Dying is part of life

Strategies for conversations around the end of life.

Martin J. Heslin MD, MSHA

Chief of the Medical Staff, UABMedicine
James P. Hayes, Jr Endowed Professor of GI Oncology
Executive Vice Chair of Surgery

UAB MEDICINE
SURGERY

6/2/2020

Disclosures

- Best Doctors: consultations

UAB MEDICINE
SURGERY

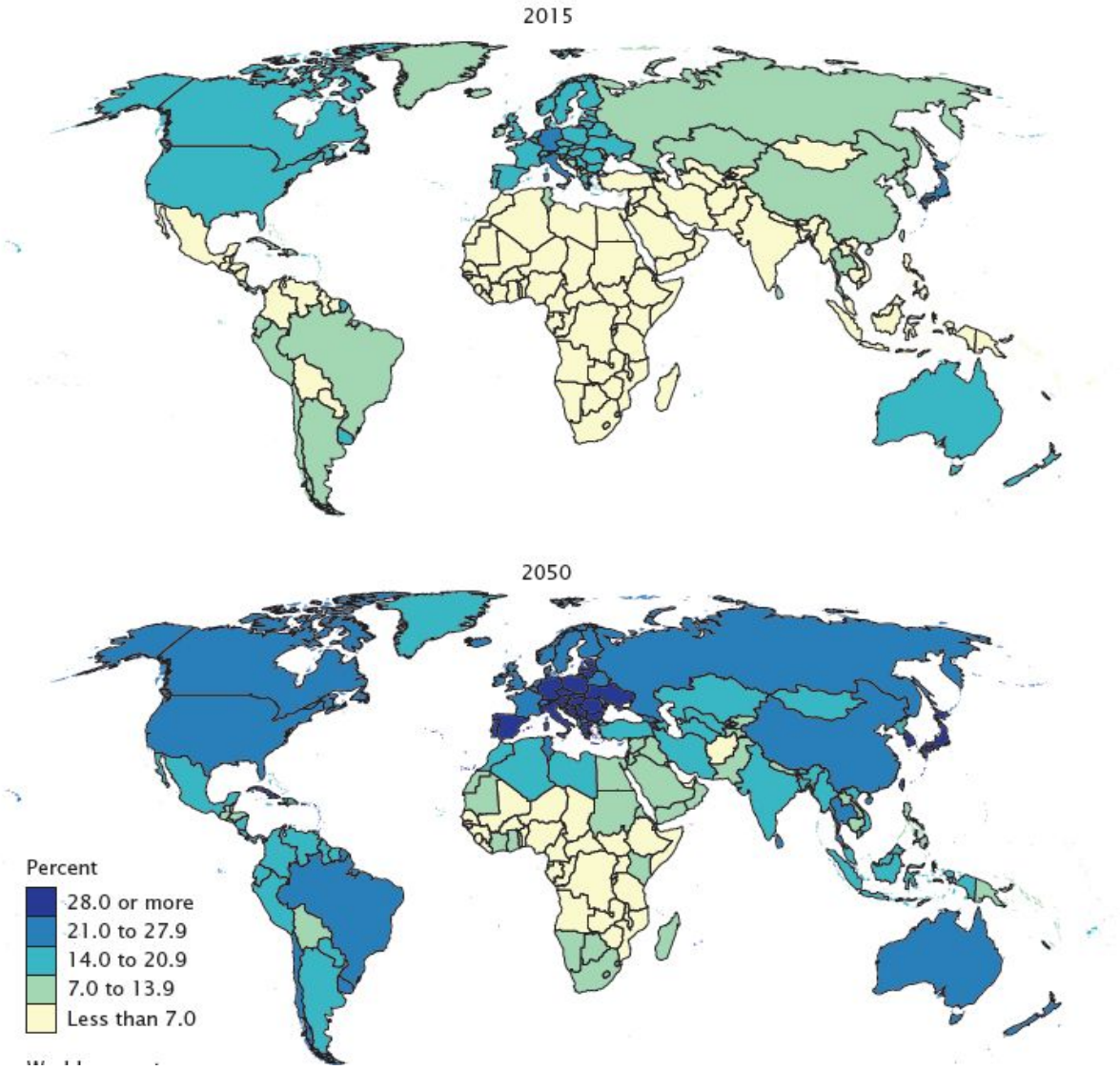
Agenda

- Why is this important to our population?
- Why may this be hard for each stakeholder?
- Data review:
  - post op (like end of life) conversations
  - perceptions of physicians by patients
- Conversation strategies/ case studies

World Population is living longer

An Aging World: 2015
International Population Reports
Issued March 2016
P95/16-1
By Wan He

Figure 2-1.
Percentage of Population Aged 65 and Over: 2015 and 2050



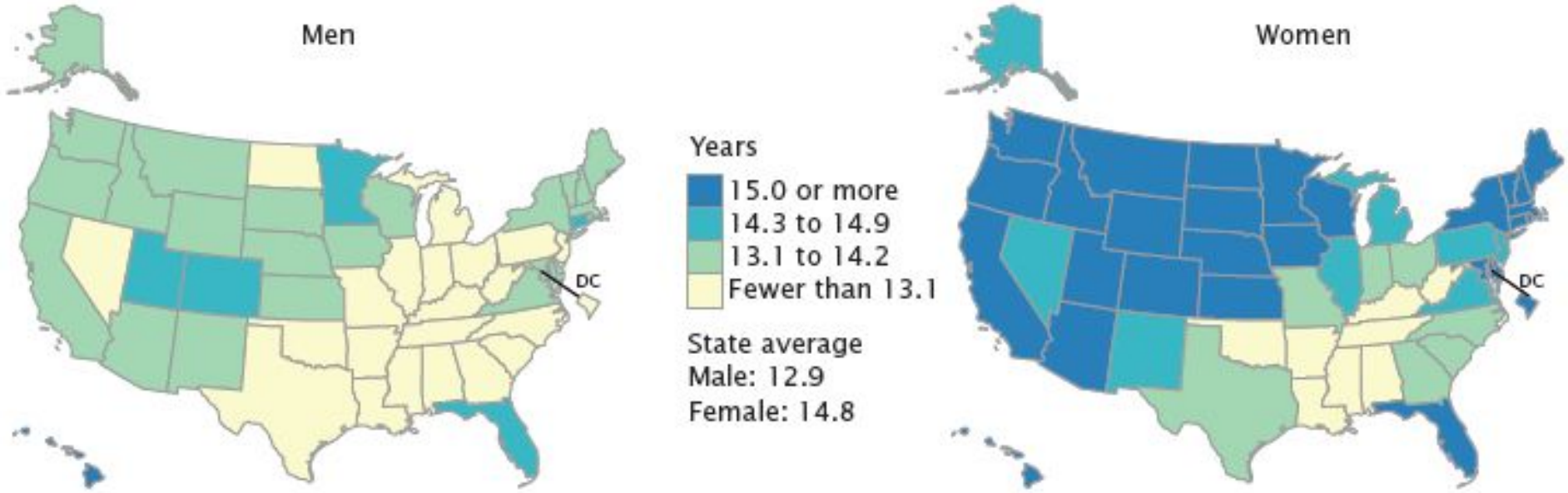
UAB MEDICINE
SURGERY

Healthy Life Expectancy at age 65 by gender and state

Figure 4-6.

United States Healthy Life Expectancy at Age 65 by Sex and State: 2007–2009

(In years)



Source: Centers for Disease Control and Prevention, 2013. Adapted from Figure 1.

Eight leading causes of US death in 2014

- The 15 leading causes of death in 2014 were:

1. Diseases of heart (heart disease)
2. Malignant neoplasms (cancer)
3. Chronic lower respiratory diseases
4. Accidents (unintentional injuries)
5. Cerebrovascular diseases (stroke)
6. Alzheimer's disease
7. Diabetes mellitus (diabetes)
8. Influenza and pneumonia

National Vital Statistics Reports Volume 65, Number 4 June 30, 2016

Conclusion:

- The US population is aging
- The diseases that people die from now and more so in the future often give time to reflect on end of life care
- Providers of the future will be called upon to discuss the risks and benefits of treatments and end of life conversations

My background and interest

- College at Cornell, med school at Upstate Medical Center in Syracuse, 5 years at NYU for residency and then 4 years at Memorial Sloan Kettering Cancer Center.
- Arrived in Birmingham in 1996.
- I went into cancer surgery because I value relationships with people and cancer allows me the opportunity to follow patients longitudinally.
- The end of life process has always intrigued me.
  - It is a delicate balance between having patients know you are going to fight for them to achieve cure and quality of life..
  - Yet, be viewed as a valued resource to discuss end of life issues as a trusted advisor who is honest, frank and compassionate.

- Why may it be so hard for the patient?
  - Fear of the unknown: No one has died and come back to talk about what happens after death..
  - Inability to accept the inevitable
    - Life closure issues/bad prognosis
  - Choices between treatment options
    - Inability to understand real benefit vs hope for good outcome
  - Children/Parents whose desires may outweigh the patients wishes

- Why may it so hard for the provider?
  - Time constraints
  - Inadequate training
  - Uncomfortable reactions to manage
  - Feel like a failure or “giving up” since nothing is zero or 100% and “I want to give my patient every chance”
  - Compensation is generally tied to actively treating the patient

The family

- Why may it be so hard for the family?
  - Fear of losing a family member
  - Inconsistent views between the family members (not the patient)
  - Fear of “upsetting” Mom or Dad
  - In denial about the actual ability to be successful in treating
  - Inability to resolve long standing family issues

The system

- Why may it be hard of the current system to support end of life care?
  - Comfortable spaces for patients, family and providers are limited and may be difficult/time consuming to find and expensive to create/maintain
  - Hospice may not be part of the health system bottom line
    - i.e. outside vendor
  - End of life conversations take longer hurting productivity

What do we know about postoperative conversations that may provide insight into the end of life conversations?

Study Aim

- Aims:
  - I. Recognize Current POC Practices
    - When, Where, How
  - II. Identify Barriers
  - III. Recognize Opportunities for Improvement

POC Results

- 15,820 operations
  - 31 surgical specialties

- Postoperative Conversation
  - Phone Call to Caregivers= 66%
  - In-Person= 34%
    - Location of In-Person → Waiting Room Lobby (81%)

What the family, provider and the desk workers say.

Theme	Surgeons	Caregivers	Staff/Volunteer
Consistent Communication With Patient/Caregivers	6.75	42	34
Maintaining Patient Privacy	7	24	5
Ensuring Adequate Environment	0.4	5	6
Standardized Communication Practice	-	59	8
Appropriate Literacy Level of Communication	5.7	66	-
Finding Family Post-Surgery	8.4	-	-
Resource Constraints	0.2	-	14
	N=13	N=35	N=9

UAB MEDICINE
SURGERY

Interval conclusions

- Providers wanted to have the relevant family available when they were available to discuss the operation which would not be different for end of life conversations (time efficiency)

- The families wanted information explained to them in a way they could understand and in a consistent fashion. (appropriate health literacy mechanisms)

What do we know about the patients perceptions of their doctors in the outpatient setting?

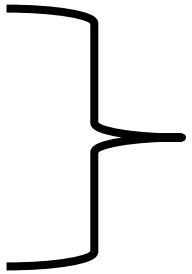
Utilizing Two Words To Evaluate Physicians

- Added a **simple** question to the Press-Ganey survey: (patients)
  - "*Please describe your physician in todays visit in 2 separate words?*"

- Perform thematic analysis to sort the words:
  - **Automatically** tabulate positive and negative

Results

- Date Range: 1/1/15-7/31/19
- Study Population:
  - 174,298 Surveys Completed: 928 Physicians; 20 Hospital Departments
  - Average Surveys per Physician= 150.1
- Survey Responses:
  - 62,532 Positive
  - 1,944 Negative



97% positive

UAB MEDICINE
SURGERY

Positive Word Cloud From Patients

UAB MEDICINE
SURGERY

Negative Word Cloud From Patients

UAB MEDICINE
SURGERY

Interval conclusions

- Physicians are perceived to be knowledgeable, caring and professional the majority of the time.
- The most common negative words are rushed, busy and hurried which is a reflection of the environment
- This environment may not be conducive for end of life conversations

Strategies to manage the patients and the families around End of Life Conversations

UAB MEDICINE
SURGERY

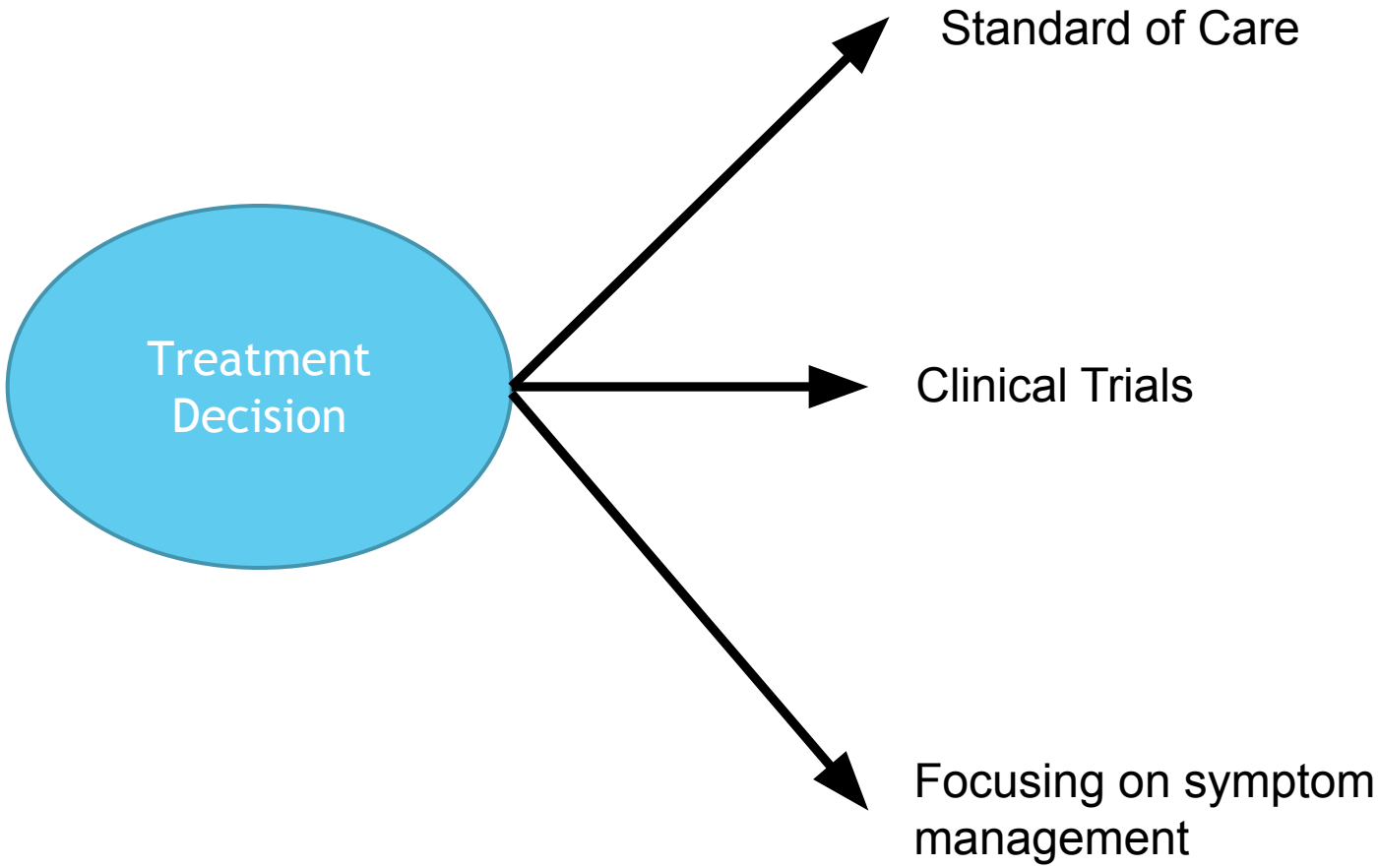
Suggestions for provider conversations with patients

- Frank but kind
- Unemotional but insightful to guide extent of information
- Concise with clear understanding of the data
- Caution with the ability to accurately predict the future in biologic systems
- Provide resources/support so that the patient and the family do not feel abandoned

How to frame (re-frame) the conversation

- Patient asks, “Am I going to die?”
- Answer, “Yes, nobody escapes death.”
  - (Give the patient time to process the information and realize that you are not being snarky)
- Follow up, “It is not whether or not you are going to die, since everyone does; you need to decide what to do from now.. until then”
  - Understands I am telling the truth in a frank and unemotional manner and actually are being serious.

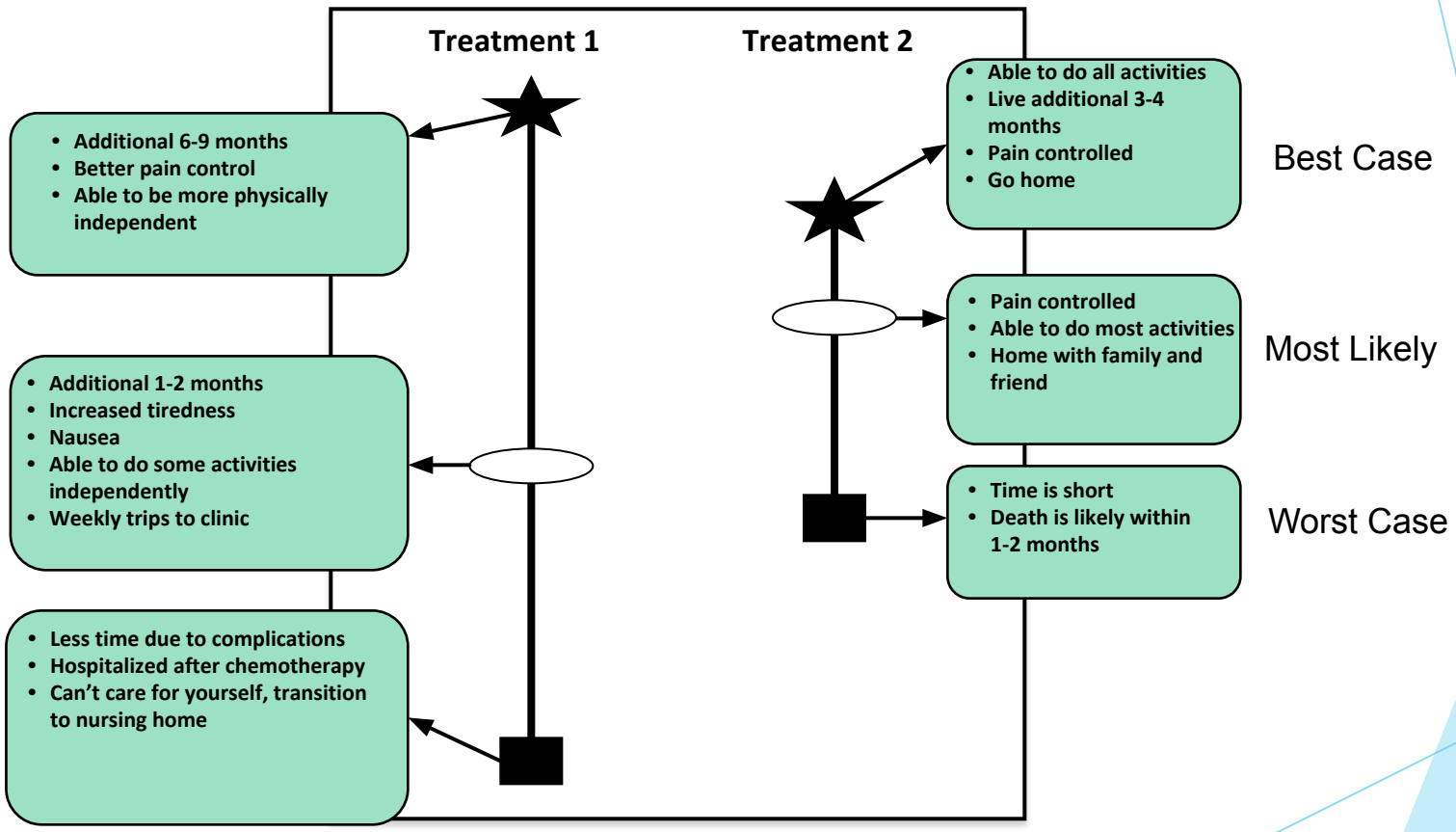
Treatment Approaches



To treat or not to treat (guide for physicians)

- Scenario
  - “Doctor, tell me what I should do?”
  - Patients want direction, and I do not believe that we as physicians can write off that responsibility as “I offered the patients a series of choices and let them decide”
  - Answer three questions about any treatment (cancer world):
    - Are you going to cure me?
    - Are you going to make me live longer?
    - Are you going to make me live better?

Best Case/Worst Case



Schwarze et al, "Navigating High Risk Procedures with More than Just a Street Map" JPM 2013

To treat or not to treat

- If any confusion, send the patient and the family home to think about the options, their goals of care, the best and worst case scenarios and return with a written set of questions

- This allows for time to process, assess the potential outcomes and realize what may be the limitations of modern medicine

Successful strategies to navigate the family

- Scenario 1
  - Don’t tell Grandma that she has a terminal diagnosis, we don’t want to upset her
  - Problem: Grandma already knows, neither party discussing situation
  - Potential solution based on EI assessment:
    - Describe a hypothetical situation:
      - a. The patient doesn’t want to “upset the children”
      - b. The children don’t want to upset mother
    - Conclude by recommendation of open conversation to reach mutually agreed upon goals, levels of support and path forward

Family follows you out of the room

- Again, trying not to upset (blank- fill in mother, father, child) about a bad prognosis or new finding

- Must, must, must
  - tell the family member that you would be happy to discuss in front of the patient, or else they may not trust “you or me” in the future

Preop setup/Post op bad news

- Many times we bring patients for procedures with the understanding that the procedure may be aborted to unanticipated reasons
  - Setup prior to procedure: You always hope for a long operation, not a short one (short means bad, family and ultimately the patient know before you talk to them)
- Commitment to the patient after the procedure:
  - Must talk to the patient after waking from anesthesia and before seeing their family so that the patient is not wondering why everyone around them crying AND you don't rely on the family to have to explain a bad prognosis

Strategies for the patients to achieve closure

- Younger patients
  - Talk about the concept of quality time spent with loved ones (especially children)
  - Suggest making videos talking about or congratulating them for upcoming major life events for each of their children or their spouses
- Older patients
  - Ask them to write an open ended letter describing “What’s important to them” which serves as a personal memoir of sorts to the family
- Either can be very emotional events at the beginning, but may provide a healthy avenue for closure

QUESTIONS?

Legal and Ethical Challenges Now and in the Future: Providers on the Hook

UAB MEDICINE
UAB HOSPITAL

Moral hazards associated with end of life conversations

- "No one should die in America" because we are marketing of health care services
  - The suggestion is that we have a "treatment for everything"
- Notion of the "Death Panel" which was politicized in the recent past
  - It's just easier for the providers to say, "I am going to do everything for every patient every day.."
- Most families are not financially tied to the choices that they make regarding their loved one
  - It's easier to say "do everything".
- Many families will ignore a living will (for many reasons) and the system is often unwilling to challenge
  - ..because "the family will still be alive and they are the only one's that can bring legal action"

Ethical Hazards Associated with Payment Reform

- Bundled payments: the hospital gets one payment to be utilized for all services surrounding a diagnosis:
  - Challenging the doctors and the hospital to justify any individual expenditure (good to reduce expenses) and potentially limiting services (potential conflict of interest).

- Capitated models: one payment for all services, essentially a “covered live” and the system is responsible for all expenditures (full risk).
  - This strategy puts the money in between the system and the patients such that reducing expenses (again good) or services (another potential conflict of interest) gets more money to the hospital and docs

Conclusions

- Ethical and moral hazards aside, we have to believe that the goal of the health care system is to deliver appropriate care including the end of life conversation

- Timely, frank, concise, data driven and compassionate conversations will help patients and families navigate this seemingly challenging time of life.

Questions?

UAB MEDICINE
SURGERY