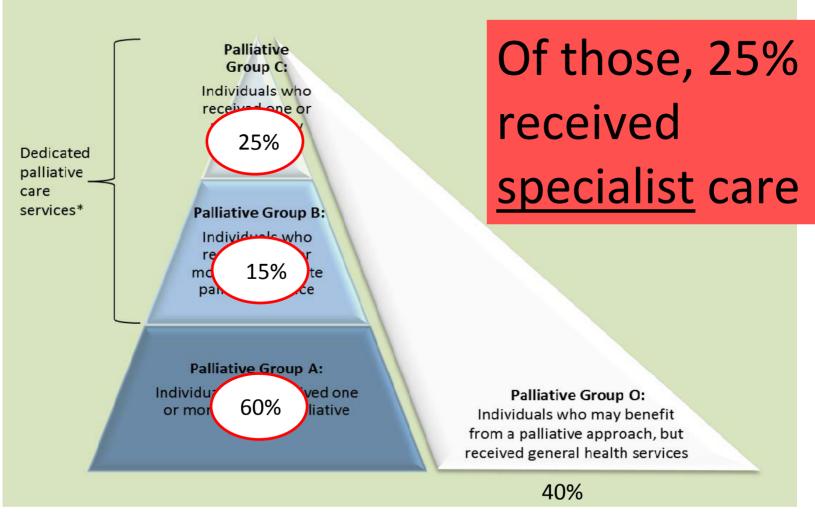


<sup>\*</sup>dedicated palliative services are hospital, hospice, community, or home-based care/ consults provided by palliative care specialist teams from a funded palliative care program.

#### The Results

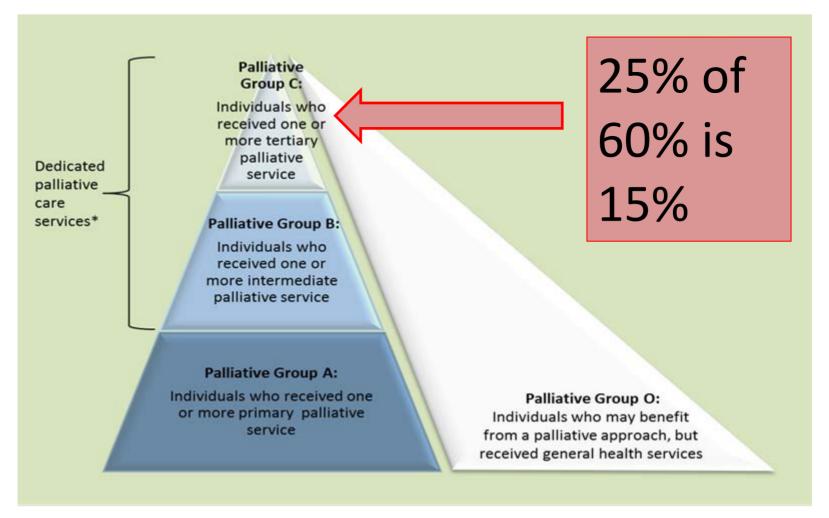


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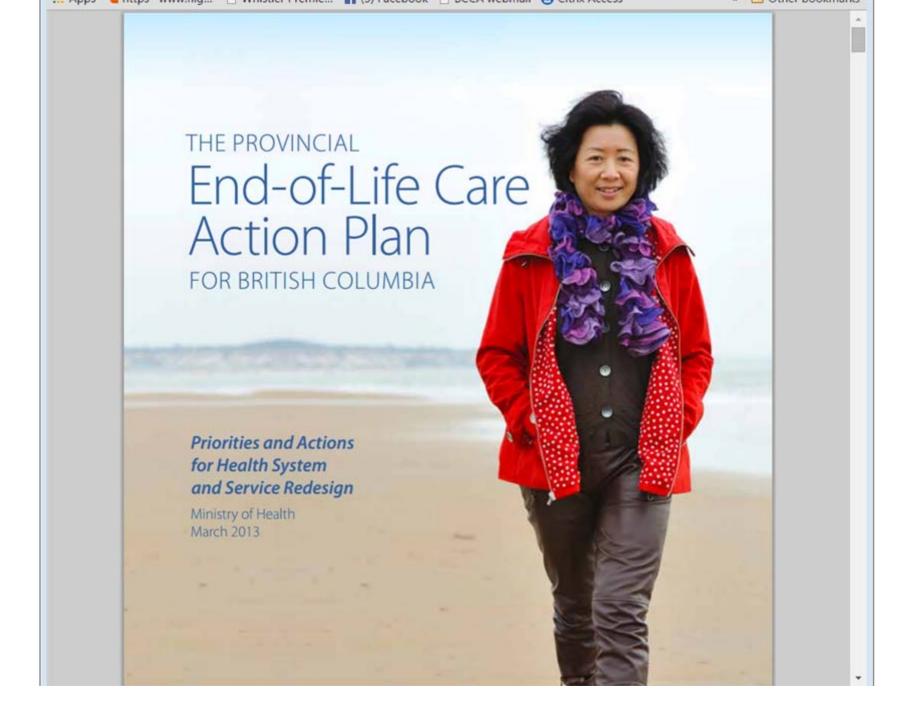
#### BC Data Exercise; 2012 Decedents



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### 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?

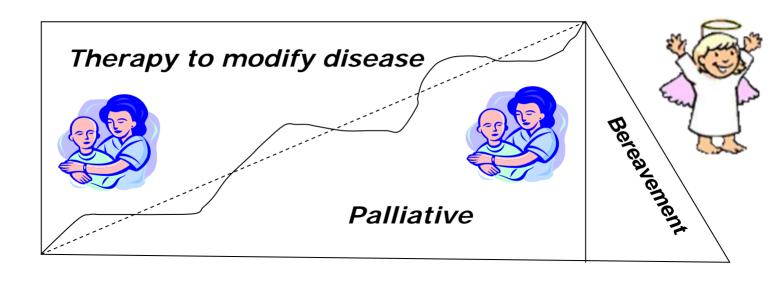


#### **Barriers to Access**

- 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



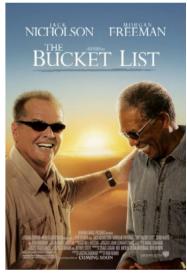
#### What Many of our Patients See

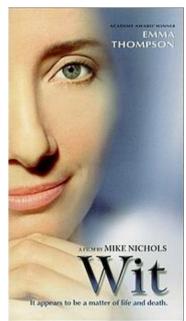
Focus of care



# 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





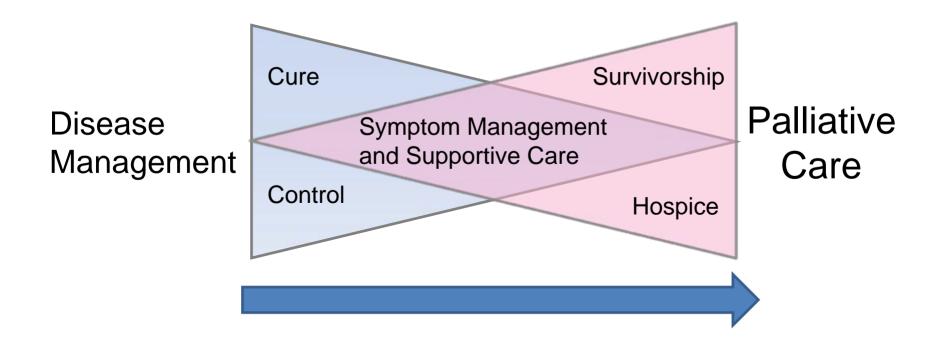


"Yes, you do have the right to die with dignity. But, until then, anything goes."

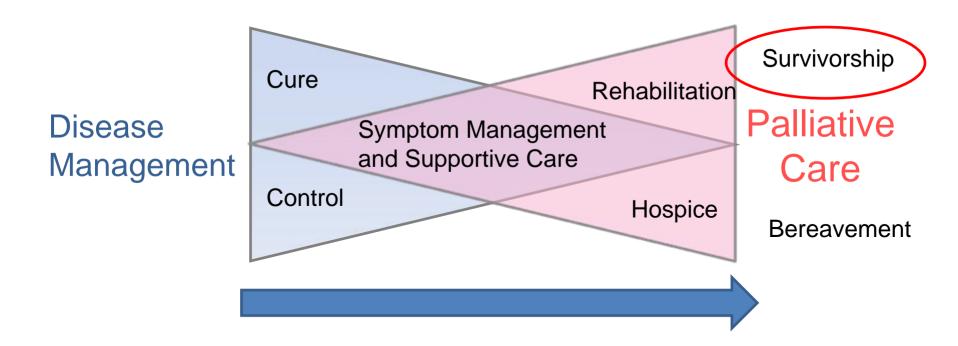


It's not Disease Management OR Palliative Care, you can have both. I can't draw this.......

# The Bowtie Model of 21<sup>st</sup> Century Palliative Care



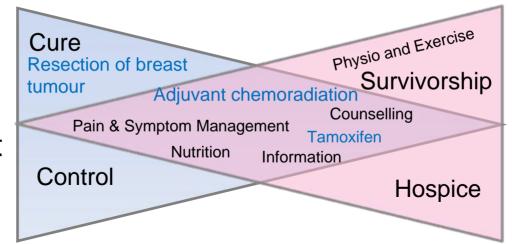
### "Palliative Care is for Living Well"



# "We need to look after the disease <u>and</u> the rest of you"

Expectation: cure

Disease Management

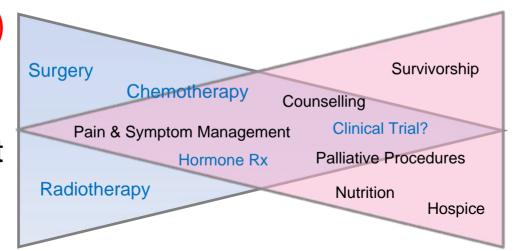


Palliative Care

# "We will always be part of your care team"

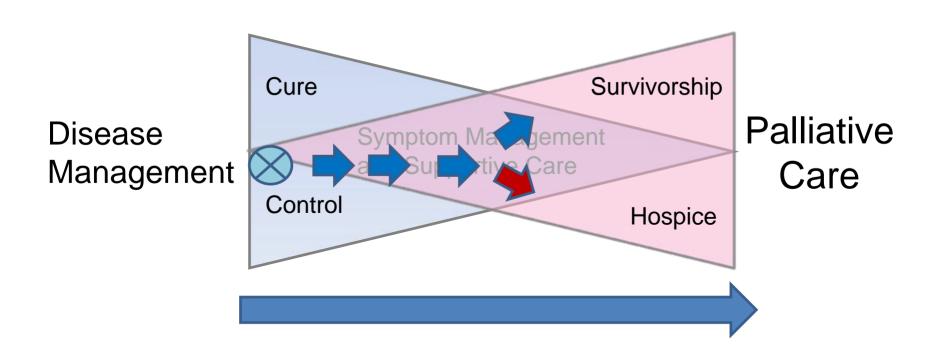
Expectation: cure unlikely

Disease Management

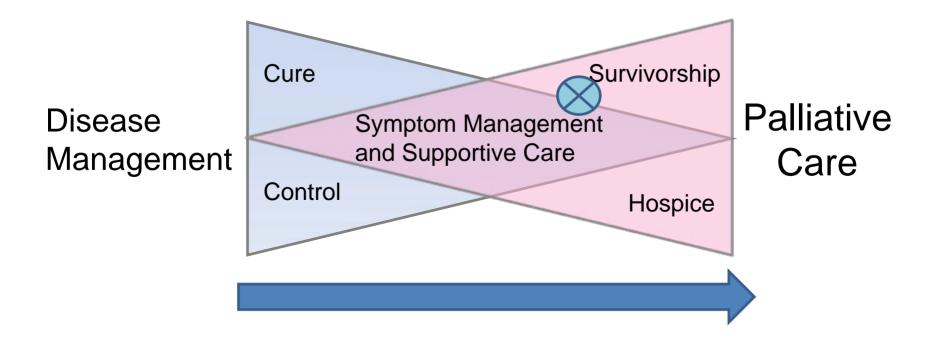


Palliative Care

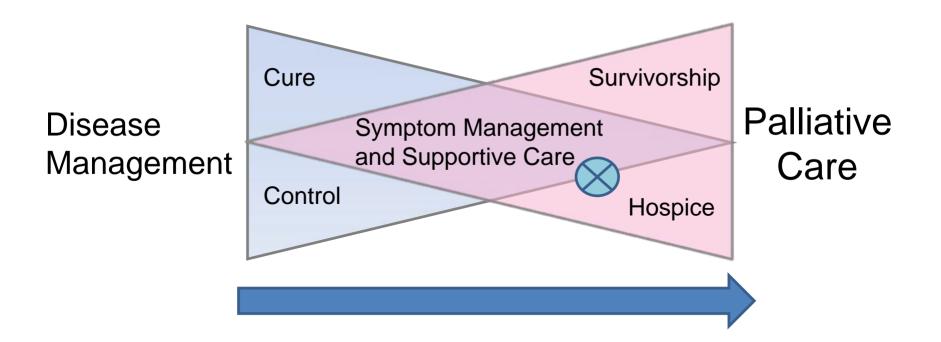
#### This is Where You Are...



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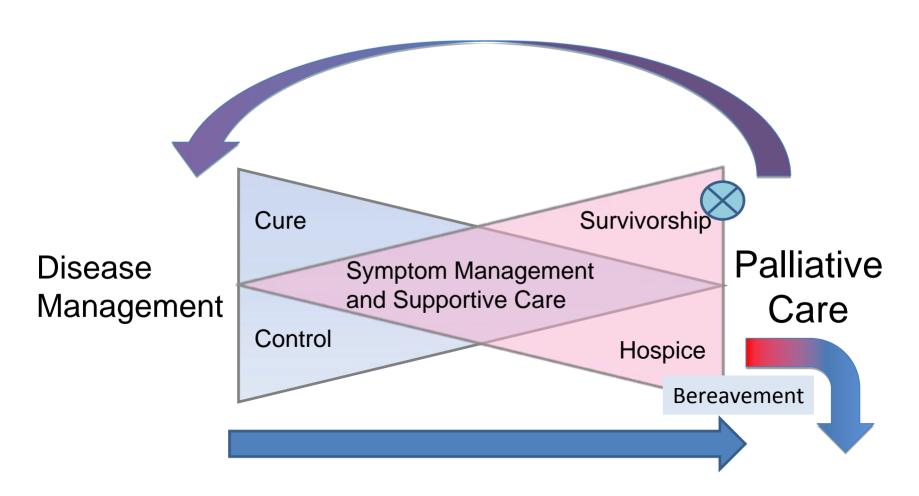


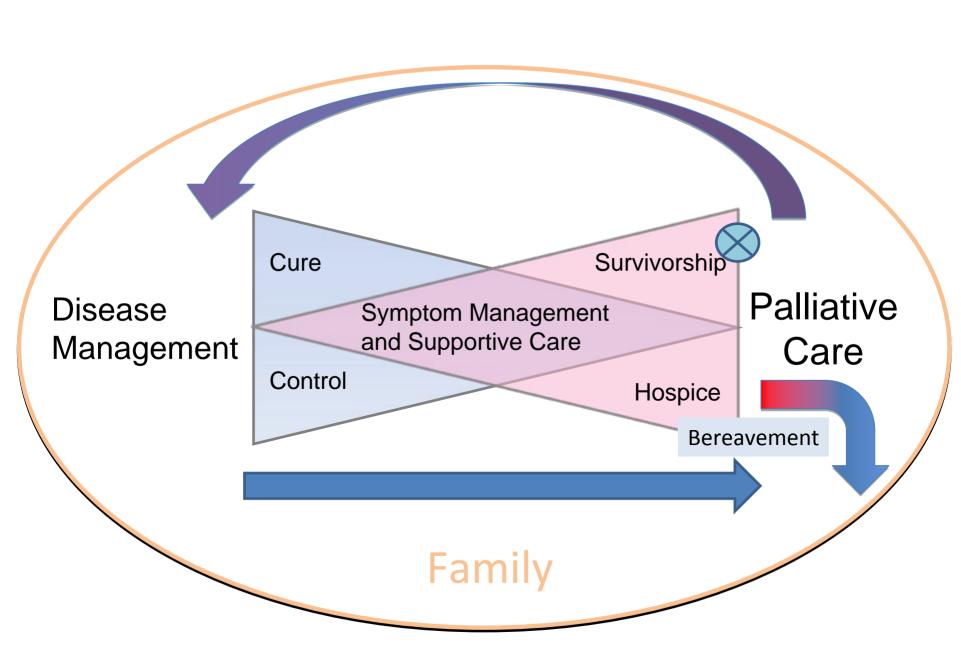
# "We can never be 100% certain what will happen"

Disease
Management
and Supportive Care
Control

Cure
Survivorship
Palliative
Care
Care

### **Cycle Repeats**





#### 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 <u>early</u> in the course of illness
- Take every opportunity to educate before it's personal