Care Beyond Cure: Palliative and End-of-Life Care

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15 years ago, if you read a medical or nursing textbook, you would never know that anyone ever died!

What is Palliative Care?

**Palliative care** is specialized care for people with serious illnesses.

It focuses on providing patients with relief from the symptoms and stress of a serious illness – not just at the end of life.

The goal is to improve quality of life for both the patient and the family.
~ 1600 hospitals have palliative care programs
vs. 5-10 fifteen years ago

The strategy has helped patients and families

But…. it could not change underlying forces.
The Marinated Mind

“Our minds have been marinated to believe more is better.”

Can we expect patients and families to make difficult decisions at the end of life if they have not been making informed health care decisions – knowing the risks and benefits -- that are far less consequential?
“I go to my doctor every three months and get a chest x-ray each time.”

State legislator from a Mid-Atlantic state

“I’ve been getting an EKG at my annual physical exam since I was 27. I’m 41 now. I don’t know why. I have no heart disease. My husband gets one, too.”

Staff member, RWJF
“I have a heart murmur and I’ve been practicing watchful waiting. I went to a diagnostic testing center for a stress test.

When I finished, I was told I needed mitral valve surgery, I needed to stop jogging immediately, and I had to take a prescription drug....

“You are going to think I am making this up but while I was on the treadmill, I overheard the young, brash cardiologist tell the nurse,

‘We’re at 9 patients a day. We have to get to 14 so this place pays for itself.’

I couldn’t believe that they were talking within earshot about the need for more business.”

Staff member, RWJF
Honest Conversation Needed so Patients/Families Can Make Informed Decisions

- Do CPR
- Intubate a patient
- Have a feeding tube
Do Medicaid health plans offer high quality palliative care provided by certified palliative care physicians and nurses?

What are indictors of poor quality end of life care?

If we don’t measure it, we can’t improve it….

If I am having a heart attack, do I need to tell doctors that I want immediate treatment in the ED (door-to-balloon time)?

What tools can you use as state policy makers to ensure that high quality palliative care is accessible?
“Build the Clock, Don’t Tell the Time”

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