Discussing Prognosis in Life Limiting Disease:

_Darned if you do and Darned if you don’t!

Allan Ramsay, MD
Fletcher Allen Health Care
Palliative Care Service
The University of Vermont
College of Medicine
in partnership with
Fletcher Allen Health Care Palliative Care Program
and Madison-Deane Initiative

presents

Palliative Care Week

Lunch Presentations: 12-1 pm
Medical Education Room 200

**Please Note: Thursday's presentation to be held in Carpenter Auditorium**

Monday, January 10
When Cure is not Possible: The Hospice/Palliative Care Option
Presented by: Dr. Brookes Cowan, PhD, MSW, University of Vermont

Tuesday, January 11
From the Other Side of the Stethoscope:
Patient and Family Perspectives on Care at the End of Life
Presented by: Zaid Berry, MD, MPH, and Panel of Family Members

Wednesday, January 12
How to Deliver Bad News: Perspectives, Advice and Experiences
Panel Discussion, Panel Moderator: Dr. Robert Macaulay, Director of Clinical Ethics, FAHC

Thursday, January 13 - **Held in Carpenter Auditorium**
Exploring the Monkey Trap: Helping Pediatric Patients and Siblings
Understand Issues of Life and Death
Presented by: Virginia Fry, MA, Director of Hospice and Palliative Care Council of Vermont

Friday, January 14
Favorite Moments: Reflections on the Intimacy of End-of-Life Care
Presented by: Joseph B. Straton, MD, MSCE, Assistant Professor of Family Medicine and Community Health at the Hospital of the University of Pennsylvania

Questions? Please contact Jonathan at Jonathan.Join@uvm.edu
Nothing to disclose----except my primary information resources

- Barb Segal, RN, MS
- Maura McClure, RN, MSN
- Ursula McVeigh, MD
  - Director of Palliative Care Education and Hospice
- Bob Macauley, MD
  - Pediatric Advanced Care Team
- Gordon Meyer, Administrative Coordinator
Objectives

- To learn ways to provide appropriate prognostic information to patients near the end of life.
- To understand how to balance cognitive and emotional communication with our patients.
- Case reports will be used to describe how hope is not a *thing we can take away* - but it is something we can support in our patients and families when providing a realistic prognosis.
Do you ever feel you are “darned” if you provide honest information about a limited life expectancy?

1. Telling a patient their illness will end their life sometimes makes me feel I am giving a death sentence.
   - True or false

2. Most studies show that over 80% of patients with serious illnesses want “all possible information” about their prognosis.
   - True or false

3. It is difficult to determine an accurate prognosis in the patients I have a long relationship with because I have seen their ups and downs.
   - True or false
How good are we physicians in giving accurate prognostic information? (BMJ 2000;320:469)

- Doctors are poor prognosticators and tend to be overly optimistic.
- Only 20% predictions (defined as within 33% of actual survival) were accurate in one study.
- As the duration of the physician-patient relationship increases, prognostic accuracy decreases.
- Ask yourself: “Would I be surprised if this patient died within the next year?” (What will you do differently if the answer is NO?)

Modern medicine is good at staving off death with aggressive interventions—and bad at knowing when to focus, instead, on improving the days that terminal patients have left. (Gawande: NYT August 2, 2010)
For those with a life limiting disease, the starting point is always treatment with curative or restorative intent—yet eventually this can become another (futile) admission to the MICU, another round of chemotherapy, another cardiac procedure, or the dreaded feeding tube.
Rx with curative or restorative intent

Rx with palliative intent including symptom management, advanced care planning and discussion of prognosis

This is the time when patients can achieve the things that are most important at the end of their lives.

Diagnosis: CHF, COPD, Cancer, ESRD

Palliative Care

Hospice Care

Death
Patients with stage IV NSCLC randomized to oncology care or oncology plus palliative care

To examine the effect of early palliative care integrated with standard oncologic care on:

- Patient-reported outcomes
- The use of health services
- The quality of EOL care among NSCLC pts

Patients with early PC lived longer!
The Prognostication Toolkit

- Karnofsky Performance Status
- Eastern Cooperative Oncology Group (ECOG)
- Palliative Prognostic Score (www.eperc.mcw.edu/fastfact/_124.htm)
- Functional Assessment Staging (FAST)
- Mortality Risk Index (MRI)
I. Late Stage Cancer (darned if you do)
   - Always another chemotherapy option
   - The pendulum of hope

II. Dementia (darned if you don’t)
   - Burdensome therapies at the end of life
   - Variable life expectancies and change can come quickly

III. Regaining Skills of our Past
Case Report #1: Malignant Bowel Obstruction

H.S. is a 64 year old man with recurrent gastric cancer first diagnosed 10 months ago. He is admitted with small bowel obstruction and ascites. H.S. has developed generalized weakness and spends most of his day in bed or chair. His pain is initially controlled with a hydromorphone continuous infusion. H.S. is only taking sips of fluids due to episodes of vomiting. CT scan of the abdomen reveals multiple peritoneal metastases and air-fluid levels at several small bowel sites. NG tube is in place and a PICC line is ordered to begin TPN. On the fifth hospital day H.S.’s family physician, who has known him for 25 years, makes a visit at the hospital. The family physician is asked to help with the treatment plan.
Prognosis in Advanced Cancer

- Cancer type, stage, and co-morbid conditions contribute to overall prognosis.
- Most important predictive factor is performance status or functional ability.
- Measured by Karnofsky index or ECOG performance scale.
- Ask patients how they spend their time; if they are in bed or laying down >50% of the time and it is increasing estimated prognosis is < 3 months.
Eastern Cooperative Oncology Group

0  Fully active, able to carry on all pre-disease performance without restriction
1  Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2  Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
3  Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
4  Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
5  Dead
<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
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<tbody>
<tr>
<td>100</td>
<td>Normal no complaints; no evidence of disease. Able to carry on normal activity and to work; no special care needed.</td>
</tr>
<tr>
<td>90</td>
<td>Able to carry on normal activity; minor signs or symptoms of disease.</td>
</tr>
<tr>
<td>80</td>
<td>Normal activity with effort; some signs or symptoms of disease. Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.</td>
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<tr>
<td>70</td>
<td>Cares for self; unable to carry on normal activity or to do active work.</td>
</tr>
<tr>
<td>60</td>
<td>Requires occasional assistance, but is able to care for most of his personal needs.</td>
</tr>
<tr>
<td>50</td>
<td>Requires considerable assistance and frequent medical care. Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.</td>
</tr>
<tr>
<td>40</td>
<td>Disabled; requires special care and assistance.</td>
</tr>
<tr>
<td>30</td>
<td>Severely disabled; hospital admission is indicated although death not imminent.</td>
</tr>
<tr>
<td>20</td>
<td>Very sick; hospital admission necessary; active supportive treatment necessary.</td>
</tr>
<tr>
<td>10</td>
<td>Moribund; fatal processes progressing rapidly.</td>
</tr>
<tr>
<td>0</td>
<td>Dead</td>
</tr>
<tr>
<td>Tumor Site</td>
<td>Response rate</td>
</tr>
<tr>
<td>---------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>Breast**</td>
<td>25-55%</td>
</tr>
<tr>
<td>Colon**</td>
<td>25-35%</td>
</tr>
<tr>
<td>Esophagus*</td>
<td>30-50%</td>
</tr>
<tr>
<td>Lung (NSC)*</td>
<td>20-30%</td>
</tr>
<tr>
<td>Stomach*</td>
<td>20-50%</td>
</tr>
<tr>
<td>Melanoma</td>
<td>15-25%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>10-25%</td>
</tr>
<tr>
<td>Liver</td>
<td>5-15%</td>
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*Modest progress
** Sig progress
Specific Cancer Syndromes that have Short Median Survival Times
(www.eperc.mcw.edu/fastfact/ff_13.htm)

- Malignant hypercalcemia (except myeloma or newly diagnosed breast cancer): 8-12 wks
- Malignant pericardial effusion: 8 wks
- Carcinomatous meningitis: 8-12 wks
- Multiple brain metastases: 1-2 months w/o radiation, 3-6 months with radiation
- Malignant ascites, pleural effusion, or bowel obstruction: < 6 months
Discussing Prognosis: Realists, Optimists and Avoiders

- **Realists**
  + Supports patient autonomy, helps patients make good decisions
  - Realists can be too blunt or even brutal

- **Optimists**
  + Support patient hopes, encouraging their patients to focus on the possible
  - Can leave patients and families unprepared for death

- **Avoiders**
  + Emphasize the limits of statistical information and inability to predict a disease course
  - Can seem evasive and unwilling to share expertise and experience, patients lose confidence
A prognosis discussion with H.S.

- "I just want to feel better so I can get home."
- "I know there is no more surgery but my oncologist says there are other chemotherapy options."
- "Am I dying."
- "I want to be prepared and I want it to be peaceful. My daughter is having a baby in a couple of months will I live to see that?"

That is the goal we will work toward.

There are burdens with chemotherapy. We should talk more about whether that will help you achieve your goals.

Tell me what you have been thinking about dying?

Most people with cancers like yours have a life expectancy of several weeks. I think that is a reasonable goal for you.
Understanding the Interaction of Hope and the Desire for Prognostic Information


- Alternate existence of hope and information
- Balance of hope and information
- Harmonious integration of hope and information
- Redirection of hope
Balancing Hope and Information

- **Back and forth**
  “Sometimes I feel hopeful and think positively about the future. Other times, I am fearful and sad because I know how sick I am.”

- **Scales**
  “I want information about my illness, but too much will depress me. I want to be hopeful but I know I can’t be too hopeful because that’s not realistic”

- **Yin-yang**
  “I can hear bad news about my disease and still hold on to hope”

- **Redirecting**
  “I used to hope for a cure but now what’s important has changed. I hope for other things.”
A Palliative Care Conversation with H.S.

- “I just want to feel better so I can get home”
- “I know there is no more surgery but my oncologist says there are other chemotherapy options” (balancing)
- “Am I dying?” (yin/yang)
- “I want to be prepared and I want it to be peaceful. My daughter is having a baby next month, will I see that?” (redirecting)

- That is the goal we will work toward
- There are burdens with chemotherapy, we should talk more about whether that will help you achieve your goals. (providing realistic info)
- Tell me what you have been thinking about dying. (ready to hear bad news)
- People with cancers like yours have a life expectancy measured in weeks, I think that is a reasonable goal for you. (Hoping for other things)
Case #1: H.S.

H.S. has a venting gastrostomy tube placed. His PCA is converted to fentanyl transdermal with liquid hydromorphone for breakthrough pain. He decides against burdensome treatments while in the hospital (CPR, MICU). H.S. is able to increase his oral intake (sip and suck) and is discharged home with VNA palliative care services. He discontinues the TPN 6 weeks before his granddaughter is born and enrolls in Hospice. H.S. lives an additional 3 weeks after the birth of his grandchild and dies peacefully at home.
L.R. is a 79-year-old woman with late-stage Alzheimer’s dementia. She has been living in a skilled nursing home for two years. Her daughter visits every day and monitors the care L.R. receives from the nursing home staff. L.R.’s daughter has insisted that everything be done for her mother when an acute illness occurs. L.R. requires total supportive care (FAST 7c). The nurses notify you on your regular rounds that L.R. has lost ten pounds in the past month and is refusing most foods that are offered to her. Supplements have already been started. Her daughter asks you about inserting a feeding tube or giving her mother intravenous fluids to “build her up”.
NHPCO recommends **FAST** for determining eligibility for hospice in patients with dementia.

- **FAST** is a 7-step staging system, step 7A (ability to speak limited to six words in addition to history of aspiration, sepsis, pressure ulcers, or weight loss) suggests a median survival of six months or less.
- 40% of the patients in the **FAST** validation study did not demonstrate dementia progression.

**Mortality Risk Index** is a composite score of 12 risk factors.

- Developed for newly admitted nursing home residents with dementia.
- 70% patients with a score of >12 died within 6 months.
- MRI has not been validated in the community setting or established long term nursing home residents.
A “Food is Love” discussion about prognosis

Daughter:
- “My mother never wanted to be in a nursing home, I am sure that is why she stopped eating.”
- “Our faith is very important, we could never let my mother starve to death.”
- “I know she would rather be home and doesn’t want to suffer.”
- “I have already talked it over with my younger sisters and they agree—we love her and have to feed her.”

Family physician:
- Tell me more about your mother and your siblings.
- Have you thought much about the end of your mother’s life?
- It is always important to hope for the best care, we should also talk about how well your mother will accept the feeding tube.
- Can we meet again so I can discuss this with other family members?
Conflict

(Back, et al. Mastering Communication with Seriously Ill Patients)

Some basic steps on how to deal with conflict:

I. Know it exists
II. Find a non-judgmental starting point
III. Acknowledge the other’s concern/viewpoint (the emotions)
IV. Move the discussion to a shared interest
V. Find options that recognize the interests of all those involved
VI. Remember--- Not every conflict can be resolved
Knowing yourself when conflict arises

Reflect on your own feelings:

1) *How important is this to the other person’s core beliefs and values? (their faith, beliefs, experiences)*

2) *How important is this to my own core beliefs/values?*

3) *How flexible can I be in this particular case without compromising an important value I hold?*
We meet again-
What would be most important to her now?

**Family Physician:**

Your sister filled me in on your mother’s goals and values. We all agree that she would not want to suffer.

I know how much you care for her. It is time to consider that her life expectancy is now only a few months, with or without TF.

I can’t imagine how hard this is to hear. You have taken great care of your mother.

This is the first time you have requested a treatment, tube feeding, that would increase her suffering and we know she would not want that.

**Family:**

“We want to be sure her weight is ok, and she doesn’t starve.”

“How do you know that? She has only changed in the last few weeks. I think you are wrong.” (tears, anger)

“Why to you tell us this, we want to do everything we can to keep her with us.”

“Why will she suffer with tube feeding, won’t she starve to death without it?”
Quality of Life with a PEG Tube
(one third of U.S. NH patients with late stage dementia have a FT)

- Restraints may be needed to keep tube from dislodging – especially in older patients
- If patient finds pleasure in eating, tube feeding may interfere with this
- Aspiration still occurs and the feeding tube may actually increase the risk of recurrent pneumonia
Prolonged Survival?

  - 50% six month mortality with or without a feeding tube

- 1386 patients with recent progression to severe cognitive impairment (Finucane et al. JAMA. 1999; 282(14): 1365-70):
  - No difference in survival between groups treated with or without feeding tubes
Hunger and thirst at the end of life?

Finucane et al. 1999

- These are not common symptoms at the end of life
- If present, can be effectively relieved with ice chips or small amounts of food
- Fast Fact #3:
  - Most actively dying patients do not experience hunger or thirst
Alternatives to Sugar Coating
(When there are complicated emotions)

When overwhelming emotions occur (crying, anger, denial, numbness), our first impulse is often to “sugar coat”-

“She could easily outlive our expectation”
“We don’t really know for sure”
“Things might get better so we can try another round of chemotherapy”

An alternative approach is:
1) Active listening (silence)
2) Validation of the exposed feelings and emotions
3) Empathic statements
What is Empathy?

- The ability to understand another’s emotions or feelings.
- Different from sympathy, which relates to a shared feeling.
- Empathy does not depend on having congruent feelings with others.
- *Clinical empathy* is the ability to understand the patient’s experience and feelings, and to communicate that understanding back to the patient or family.
Empathetic Communication

- Strengthens provider-patient relationship
- Improves patient compliance
- Reduces malpractice risk
- Improved satisfaction of clinicians and patients
- Is time efficient

### Finding a common interest

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<tr>
<th><strong>Family Physician:</strong></th>
<th><strong>Family:</strong></th>
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<tbody>
<tr>
<td>Your mother will not starve to death, she is much more likely to develop a pneumonia or other problem.</td>
<td>“Won’t going without food make her suffer, even before she gets an infection?”</td>
</tr>
<tr>
<td>We can still let her eat and slowly decreasing her food does not cause end of life suffering.</td>
<td>“So if we don’t give her an IV or put in a feeding tube, is there anything else we can do to make her better?”</td>
</tr>
<tr>
<td>Hospice would be a better option than tube feeding, do you know about hospice care?</td>
<td>“We have heard hospice is wonderful but doesn’t hospice just mean the last few days?”</td>
</tr>
<tr>
<td>People like your mother can be on hospice for many months before they die.</td>
<td>“OK, no feeding tube but we still want Mom to have CPR!”</td>
</tr>
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Our Core Beliefs and Values

- Improving quality of life, not prolonging death
- Decision to place a feeding tube is never urgent.
- If a feeding tube is instituted, this should be done with highly specific goals in mind.
- If a complication occurs or the goals are not met after a certain period of time, consideration should be given to withdrawal of the feeding tube.
  - Once inserted, majority of patients with advanced illness have the PEG tube until they die
    (Rimon et al. Age Ageing 2005 34: 353-357)
Case #3: Nineteenth Century Empathy

- You have damage in your eye that makes those halos.
  - “What causes it?”

- We don’t know why this happens but do know it will progress to more loss of vision.
  - “How long will that go on and what is the best treatment?”

- Our experts believe that patients with this disorder should stop reading and writing—which causes more stress on the eye.
  - “How can I do that? I am a writer.”

- I have read and greatly admired some of your unpublished poetry. I can’t possibly imagine how hard this is for you.
Tell All the Truth
(www.online-literature.com/dickinson/)

Tell all the Truth but tell it slant-
Success in Circuit lies
Too bright for our infirm Delight
The Truth's superb surprise

As Lightning to the Children eased
With explanation kind
The Truth must dazzle gradually
Or every man be blind-

Emily Dickinson
Questions and Comments

- Affirms life
- Promotes quality of life
- Treats the person
- Supports the family
Fletcher Allen’s Rural Palliative Care Network

(http://www.youtube.com/watch?v=S2_cYHqXCtY)

1. **Telemedicine Palliative Care Consultation**
   - In collaboration with the MICU

2. **Mentorship Program**
   - Spend a day with the FAHC PCS

3. **The Palliative Care Hotline**
   - (802) 847-2700

4. **Palliative Care Case Conferences**
   - Interactive via telemedicine Wed noon (CME)

5. **Web log discussion group**
   - “Ask Dr. Ramsay”