HOPE

#### "Hoping for Hope": Translating Hope Theory Into Hospital-Based Palliative Care Practice

#### Todd R. Cote MD, FAAHPM, FAAFP

Chief Medical Officer, Hospice of the Bluegrass and the Palliative Care Center of the Bluegrass Program Director, UK College of Medicine and Hospice of the Bluegrass Fellowship in Hospice and Palliative Medicine Assistant Professor, UK College of Medicine

#### **Disclosure Statement**

### Dr Todd R. Coté has disclosed no relevant financial relationships.

#### Objectives



**Discuss Nature and Definition of Hope** 

**Review Three Current Hope Theories** 



**Examine Hope-Enhancing Clinical Interventions** 

# The Nature and Definition of Hope

"Hope is a mystery....a human struggle between acting (the hoping for something) and being (the lived experience of hope).

Gabriel Marcel (1889-1973)

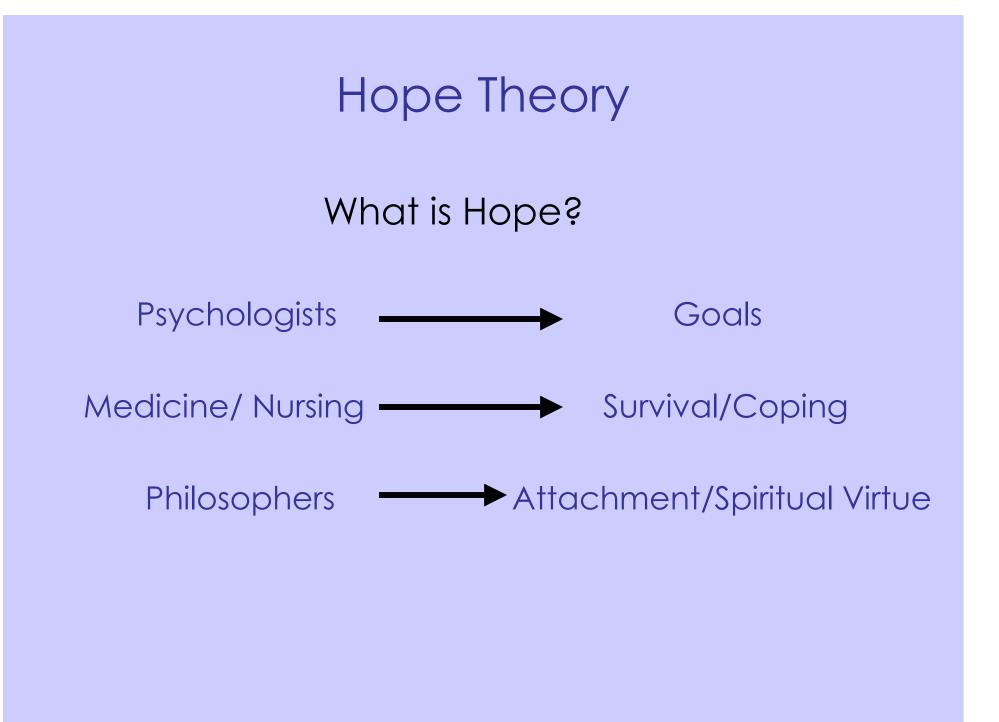
### "Our shelves are bare. The journals are silent."

Karl A. Menninger MD (1959 Keynote Speech on "Hope" to American Psychiatric Society)

### Hope Theory

An Interdisciplinary Approach?





#### "There appear to be no well-developed measures of a patient's own sense of hope."

Daniel P. Sulmasy MD, OFM, PhD (2002)

#### The Nature of Hope in Healthcare

- Hope = Cure
- Hope = A Tangible Treatment
  - » Cripe LD (2006) Hope is the thing with feathers. JAMA 296:1815-6

#### Hope Theory

#### • Currently:

- No universal definition of Hope
- A multitude of conceptual frameworks
- Theories are diverse and divisive.

» Nekolaichuk C.L. Diversity or Divisiveness? A critical Analysis of Hope. In : Essential Concepts in Nursing. Oxford: Elsevier (2005):179-212.

### Hope in Clinical Practice

- Evidenced-based literature review:
  - **Hope**: most important psychological factor in cancer patients( Nowotony 1991, Miller 1992, Koopmeiner et al. 1997).
  - Hope: explored in newly-diagnosed cancer, cancer survivors, end stage disease including HIV, ESRD and Heart Failure (Rustoen & Wikland 2000, Little & Sayers 2004, Hall 1990; Fleming 1997; Weil 2000; Benzein et al. 2000; Davidson et al. 2007).
  - **Hope**: contributes to improvement in QOL and coarse of illness( Stephensen 1991, Gottschalk et al. 1993, Farran et al. 1995).
  - **Hope**: positively linked to effective coping during chronic illness and first recurrence of cancer(Herth 2000, Kim et al. 2005).
  - Hope: leads to improvement in immune system function. (Udelman & Udelman 1985,1991).
  - **Hope**: Truth-telling and prognostication assist hopeful thinking for surrogate decision makers and families in the intensive care unit in adults and pediatric patients. (Verhaeghe et al. 2007; Apatira et al. 2008; Mack 2006)
  - **Hope:** important to a meaningful life and dignified death in terminally ill homebound patients. (Benzein et al. 2001)
  - Hope: lack of hope associated with increased depression and suicidal intent (Beck et al. 1974, 1985, Chochinov et al. 1998).

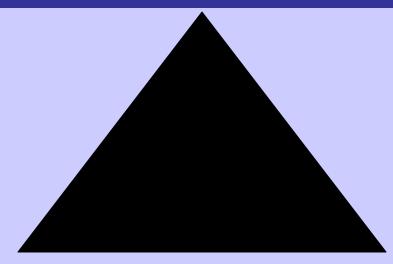
#### Hope Theory

<u>Particularized</u> Specific, tangible **Cognitive** Thinking "Realistic Hope" Universal Attributes



#### <u>Generalized</u> Less tangible **Emotional** Feeling

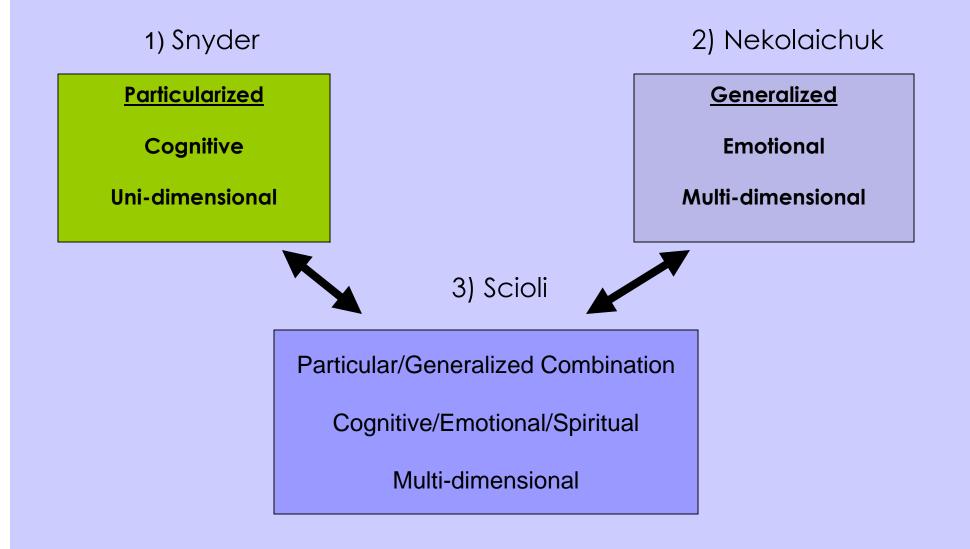
"Magic Hope" Dynamic Process

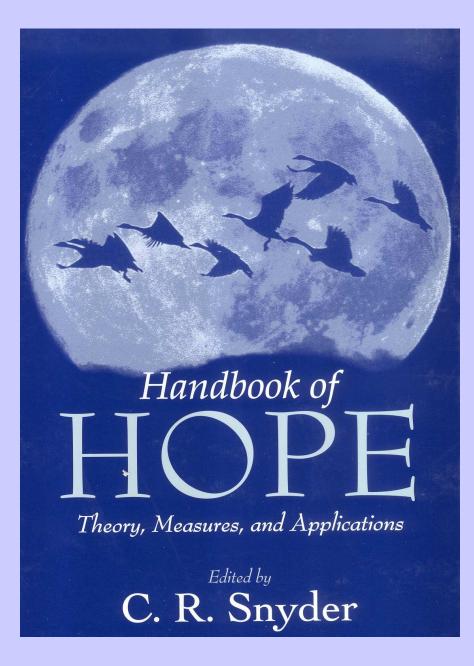


Dufault K, Martocchio B C. Hope: Its spheres and dimensions. Nursing Clinics of N A, (1985), 20, 379-391.

Three Hope Theories

#### Hope Theory Frameworks





#### Hope Theory: Snyder Framework

- Hope definition: The perceived capability to derive pathways to desired goals, and motivate oneself via agency thinking to use those pathways.
- Hope is a positive motivational state that is based on an interactively derived sense of successful:

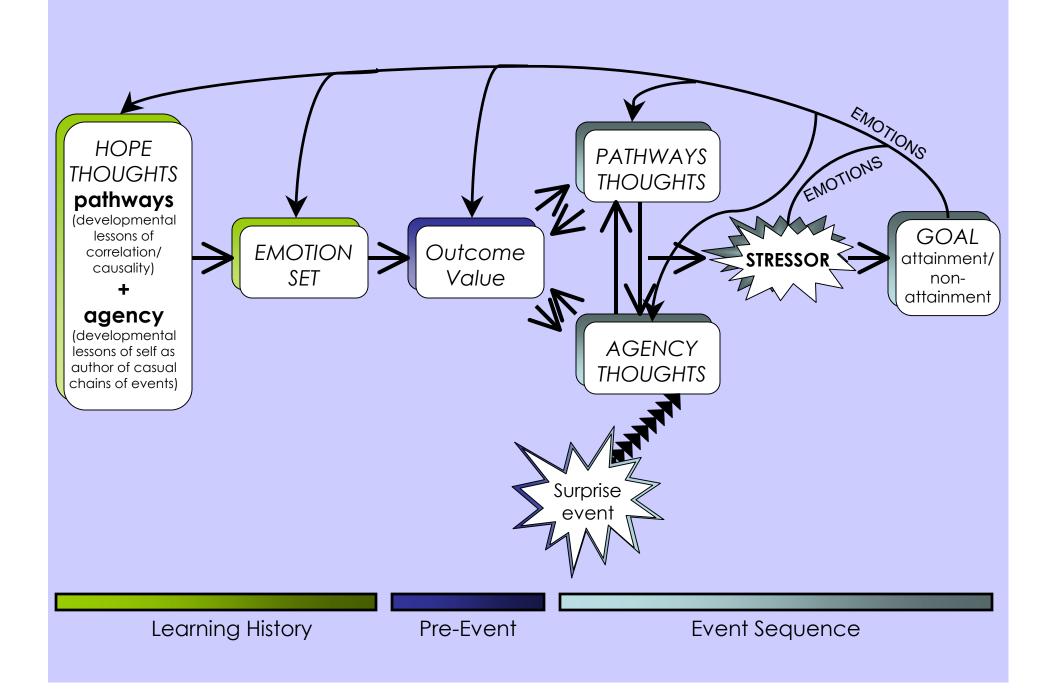
   (a) agency (goal-directed energy)
   (b) pathways (planning to meet goals)
- The trilogy: goals, agency and pathways
  - » Snyder CR (2002) Hope Theory: Rainbows in the Mind. Psychological Inquiry 13:249-275.

#### Hope Theory: Snyder Framework

- <u>Goals</u>: Those that anchor their thinking about the future to specific goals are more hopeful.
- <u>Agency</u>: Those that are capable of pursing goals , who believe in their own capacity, are more hopeful.
- <u>Pathway</u>: Those that can imagine or plan ways to achieve goals step by step along a pathway) are more hopeful.



• Snyder CR (2003) "Hope Theory: Rainbows in the Mind", Psychological Inquiry 13:249-275.



#### Hope Theory: Nekolaichuk Framework

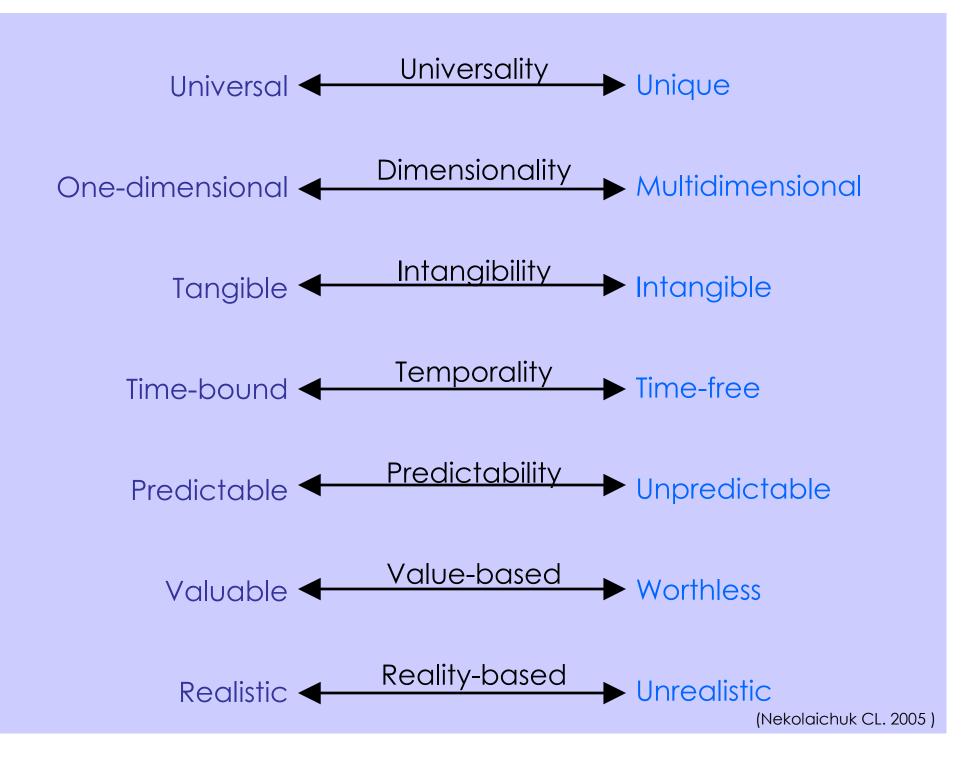
- Hope Definition: associated with finding meaning in life, taking risks in spite of uncertainty, and experiencing credible and caring relationships.
- People experience hope along three dimensions;
  - a) personal spirit
  - b) Risk
  - c) Authentic caring
    - » Nekolaichuk CL, JevneRF, Maguire TO. (1999) Structuring the meaning of hope in health and illness. Social Science & Medicine, 48, 591-605.

#### Hope Theory: Nekolaichuk Framework

- <u>Personal Spirit</u>: the personal experience revolving around a core theme of meaning
- <u>Risk</u>: the situational dimension that is characterized by uncertainty
- <u>Authentic Caring</u>: the relational dimension with underlying themes of credibility and caring.



• Nekolaichuk CL, Jevne RF, Maguire TO. (1999)Structuring the meaning of hope in health and illness. Social Science & Medicine, 48, 591-605.

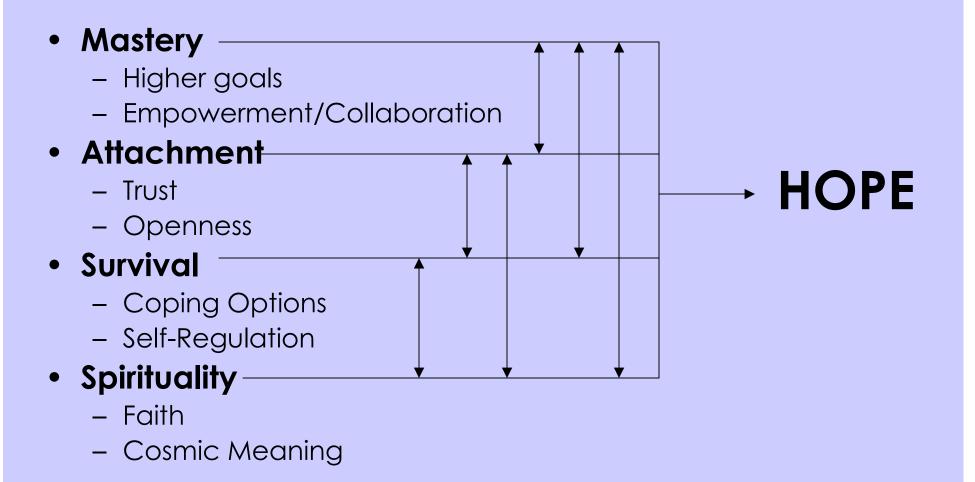


#### Hope Theory: Scioli Framework

- Hope Definition: emotional circuits or networks
   unique to each person
- People experience hope along four dimensions;

   a) Mastery: Goal-setting
   b) Survival; Coping, Terror Management
   c) Attachment: Trust and Openness
   d) Spirituality

### Hope Theory: Scioli Framework



#### Hope Theory: Scioli Framework



**Courage** Survival Heart Attachment **Brain** Mastery

HOPE

#### Translating Hope Theory into Hope Enhancing Interventions in the Hospital Setting



#### Case Study 1

## When "Hopelessness" Overwhelms Decision-Making.

#### Strategies for Healthcare Providers (Snyder)

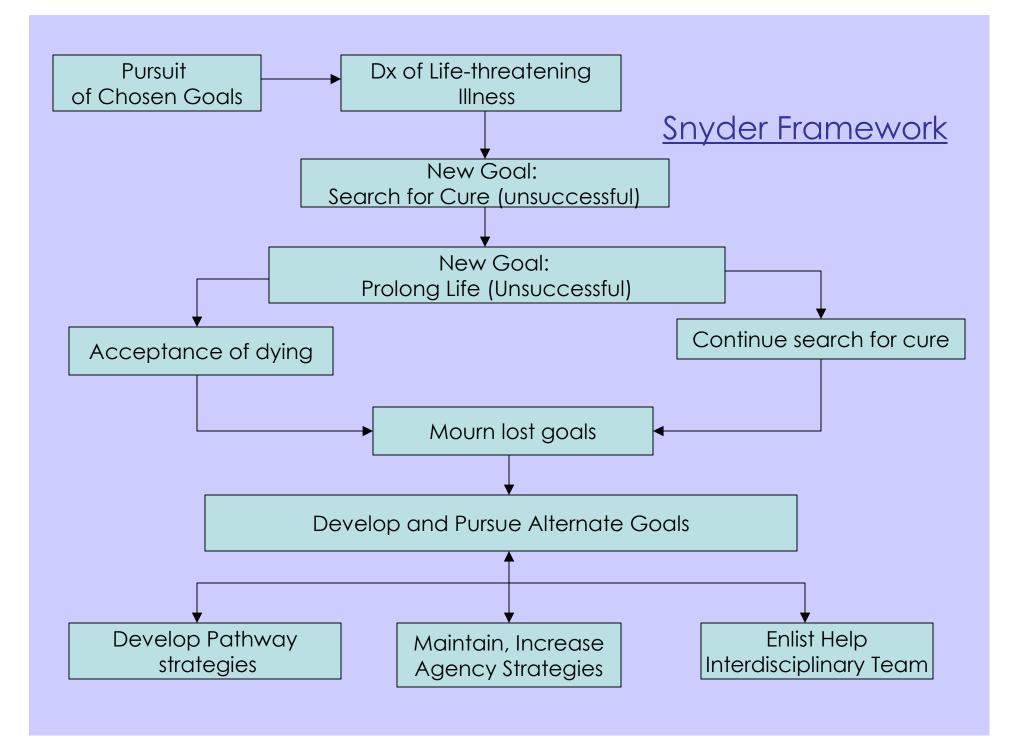
Goals	Pathways	Agency
Let patient choose goals.	Help patient identify pathways , sub goals, obstacles.	Do all you can for pain and symptom management.
Assess goals on individual basis. Encourage	Provide interventions for cure, prolongation, improved QOL.	Encourage, support, be sensitive.
developing alternative goals. COMMUNICATE	Support the patient/family's pathways.	Appropriate humor.
Re-assess	Work together with individual, family and other healthcare providers.	Ask and remind of past goal successes.
	th Terminal Illness: The Role of Hopefu	Libipling L Doll Mod (2002) 5:(-22

Gum A, Snyder CR, Coping with Terminal Illness: The Role of Hopeful Thinking, J Pall Med, (2002), 5:6, 883-894

#### Strategies for **Patient/Family** (Snyder)

Goals	Pathways	Agency
Mourn losses of valued	Use positive , active	Manage pain and
goals.	strategies and actively confront.	symptoms
Recognize one's worth.	Believe in personal	Exercise
Recall past	control.	Rest
goals/achievements/	Break goals into sub	Plan during peak of
relationships.	goals.	day Be compliant
Develop alternative	Practice plans.	Expect and plan for
goals important to self,	Develop alternative	difficulties
communicate and	pathways.	Positive, self –
enlist others help.	Learn new skills.	motivating talk.
Describe goals clearly	Communicate.	Develop social support
and measure progress.		Appropriate Humor
Enhance goals by	Enhance by new goals and agency	Enhance by new goals and pathways
agency and pathways		

Gum A, Snyder CR, Coping with Terminal Illness: The Role of Hopeful Thinking, J Pall Med, (2002), 5:6, 883-894



#### Strategies for Patient/Family (Nekolaichuk)

Theme	Question for the patient
Caring	Tell me about a time in your life when you experienced a moment of caring?
Communication	Tell me about what it's like to be ill?
Commitment	What might be one small thing that you do on a regular basis to help strengthen hope?
Coping	What has helped you through difficult times in the past?
Creating	If you were to create a hope kit, what kind of things would you put in it?
Community	How is hope experienced in your community (culture)?
Celebrating	If you were to plan a celebration of hope , then what might you do?

Nekolaichuk CL, Jevne RF, (2003)

#### Case Study 2

### When "Unreasonable" Hope Guides Decision-Making.

#### "Unreasonable" Hope

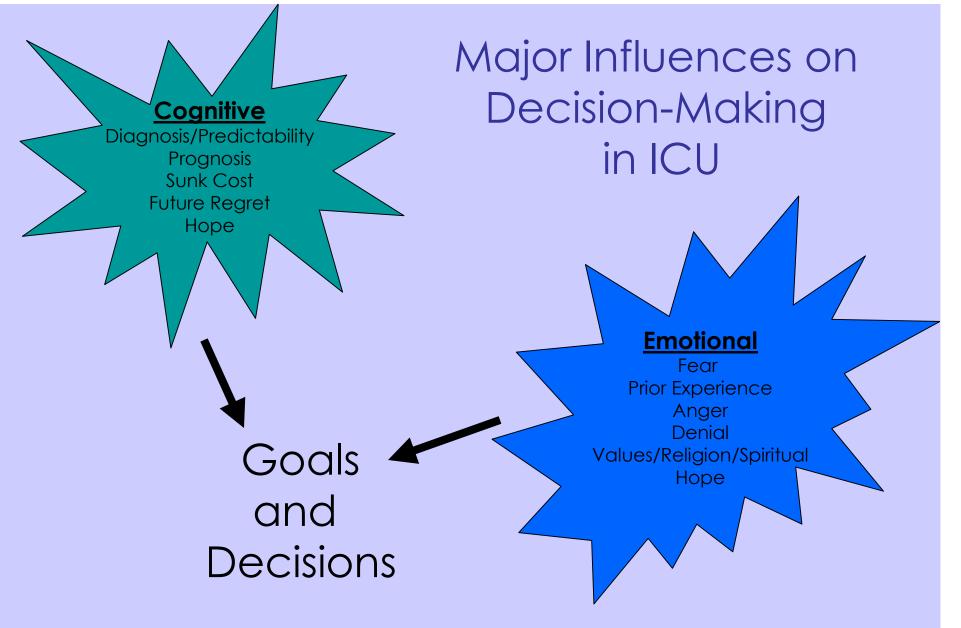
- Values (Religious Beliefs)
  - Divine Intervention > Your Knowledge
  - A Miracle ≠ Medical Prognostication
- Survival
  - "When there is room for error , there is room for hope."
  - "My cousin's wife was told her baby was gonna die , and now he's 16 years old and playing foot ball for high school. "
- Denial
  - "The ultrasound/lab must be made a mistake!"

#### Impact of Hope on Decision-Making in the ICU

#### **Shared Decision-Making**

- Clinicians and patients/families can:
  - 1) Evaluate the options together in a systematic way.
  - 2) Consider the benefits and burdens of each treatment.
  - 3) Arrive at a clear and logical decision

Chapman GB et al. Cognitive processes and biases in medical decision making. *Decision Making in Healthcare: Theory, Psychology, and Application*. Cambridge Univ. Press 2000, 183-210.



Chapman GB et al. Cognitive processes and biases in medical decision making. Decision Making in Healthcare: Theory, Psychology, and Application. Cambridge Univ. Press 2000, 183-210.

# Impact of Hope on Decision-Making in the ICU

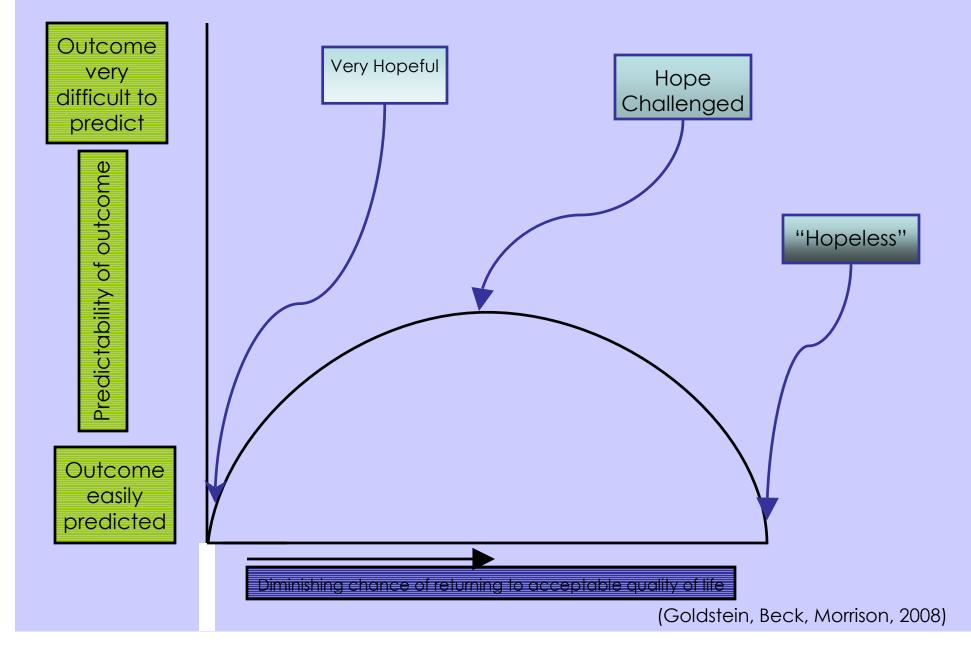
#### "Titrating Guidance"

- Clinician's role in decision-making adapts over time to changes in the patients state of health based on likelihood of recovery.
- Five steps:
  - 1) Determine where (predictability of outcome/acceptable QOL) the patient is in the ICU.
  - 2) Identify the cognitive and emotional factors and preferences for outcomes that affect the decision-making process of the patient/family.
  - 3) Reflect on your own cognitive and emotional reaction to decisions.
  - 4) Acknowledge how these factors can be addressed in conversation.
  - 5) GUIDE the patient/family in creating a plan.

Goldstein NE, Back AL, Morrison RS,

Titrating Guidance: A Model to Guide Physicians in Assisting Patients and Family Members Who are Facing Complex Decisions. Arch Intern Med (2008); 168(16): 1733-1739

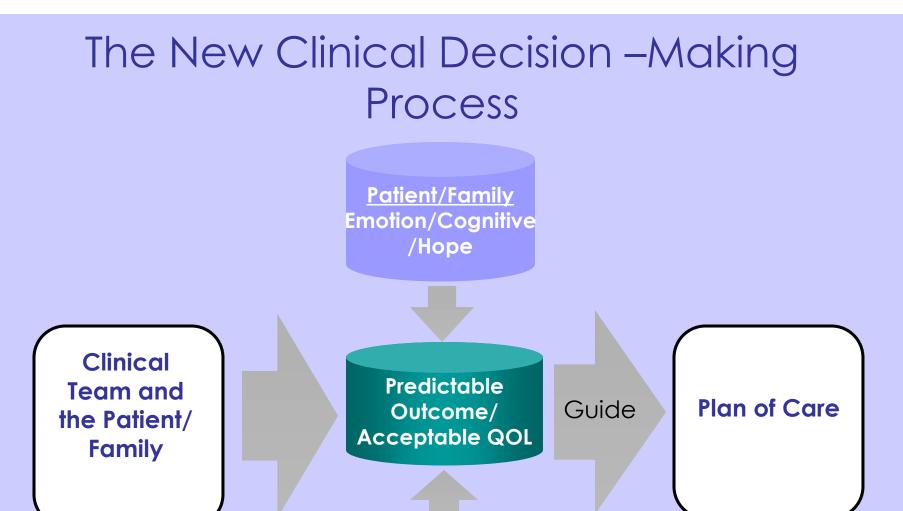
#### Transforming Hope in the ICU



#### Back to Case Study 2

# Addressing "Unreasonable" Hope in Decision-Making

- Clear, truthful, compassionate.
- Acknowledge their faith.
  - "Test of faith"
  - "Guilt from God"
  - "Fear of church"
  - "Accepting Death also requires faith."
  - "Not all miracles are ones that save lives."
- Have follow-up discussions.
- Indentify your own frustration.
- Use your resources. (Chaplain, Bereavement counselor)
- Focus on goals of care
  - Longevity, comfort, dignity?
- Consider Limitation Contracts.
- Transform Hope



<u>Clinician</u> Emotion/ Cognitive/ Hope

#### Hoping....Forward



#### Thank you tcote@hospicebg.org