

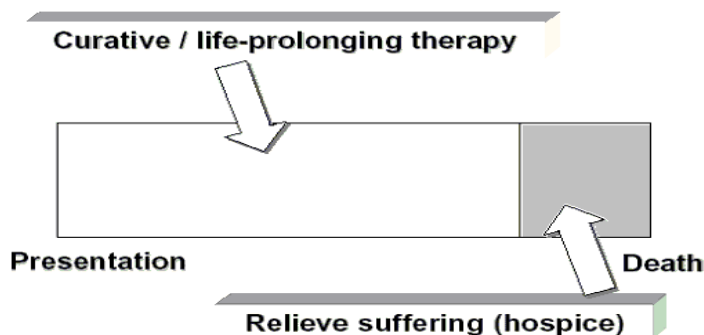
## INTRODUCTION TO GOALS OF CARE

### Historical Perspective

- Primary goal of medicine before the last century was to provide comfort
- Science and technology developments since 1900 have contributed to a focus on curing illness and prolonging life
- Concomitantly, less attention to the management of symptoms, relief of suffering or care of the dying
- Hospice and palliative care movements were born during the 1960s and 1970s to fill the growing void and provide care for the dying
- Historically, hospice in the United States has been primarily restricted by the Medicare Hospice Benefit to the last 6 months of a person's life, and programs have tended to serve patients with cancer only when cure was no longer possible
- More recently, hospice programs have been evolving into medical practices and programs that focus on **relieving suffering and improving quality of life for patients with any life-threatening illnesses**
- However, many patients, families, and professionals are not prepared to give up therapies aimed at cure and life-prolongation in order to focus totally on relief of suffering

The first figure shows the division between goals of care if medical decision-making occurs in a dichotomous way

**Figure 1: A dichotomous intent**



- Consequently, the majority of dying Americans are never referred to hospice programs
- Moreover, studies show that patients with life-threatening illnesses, and their families, will experience multiple symptoms and have ongoing needs for psychological, social, spiritual, and practical support throughout their illness

### Questions for Consideration

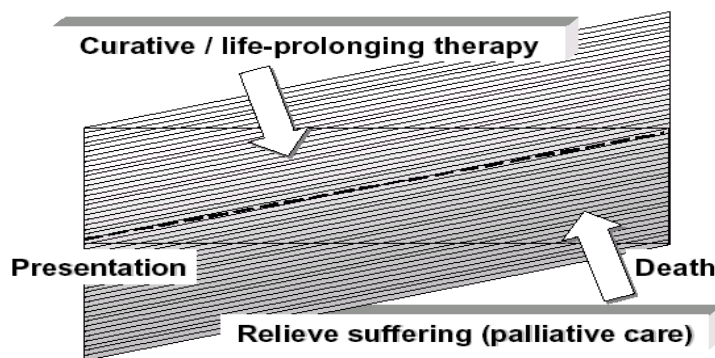
- Why shouldn't the relief of suffering be pursued at the same time as cure and life prolongation?
- Why wait to focus on the relief of suffering until all attempts at cure have been exhausted or the patient and family plead for such efforts to stop?
- Is it not possible that with earlier access to symptom management and supportive care, patients and families will feel better, continue more of their normal lifestyle, and maintain more capacity to fight their illness and sustain treatment?

### The Interrelationship of Goals

- Multiple goals apply simultaneously
  - Goals may seem to stretch along a continuum in a linear fashion

- In fact, patient and physician may seek **both disease control and symptom palliation** together
- They may not consider a therapeutic intervention (e.g., chemotherapy), unless it addresses both goals. In clinical practice this is more the rule than the exception

**Figure 2: The interrelationship of therapies with curative and palliative intent**



- Goals may be contradictory
  - A patient may want prolongation of life as the overriding goal but also insist that nothing should be done that increases discomfort
  - The physician knows, however, that treatments aimed at curing disease, such as a surgical operation or chemotherapy, may unintentionally cause temporary or permanent functional deterioration and suffering
  - It is the physician's role to help the patient and family understand the balance between the benefits and burdens of a particular treatment
- For a particular patient, some goals take priority over others
  - Over the course of an illness, the relative weight given to each goal may change in response to numerous factors
  - It is only in the context of an individual's life that an adequate balance can be achieved among goals
  - Clinical decisions routinely require prioritization among potentially contradictory goals
  - Such tradeoffs are an inevitable part of medical care
  - The integration of goals of care can be particularly important for progressive illnesses that will be predictably fatal
  - Medical treatment for most illnesses will only change the natural history of the disease and prolong life, but not provide a cure
- Continuum of care
  - In contrast with the previous dichotomous model of care, this model integrates the relief of suffering into the continuum of care
  - It can more easily become the total focus of care at the end-of-life
  - It is not an alternative to, or an abrupt change from, the preceding care plan
  - Today, palliative care strives to expand the availability of the services developed and so well provided by hospice programs to:
    - Include all patients with any life-threatening diagnosis
    - At any time during their illness when they have symptom control or supportive care needs and are prepared to accept care
- Goals may change near the end of life
  - Some goals take precedence over others
  - As a patient's prognosis and health status worsen, the goals of prevention, cure, or avoidance of death may become less important as they become less possible
  - At the same time, the goals of maintaining function, relieving suffering, and optimizing quality of life may become the focus of care
- Ideally, this shift in focus of care is gradual
  - It is usually negotiated over time

- An abrupt transition from primarily curative care to primarily palliative care is rarely appropriate
- The shift in goals is an expected part of the continuum of medical care
  - Changes occur throughout the patient's life and illness
  - The physician plays a key role during all phases of the continuum
  - In all situations, the nature and course of the illness, and the patient's and family's goals for care, should determine the relative emphasis on cure versus palliation

### Aspects of Care According to Primary Goal of Care

Aspect of Care	Primary Goal of Care		
	Curative	Life-Prolonging, Palliative	Symptomatic Palliative
Impact on disease	Eradicate	Arrest progression	Avoid complications
Acceptable adverse effects	Major	Major-moderate	Minor-none
Psychological attitude	"Win"	"Fight"	"Accept"
Preference for CPR	Yes	Probably	Probably not
Hospice candidate	No	No	Probably
Symptom prevention/relief	Secondary	Balanced	Primary
Support for family	Yes	Yes	Yes
Advance care planning	Yes	Yes	Yes
Bereavement support	Not usually	Sometimes	Usually

### Caring For a Dying Child: A Different Pattern of Evolving Goals

- It is particularly hard for the parents and family to shift away from their hopes for cure for their child
- The realization that the disease will take their child's life may come quite late for many parents
- Consequently, the pattern for changing goals of care can be somewhat different than when the patient is an adult
- To help parents prepare, the physician will want to explicitly include a goal of comfort along with the goal of cure from the beginning of treatment planning
- When curative goals are no longer appropriate, this strategy permits some aspects of the treatment plan to continue until death, rather than necessitating a change from one goal to another with its implications for abandonment and "giving up hope"

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