Never ‘Nothing’ More To Do: Care and Hope when Cancer Treatment is Limited

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What does “nothing more” imply?
‘Nothing more’ =

- loss of Hope?
- inactivity?
- abandonment?
- peace? Release?
False Dichotomy

Curative Therapy

Diagnosis | Incurable/Treatable | Untreatable | Death

Hospice
Palliative Care: The Integrated Model

Curative Treatment

Palliative Treatment

Hospice

Bereavement

Diagnosis

Death

Incurable/Untreatable
Hope is...

‘a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant’

- Dufault and Martocchio, 1985
Hope is a Good Thing

- allows patients to deal with crises and **uncertainty**
- better follow treatment recommendations
- better tolerate discomfort
- more active involvement in self-care
- ‘Hopelessness’ is associated with:
  - depression
  - decreased physical health
  - desire for hastened death
When HOPE is tied to treatment success alone, it creates a difficult situation.

What happens when treatment does not turn out as we’d hoped?
“I realize how open we are to the persistent message that we can avert death. And to its punitive correlative, the message that if death catches us, we have only ourselves to blame.”

- Joan Didion

The Year of Magical Thinking
1. hope as a ‘process’

“Hope” as a noun
• an attribute of the situation (or disease): probability of cure, life vs. death
  – a tool (a thing) to “fight” with and succeed against disease
  – only one outcome is acceptable
  – patient is passive (either has it or doesn’t)

“hoping” as a verb/process
• an attribute of the process
  – a way of engaging in life and beyond
  – acknowledges both positive and negative outcomes
  – active engagement in life and beyond

Hope does not always come from treatment...

“My hope is not based on what doctors tell me, it’s based on how I feel as a person, my spiritual beliefs, my...you know, how my family and I interact with each other and hold each other up and whatever.”

Exploring Hope: Reframing Hope

A Sunday on La Grande Jatte
- Georges Seurat, 1884-85, 88-89
Exploring Hope: Reframing Hope

A Sunday on La Grande Jatte
- Georges Seurat, 1884-85, 88-89
“Judging such a hope as either realistic or false misses the point; rather, we should judge ourselves as clinicians by the degree to which we can help nurture our patients’ collection of diverse hopes.”

- C Feudtner, MD, PhD, MPH
NEJM. 2009; 361(124): 2306
What else is there to hope for?

what keeps people going?

Pattison NA and Lee C. J Reilig Health. Published online: 16 June 2009.
What else is there to hope for?

... living longer than expected
... good symptom control and a peaceful death
... finding meaning in everyday life
... being well cared for and supported
... reunion with God
... life after death
... giving back to science

Pattison NA and Lee C. J Reilg Health. Published online: 16 June 2009.
2. Hope: Defining Meaning

“We must never forget that we may also find meaning in life even when confronted with a hopeless situation...

When we are no longer able to change a situation...we are challenged to change ourselves.”

- Viktor E. Frankl, “Man’s Search for Meaning”
3. ‘Hope for the best, Prepare for the worst’

- Patients (and families) may vacillate between trying to ‘fight’ illness and preparing for dying
- Focusing on either “cure” or “dying” exclusively may be limiting
- Process over time: allows for continued exploration

Back AL, Arnold RM, Quill TE. Ann Internal Med. 2003; 138(5): 439-443
C  Control
P  Preparation
R  Relationships
Important Considerations at the End-of-Life

1. Freedom from Pain  
2. At Peace with God  
3. Presence of Family  
4. Being Mentally Aware  
5. Treatment choices followed  
6. Finances in order  
7. Feel life was meaningful  
8. Resolve Conflicts  
9. Die at Home  

Steinhauser KE, et al., 2000
There’s a lot to do!!
Palliative care, WHO 1990

“The active total care of patients ... The goal of palliative care is 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.”

WHO 1990
What is palliative care?
What is hospice care?

• **Palliative care = symptom management, addressing suffering** (for both patient and family)
  – Addresses physical symptoms (pain & non-pain)
  – Goals of care, in context of disease progression
  – Emotional, spiritual concerns
  – Care needs beyond the hospital setting

• **Hospice care = palliative care at end-of-life**
  – More than 90% care provided in the home
The Palliative Care Spectrum

Palliative Care

Hospice Care
Communication is Key

Coping with Cancer Study
Cohort study of 332 patients with cancer and their family caregivers

• Those who reported EOL discussions had:
  – Better quality of life
  – lower rates of ventilation, ICU admission, resuscitation
  – earlier hospice referrals and more time in hospice

• Did NOT lose hope
  – Not associated with higher rates of depression or anxiety

Wright AA, et. al. JAMA. 2008
Early Palliative Care for Patients with Lung Cancer

- 150 patients randomized to standard care vs. standard + palliative care

Outcomes:
- Improved QOL
- Less depression
- Fewer ED visits
- Less chemotherapy in last weeks of life

Early Palliative Care ≠ Limiting Care

- 150 patients randomized to standard care vs. standard + palliative care

Compared with controls, early PC patients:

- Developed or maintained accurate prognostic understanding of their illness
  
  (Temel JS, et al. JCO. 2011; 29: 2319)

- Received same # of chemotherapy regimens (just less at the very end of life)
  
  (Greer JA, et al. JCO. 2011; 30: 394)
Components of Early Palliative Care for Lung Cancer
(Median Duration ~ 55 minutes)

- Symptom Management (20 min)
- Coping (15 min)
- Other (10 min)
- Illness Understanding (10 min)

What can YOU do?

- Ask for help in managing your symptoms – pain, shortness of breath, nausea, fatigue, depression, anxiety

- Request concurrent Supportive and Palliative Care!
Empowering YOU to have The Conversation

PREPARE
A program to help you make medical decisions for yourself and others

Created by The Conversation Project and the Institute for Healthcare Improvement

Respecting Choices
Advance Care Planning

engagewithgrace.org
What can YOU do?

- Talk to your loved ones about what’s most important to you
- Talk/think about how your priorities may change if the illness worsens or time is shorter than hoped
- Ask for help in having these conversations
- Request concurrent Supportive and Palliative Care!
www.palliativedoctors.org
Questions/Comments?