"I'M NOT READY FOR HOSPICE": THE PATIENT OR THE PHYSICIAN?

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LAUREN HILL

- 19 yo freshman at Mount St. Joseph dx w diffuse intrinsic pontine glioma-inoperable and terminal prognosis within 6 months
“EVERY MEDICAL STUDY EVER CONDUCTED HAS CONCLUDED THAT 100 PERCENT OF ALL PEOPLE WILL EVENTUALLY DIE.”

Why Hospice-

Providing a unique set of benefits for dying patients and their families

- Medications related to their hospice diagnosis,
- Durable medical equipment,
- Home health aide services (home hospice),
- Care from an interdisciplinary team.
- Families receive emotional and spiritual support and bereavement counseling for at least a year after the patient's death
HOME HOSPICE COST UTILIZATION

“Utilization and cost of services in the last 6 months of life of patients with cancer - with and without home hospice care.”

- Their average cost was $13,648 compared to $18,503 for patients without home-hospice care. Hospitalization contributed 32% to the total cost of patients with home-hospice care and 64% for those with it. The findings support the justification for significant expansion of home-hospice care.

CURRENT HOSPICE UNDER UTILIZATION

- Hospice patients in 2013
  - one third of the dying population
  - late in the course of illness.
  - The median length of stay in hospice is approximately 3 weeks, and 10% of patients enroll in their last 24 hours of life
REFERRAL PATTERNS

“When I first came to hospice in 2003, there were a significant number of referrals (50% or slightly greater) that came directly from the physician. The patient would be in the office that day, doc would either send them home to wait for our call or actually keep them in the office and we went to the office. When I got a referral call from a doctor, they would give us the patient's entire social history! Referrals were made much earlier in the disease trajectory and most patients had not received the amount of aggressive curative treatment they are receiving today so acuities were not as great because the patient was in better physical shape!”

“Today it is rare to speak to a physician in their office. The rare occurrence is provider specific. Often times, the primary provider finds out their patient has declined to the point they are hospice appropriate when we call for a verbal admission order following a hospital referral”

Marilyn Connor, CHPCA, Executive Director
Barriers to hospice referral arise from the way that hospice care is designed.

- The eligibility requirements—that patients must have a life expectancy of 6 months and must forgo curative treatment—are fixed by the Medicare Hospice Benefit
- Patients may delay enrolling because reimbursement rates make it difficult for many hospices to provide expensive palliative treatments.
- Some patients and families cannot accept that effective, disease-directed treatment is no longer available or that the patient has fewer than 6 months to live.
## Referral patterns for CWHTP

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<th>Category</th>
<th>2014</th>
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<td>Physicians offices and clinics</td>
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<td>Hospitals</td>
<td>57%</td>
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<td>30%</td>
</tr>
<tr>
<td>Families &amp; friends</td>
<td>20%</td>
<td>26%</td>
<td>5%</td>
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<tr>
<td>Other providers</td>
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LOS AT CWHTP-CASPER

- Median Days
  - 2010: 17 days
  - 2011: 10 days
  - 2012: 11 days
  - 2013: 8.5 days
  - 2014: 8.33 days

Average length of stay

- 2010: 48 days
- 2011: 49 days
- 2012: 34 days
- 2013: 27.9 days
- 2014: 28.10 days
THE DREADED “H” CONVERSATION

“The average time of the first conversation about end-of-life is 33 days before death,” says Dr. Block, chair of the Dept. of Psychosocial Oncology and Palliative Care at Dana-Farber.

- Physicians who initiate discussions about hospice face several challenges.
  - Is the “H” conversation appropriate, given a patient's goals and prognosis??
  - The initial discussion IS uncomfortable for everyone
COMMUNICATION BARRIER

Physicians can overcome these challenges by considering the following:

- limited prognosis
- framing the hospice discussion in terms of the patient's goals and needs for care
- recommending hospice when they think it is the best option
  - Goldilocks and the Three Bears— the question of timing of hospice referral concerning whether it is too late, too early, or just right
FACTORS THAT ARE ASSOCIATED WITH A LIMITED PROGNOSIS AND THAT SHOULD TRIGGER CONSIDERATION OF HOSPICE IN SELECTED DIAGNOSIS

- **Congestive Heart Failure**
  - NYHA class IV, serum Na <134, Cr >2.0 mg/dl
- **COPD**
  - Cor Pulmonale, ICU admissions for exacerbations, chronic hypercapnia PaCO2 >50 mm Hg, new dependence in 2 ADLs
- **Dementia**
  - Dependence in all ADLs, language limited to several words, inability to ambulate, acute hospitalization for acute problem (PNA, hip fx)

- **Cancer**
  - **Performance Status**
    - Karnofsky score <50
    - Eastern Cooperative Oncology group score >2
  - **Signs and Symptoms**
    - Liver mets
    - Multiple tumor sites
    - Malignant bowel obstruction
    - Malignant periciardial effusion
    - Carcinomatous meningitis
UNFORTUNATE TREND

- Cancer is the most common primary dx of hospice pts accounting for 38%

- And while nearly 90% of patients with cancer have documented end-of-life care talks with doctors, most of the discussions happen while patients are hospitalized, less than five weeks before death, with physicians other than the patient's oncologist, according to a Feb. 7, 2012, *Annals of Internal Medicine* study.
2014 Diagnosis:

- Cancer 29.7%
- Cardiovascular 12.9%
- Pulmonary diseases 11.8% (COPD, Pulmonary Fibrosis etc.)
- Alzheimer's Disease 7.2%
- Renal 4.3%
- Liver disease 2.9%
- Neuromuscular 1.5%
- Misc others 28.8%
Talks about hospice should emerge from a series of discussions about the patient's care, values and goals.

**Identify other decision-makers.** “Who in the family should be there with us when we discuss the results?”

**Assess understanding of prognosis.** “What have other doctors told you about your condition? … From what you know, do you think that over the next month your cancer will get better or worse, or stay the same?”

**Define the patient's goals for care.** “What do you hope for most in the next few months? … Is there anything you're afraid of?”
THE STRUCTURED APPROACH

- Establish the Medical Facts
- Set the Stage
- Assess the Patient's Understanding of His or Her Prognosis
- Define the Patient's Goals for Care
- Define the Patient's Goals for Care.
- Identify Needs for Care
- Introduce Hospice
- Respond to Emotions Elicited and Provide Closure
- Recommend Hospice and Refer
Reframe goals. “I wish we could guarantee that we could keep you alive until your daughter's graduation, but unfortunately we can't. Perhaps we can work together on a letter for her to read on that day, so she will know you are there in spirit in case you cannot be there.”

Identify needs for care. “It can be very difficult to care for a family member at home, and no one can do it alone. Have you thought about what kinds of help you might need?”

Summarize and link goals with care needs. “So I think I understand that your main goal is to stay at home and spend time with your family. To do that, we will need to help you in several ways, for instance, by sending a nurse out to your home and giving you both some help around the house. Is that right?
HELPFUL TIPS FOR COMMUNICATION

- **Introduce hospice.** “One of the best ways to give you the help that you will need to stay at home with your family is a program called hospice. Have you heard of hospice? ... Hospice can provide more services and support at home than most other home-care programs, and the hospice team has a lot of experience caring for seriously ill patients at home.”

- **Acknowledge emotional response.** “You seemed surprised to learn how sick you are. ... I can see it's not easy for you to talk about hospice.”

- **Legitimize reaction.** “Many people are understandably upset when they learn how ill their loved one is and that hospice is a possibility.”
HELPFUL TIPS FOR COMMUNICATION

- **Empathize.** “I can imagine how hard this is for both of you; you care about each other so much.”

- **Explore concerns.** “Tell me what's upsetting you the most.”

- **Explain hospice goals.** “Hospice doesn't help people die more quickly; it helps people die naturally, in their own time.”

- **Reassure.** “Hospice's goal is to improve your quality of life as much as possible, and to help you and your family make the most of the time you have left.”
HELPFUL TIPS FOR COMMUNICATION

- Reinforce commitment to care. “Let's think this over for a day or two; you know I will continue to care for you whatever decision you make.”

- Recommend hospice. “Hospice could be very helpful to you in the ways that we've talked about, but I realize it's a big decision. I'd like to arrange for a hospice nurse to visit you so you can decide for yourself whether hospice is right for you.”
A Female in her mid 50s who always wanted to ride on a Harley. A volunteer came and took her for about a 30 minute ride around Casper. She was elated! We had to lift her on and off the Harley but it was worth it!

We had another Mrs. Doe who was in her late 40s. Her daughter was engaged to be married and the wedding was not to take place for another 6 months. We pulled together a wedding that took place in the Chapman Home so she could be present at her daughter's wedding and had a reception in the backyard.
Mr. D. was a homeless gentleman with liver cancer secondary to hep C and alcoholic cirrhosis. He had no one in Casper that cared about him. His final wish was to see his best friend from his "past" in Colorado. He had no money. So--- we collected money and bought him a bus ticket and sent him to Estes Park.
We have a current patient, Mr. S. who loves to go to Las Vegas just to people watch. Twice we have been able to assist him in making those trips he loves so much (with the help of the hospice in Vegas!).

This year we had an Alzheimer's patient and our volunteers organized an anniversary party for him and his wife (it was more than 50 years) in the hospice home. His wife said he was more clear the day of the party than in many years. He became more lethargic each day following the party and died about a week or two later. I have a pic attached.

On the receiving end - this past year we got a call from a Nebraska hospice about a patient they had that had given up his son for adoption and they helped find the son and reunite them. The son lived in Casper so they helped the patient travel here and we provided short term assist during the visit.
LAUREN HILL AFTER TERMINAL DX

1) Played a college basketball game for Mount St. Joseph University (she played in four and scored a total of 10 points)

2) Celebrated the holidays with her family, even though doctors told her in September she wouldn't live to see Christmas;

3) Raised $1 million by the end of the year for research to find the home-run cure for cancer. She did that and more. The Lauren Hill Tribute Fund, benefitting the Cure Starts Now Foundation, is over $1.3 million and growing.

And as of 12/14, "We are excited to have additional resources coming to our home," the Hill family facebook post states. "We have already been able to get supplies to help make things easier here at home."