

Sustaining Hope, Providing Help: Case Studies in Advanced Illness

Laurence E. Carroll, MD, FASN

Joan K. Harrold, MD, MPH



Objectives

- Benefits of palliative care
 - Patients
 - Physicians
- Conversational tools
- Reducing caregiver burdens

Advanced Illness

- Life expectancy of a year or less
- Extreme?
- Average?

Case Study #1

78 yo woman died May 2004 in Hospice inpatient unit

- Mid 1980's progressive CKD/ESRD (stage 5)
 - Hemodialysis x 1 year
 - Cadaveric renal transplant
- 1999 transplant failed; Hemodialysis restarted
- 2000 admitted to Hospice with severe CAD

After Hospice Admission

- Hemodialysis 3 x week
 - 8 hospital admissions
 - 7 ER visits
 - 3 inpatient Hospice admissions
- Husband as primary caregiver, since mid-1980's
- Continued on and off of the Hospice Medicare Benefit

Ongoing Problems

- Recurrent chest pain
- Peripheral vascular disease
 - Amputations/Wound Care
- “Ischemic” abdominal pain
- Hypotension on dialysis
 - Carnitine responsive
- Depression
- Skeletomuscular injuries
 - Shoulder dislocation/Right Hip Fracture

Course of Illness

May 2000 “Reasonable comfort” on continued Hemodialysis

- Chest pain
- SOB at night

May 2004 Withdrew from Hemodialysis

- Cachexia
- Seizures
- Distal right femur fracture

Hopes for . . .

- Continuing treatment
- Managing symptoms
- Supporting family
- Maximizing function
- Someone to call for help
- Living well

Palliative Medicine

“...the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life.”

Great Britain, 1987



Palliative Care

- Affirms life
- Recognizes dying as a normal process
- Neither hastens nor postpones* death
- Relieves pain and other symptoms
- Integrates medical, emotional, & spiritual care
- Supports patients & families/caregivers

Common Palliative Therapies

- Analgesia
- Treatment of non-pain concerns
 - GI effects, dyspnea, anorexia, fatigue, stress
- Chemotherapy / Radiation therapy
- Other disease-specific therapies
- Helpful nutritional supplements
- Time-limited trials

Treatment of Early Disease

BENEFITS

- cure
- longer life expectancy
- prevention of complications
- preservation of function

BURDENS

- ↑ risk of mortality and morbidity
- pain and other discomfort (reversible)

Treatment of Advanced Disease

BENEFITS

- longer life expectancy
 - less achievable
- prevention of complications
- preservation of function

BURDENS

- pain
- dyspnea
- other discomforts
- fatigue and loss of energy
- loss of time to do important things

How Palliative Care Can Help

- Management of patients' symptoms
 - Pain
 - Dyspnea
 - GI distress
 - Depression and anxiety
 - Insomnia

How Palliative Care Can Help

- Contingency planning
 - What to expect
 - What to do when symptoms occur or recur
 - Medications that might be needed
 - After hours help for crises or concerns
 - Nurse visit may prevent unwanted hospitalization

How Palliative Care Can Help

- Time-intensive conversations
 - What things are important for you?
 - Are your treatments helping you do these things?
 - Are there burdens related to your treatments?
 - For patient? For family?
 - What would be important to do if you have less time than you hope for?

Caregiver stressors

- Isolation & frustration
- Overwhelmed
- Too little time to care for self
 - Sleep deprivation
 - Poor eating habits
 - Lack of regular exercise
 - Delay own medical care

How Palliative Care Can Help

- Isolation & frustration
- Overwhelmed
- Too little time to care for self
 - Sleep deprivation
 - Poor eating habits
 - Lack of regular exercise
 - Delay own medical care
- *NOT ALONE*
- *Help with care and planning*
- *Symptoms managed*
- *Helpful hints*
- *Respite*
- *Active listening and support*
- *Other resources*

How Palliative Care Can Help YOU

- Good clinical outcomes
 - Symptoms managed
 - Contingency plans made
 - Goals of care discussed
 - Patient and caregivers supported
- Fewer after hours calls and crises
- Satisfied patients and families



How Palliative Care Can Help YOU

- More control over patient care
 - Less compelled to offer treatments you believe to be futile because there is “nothing else”
- Enhanced ability to care for patient at home
 - Physician and/or RN to assess and keep you informed
 - Symptom management protocols
 - Avoid unnecessary hospitalizations



Case Study #2 . . .

82 yo man currently in hospice care

- 1987 Open heart surgery
- 1992 AAA repair; Vascular disease
- 2001 CKD stage 4 (GFR 15-29cc/min)
 - DM (II); Proteinuria
 - ↑BP (MRA—normal renal arteries)
 - Renal stones (US without hydronephrosis)

... Case Study #2

2002

- Pacemaker
- Carotid stenosis
- Moved to assisted living with wife

2003

- Shingles
 - Back pain (Neurontin, Elavil)
- Wife expired
- Multiple eye surgeries
- Stage 5 CKD (GFR <15cc/min)

Treatment Options

2002

- Hemodialysis discussed
- 6-12 months life expectancy without Rx

2003

- Goals of care
- Palliative treatment

2004

- Hospice referral

Ongoing Problems

- Hiccups
- GI upset
- Unsteadiness
- Anemia (on Aranesp™)
- ↑ K⁺
 - Loop Diuretic; K⁺ restriction
 - Kayexelate™ (oral) weekly
 - D/C fosinopril

“If you want something different from
what you’ve always gotten,
***you must do something different
from what you’ve always done.***”



Talking about Palliative Care

- Foreshadowing
- Treatment, not absence of treatment
- Collaborative relationships, not abandonment
- Extra-ordinary help for extra-special patients
 - Pain and symptom management
 - Aggressive monitoring & prevention of problems
 - Family support

Talking about Palliative Care . . .

- Foreshadowing

We are going to treat this tumor aggressively. If the tumor becomes harder to control, we will also focus on treating the problems that the tumor causes. No matter what, though, we are going to fight this together.

... Talking about Palliative Care

- Treatment of current symptoms

This pain is more and more of a problem. It's making it more difficult for you to even get here. I want to manage this pain aggressively. I like to work with pain and palliative care specialists to treat pain like this and keep it from limiting your treatment.

... Talking about Palliative Care

- Prevention and monitoring of other symptoms

There may be other symptoms that start to bother you. To stay on top of those, day or night, it would be helpful to have a nurse available to see you at home—even to come to your house after hours. It could save you a late night visit to the emergency room.

... Talking about Hospice Care

- Additional help for family

I know it takes a lot to keep everything going right now. There are other people I work with who can give us some ideas about how to manage all the different things that you and your family are facing right now. I'd like to call them and have them talk with you about how they can help.

When to consider Palliative Care

- Advanced or rapidly progressive disease
- Increasing health care needs
- Pain and symptom management
- Emotional and spiritual support for patient and family
- “Would you be surprised...?”

What about Hope?



Hope

1. (v) To wish for something with expectation of its fulfillment.
2. (v) To look forward to with confidence or expectation.
3. (v) To expect and desire.
4. (n) A wish or desire accompanied by confident expectation of its fulfillment.
5. (n) Something that is hoped for or desired.

“Contrary to fears that discussions of prognosis will destroy patients’ hope, such discussions can refocus hope more realistically and prevent false hope.”

When you think of the future,
what do you hope for?

Pantilat S and Steimle AE
JAMA, May 2004; 291: 2476 - 2482



People *have* hope.
We offer *HELP*.



Help

1. (v) To give assistance to; aid.
2. (v) To give relief to, ease, relieve.
3. (v) To change for the better; improve.
4. (n) The act or an instance of helping.
5. (n) Aid or assistance; relief; remedy.
6. (n) One that helps

“Helpfulness” Language

- Evaluate helpfulness of interventions
- Talk about the helpfulness of interventions
 - not just what can be “offered”
 - not a matter of “giving up”

This medication is not helping fight the disease. And it is not helping you feel better, either. I think that we should try a different treatment.

How Palliative Care Can Help

- Symptom management expertise
 - assessment, management, protocols
- Facilitate time-intensive patient-family communication
- Provide help and support to caregivers
- Enhance patient and family satisfaction

*“Although the world is
full of suffering,
it is full also of the overcoming of it.”*

Helen Keller, *Optimism*, 1903

