

Hospice and Palliative Care Update for the Internist

Marianne M Holler, DO FACOI
Medical Director of Hospice and Palliative Care
VNA Health Group, Red Bank, NJ

Disclosure

- I have nothing to disclose

Goals

- Recognize ways in which palliative care benefits patients with life-limiting illnesses
- Identify ways to integrate palliative care in practice



The New York Times



THE LANCET

Volume 376 • Number 9734 • Pages 1–68 • July 3–9, 2010

www.thelancet.com



THE
HUFFINGTON
POST

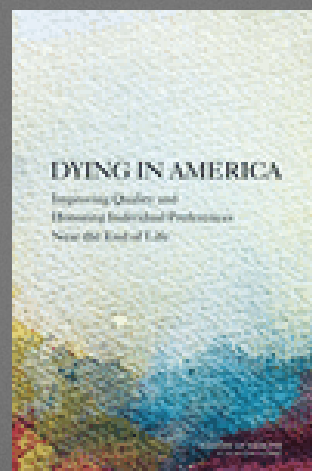
"A timely book, written with sensitivity, on a subject that pertains to every single human being and family in the world today." —RICHARD SELZER, M.D.

The Conversation



A REVOLUTIONARY PLAN
FOR END-OF-LIFE
CARE

ANGELO E. VOLAN



DYING IN AMERICA
Improving Quality and
Honoring Individual Preferences
Near the End of Life

WHEN BREATH BECOMES



air

PAUL KALANITHI
FOREWORD BY ABRAHAM VERGHESE

NEW YORK TIMES BESTSELLING AUTHOR OF
THE CHECKLIST MANIFESTO

Atul Gawande



Being Mortal

Medicine and What Matters in the End

The Inevitable Hour

A HISTORY
OF CARING
FOR DYING
PATIENTS
IN AMERICA

Emily K. Abel

TRIP OF A LIFETIME

France



Top Tourist Sites in Paris
Lieux Touristiques Les Plus Visités à Paris

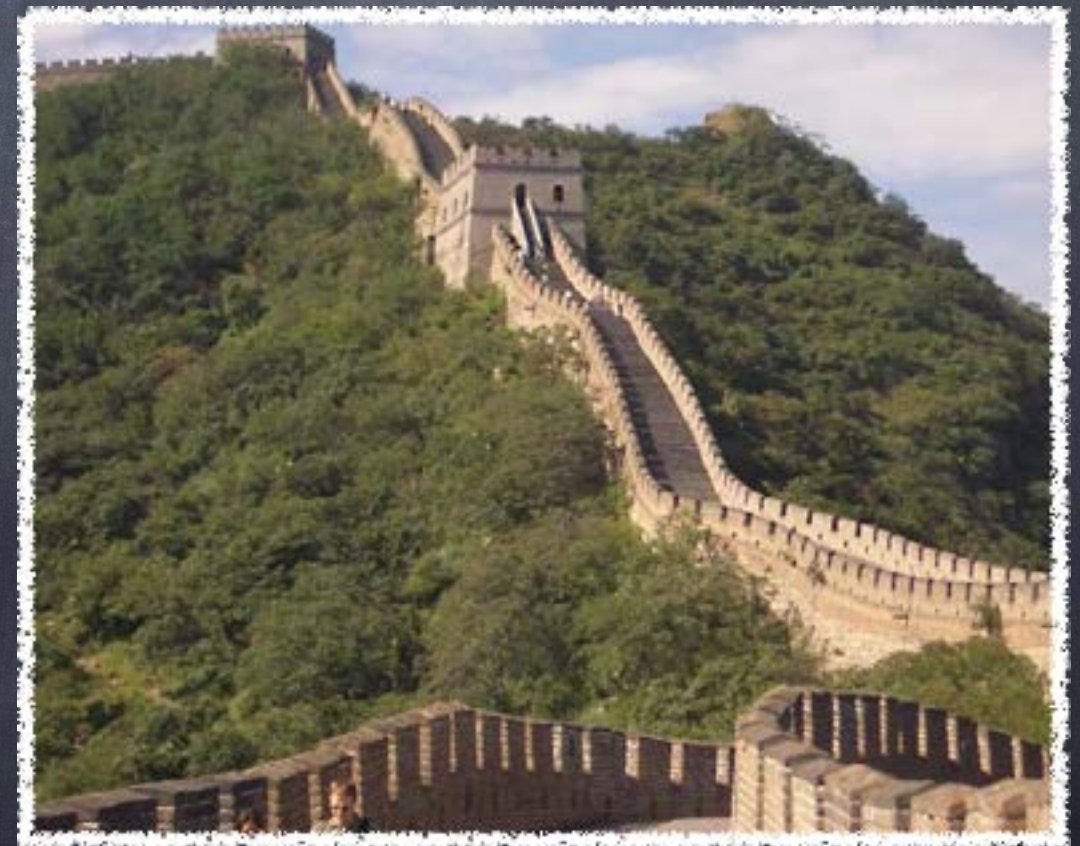




Wake up and Look out the Window

China





Medical School

- We were all taught patient has “A” we do “B”
- We were all prepared to land and function in “France” not “China”

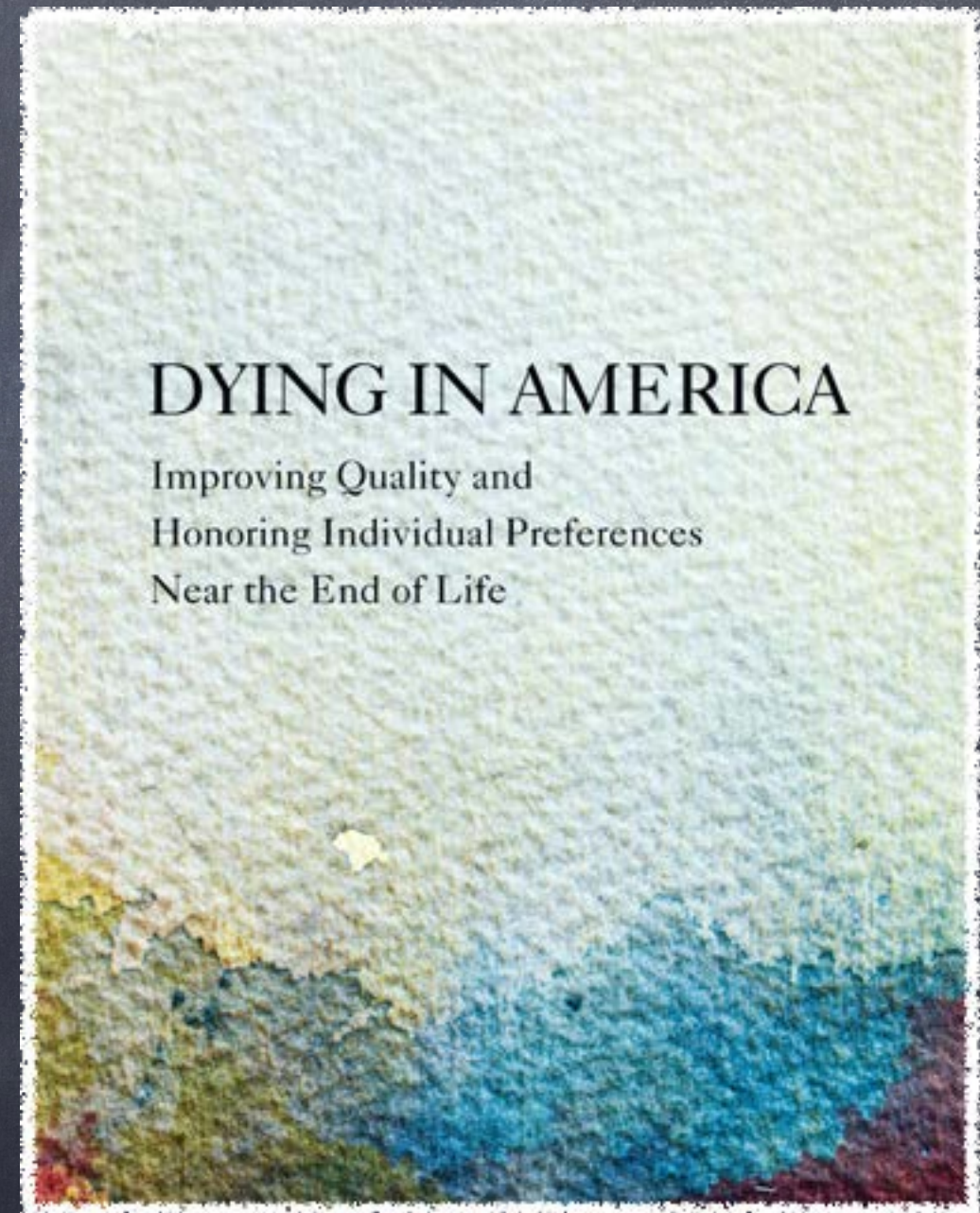


End of Life Care

- Like learning a new language, a new skill set
- Not impossible, harder for some
- But necessary if you need to get around effectively and efficiently in this healthcare environment

Today's reality

- The patient has “A”
- Before going forward we must ask: What is the Goal? What treatment/interventions will get us to the goal?
- We need to prepare to get around in “China”



AARP Study

- Nearly all doctors agree they should discuss end of life care with their patients
- 50% of Docs are unsure what to say, are concerned patients will give up hope, concerned the patient will think they are giving up (only speak “French”)
- 75% think they should initiate the talk (only 14% have billed medicare for it)

Oncology

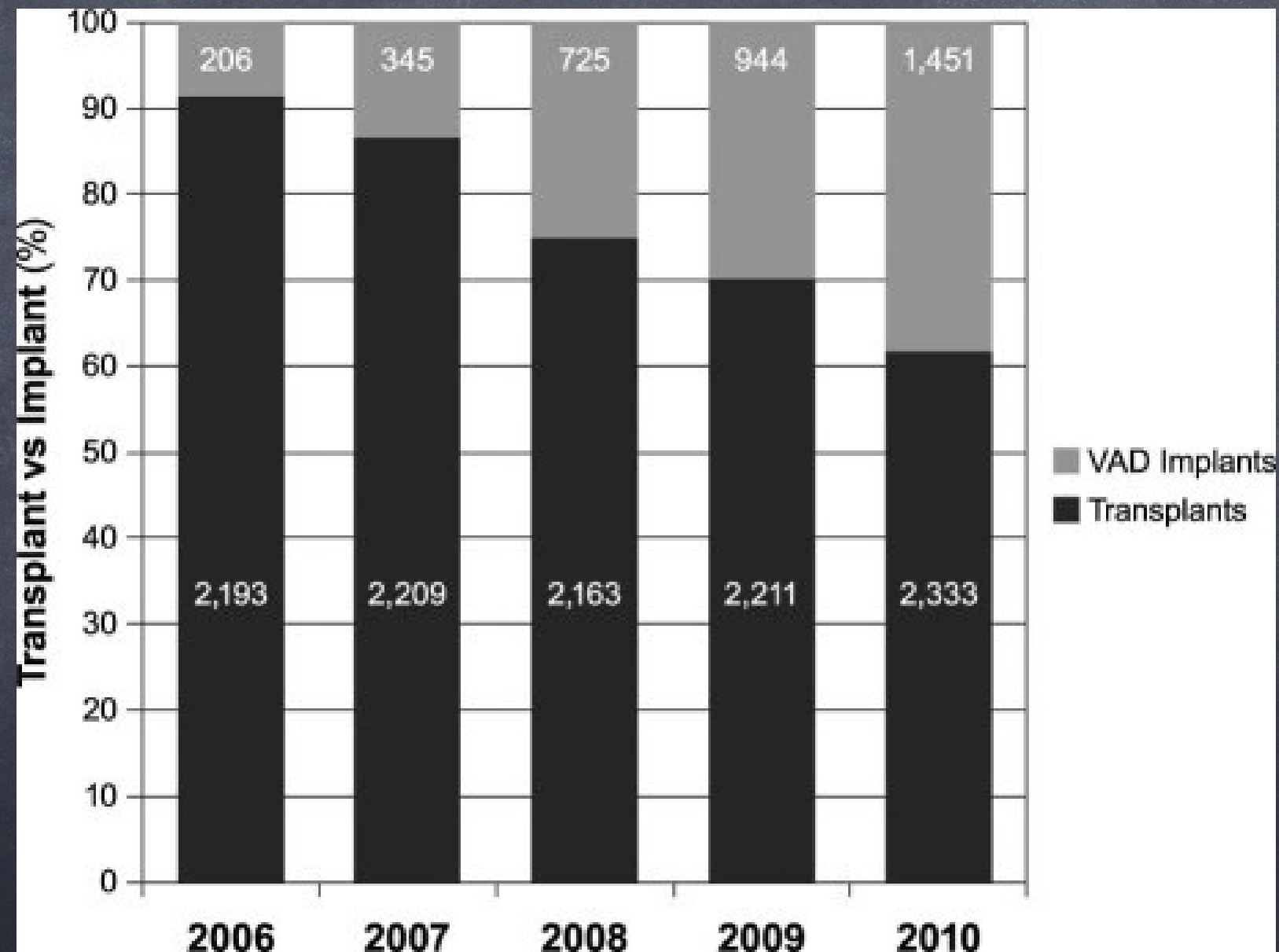
- 236 patients with advanced cancer
- 38 doctors said they would not be surprised if pt died within the year
- 68% of patients rated their survival different than their doctor
- 70% of patients said they would opt for supportive care rather than aggressive care as their life came to an end

Jama-Onc July 14, 2016

Cardiology

- 50% of patients facing replacement of Defib batteries did not know it was optional
- 27% would have considered not replacing it
- 87% felt it was important to review the benefits and burdens of the decision

LVAD as Destination Therapy



LVAD

- Initially was bridge to transplant
- 3500 Heart transplants worldwide
- 2000 LVADs in US/50% are destination therapy
- REMATCH STUDY: @12 months 52% vs 25%,
@24 months 23% vs 8%

LVAD

- Study of survivors of LVAD patients
- 87.5% surprised family member was at the end of life
- 62% confused about how the patient would die and were uncomfortable with the decision to deactivate the LVAD when other medical problems caused the need for end of life care

JAMA-IM April 2016

Neurology

- 2000-12% of End Stage Dementia patients had feeding tubes inserted
- 2014-the number has fallen to 6%
- 2014 American Geriatric Society recommends AGAINST feeding tubes for patients in the final stages of dementia
- Yet physicians continue to recommend them

Is it Me?

- 62 yo female found down in the field. Transported to the ED in full arrest. Palliative Care is consulted on day 1. Review of medical records reveals 7 hospitalizations over the past 4 months and the following history...

Is it Me?

- Stage 4 lung Cancer at Dx 18 months ago, now on salvage chemo, cardiomyopathy with EF <10%, advanced O2 dependent COPD at the time of Cancer Dx
- No family (well documented on previous admissions)
- No documented conversations about goals or end of life care at office of Cardio, Pulm, Heme/Onc or PCP or on any previous admission

No Chinese
spoken here!
Only French

Hypertension

高血壓

Diabetes

糖尿病

Why do we do these things

- As practitioners we are taught HOW to do but not WHEN to use that HOW judiciously
- Problem A=Solution B
- It makes us feel better and more comfortable that we DID something

Why talk about this?

- WW II to Mid 70s
- Explosion of medical advancements
- Heart Surgery, pacemakers, ICUs, ventilators, CPR, 911



The Rise of the “Treatment Train”

Berlin 2016



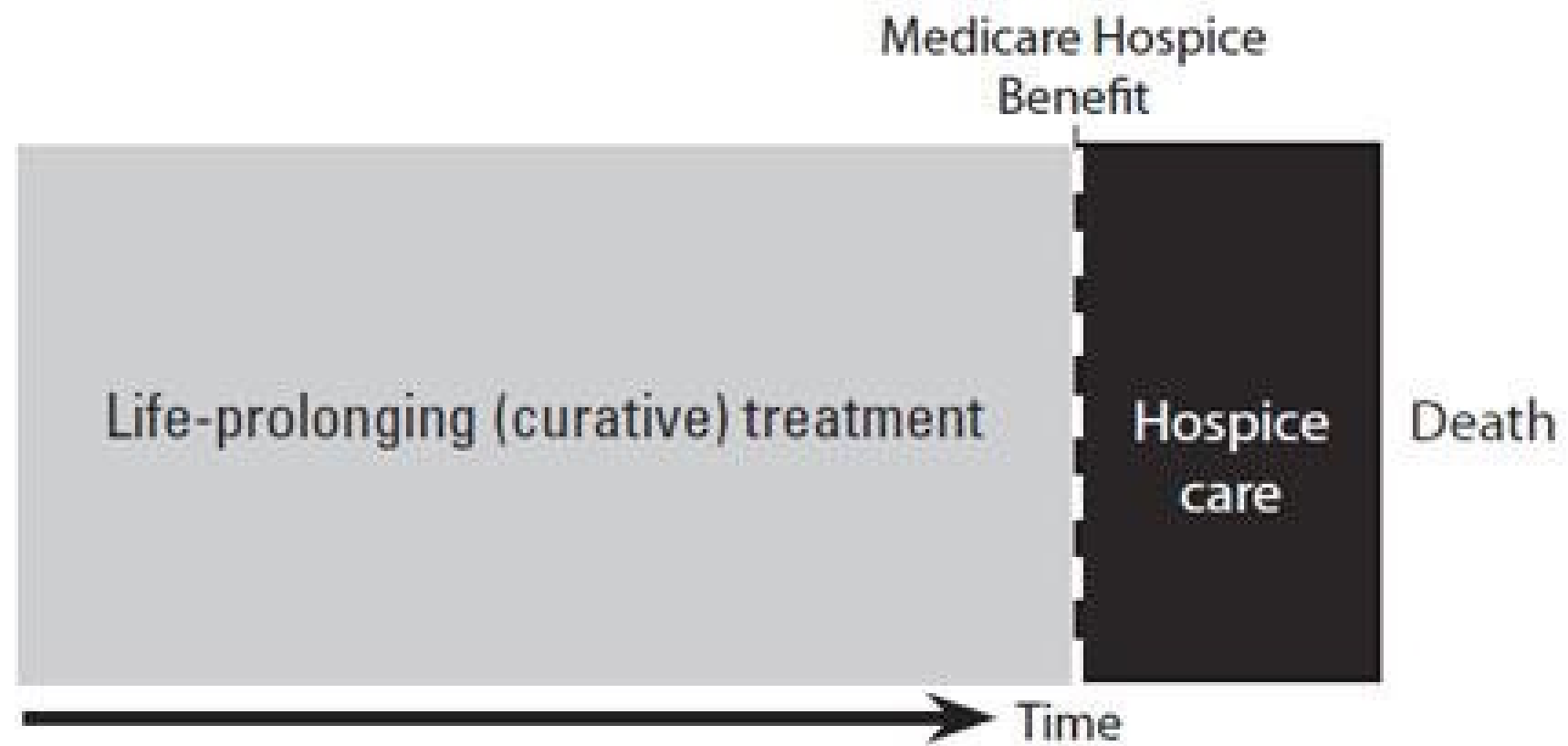
Treatment Train

- Who is the conductor? (patient vs family vs doctor vs system)
- What is the destination?
- When is it time to re-route?
- How do we stop, redirect

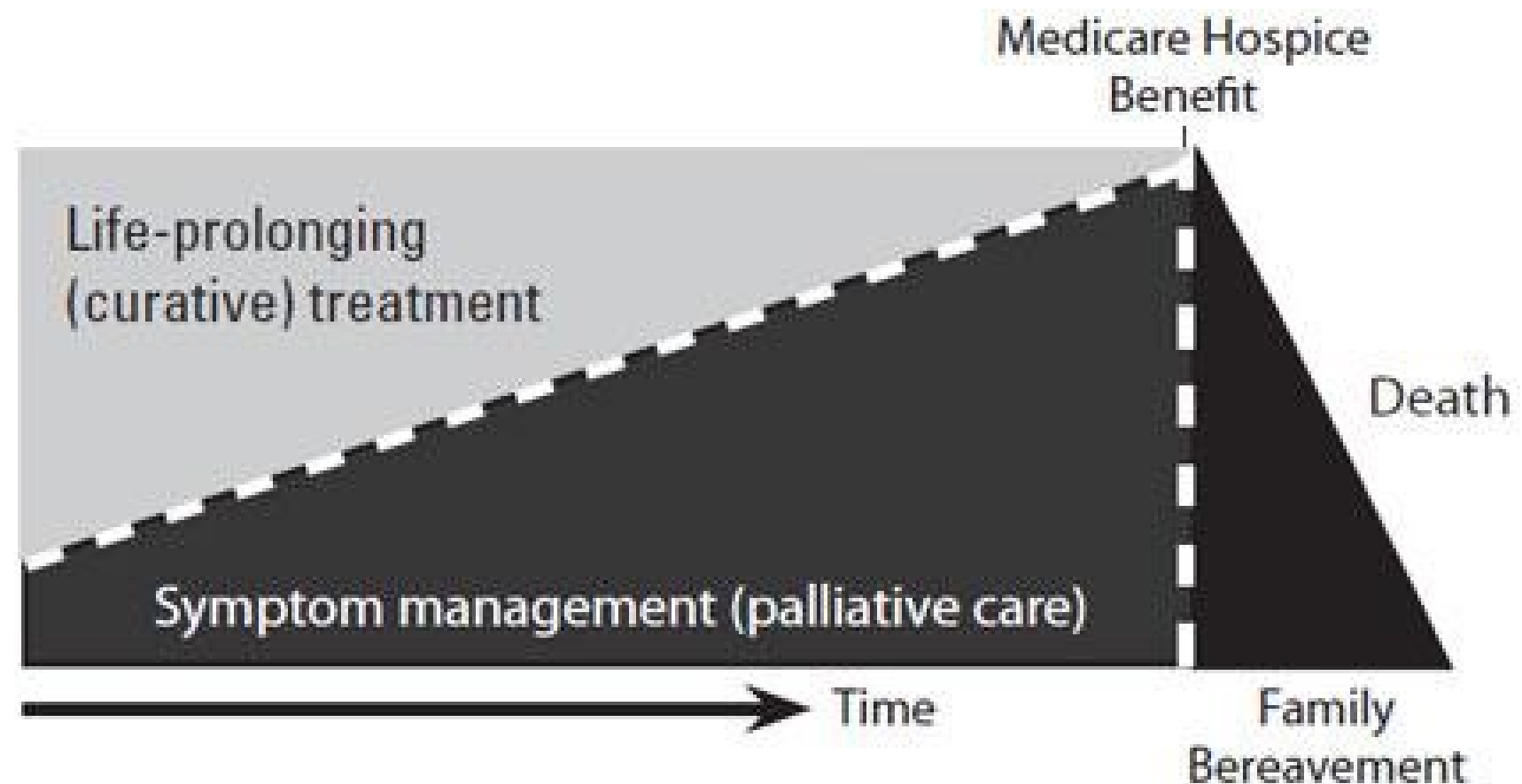
New Paradigm

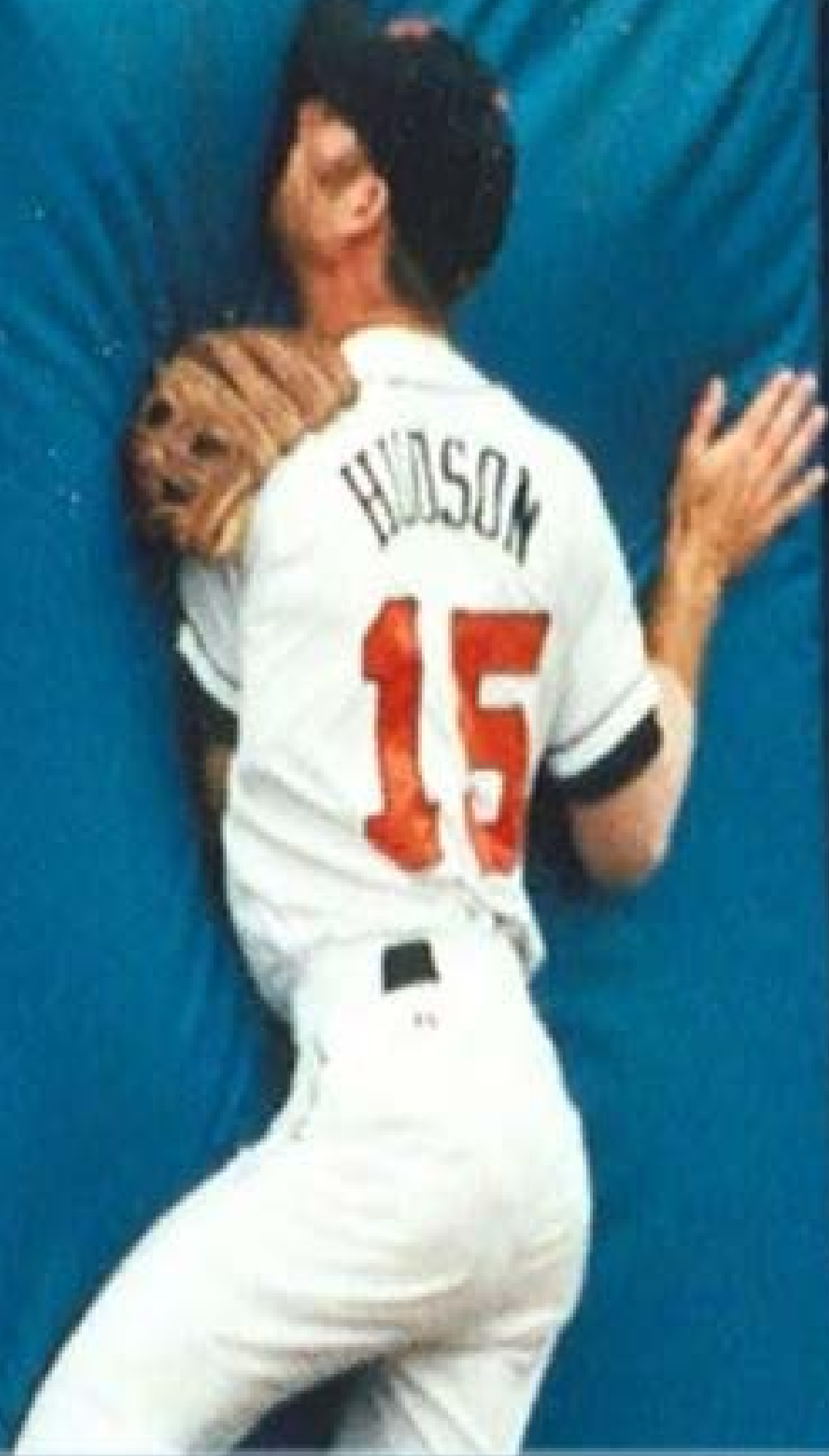
- BECAUSE A DOCTOR CAN DO SOMETHING
NEVER MEANS THEY SHOULD!

Diagnosis of
Life-Limiting
Disease



Diagnosis of
Life-Limiting
Disease





Discussing Goals in Advanced Illness

- What are the two most important questions that must be asked to start the conversation?



Question #1

- What is your understanding of what is happening with your (your family members') health at this time?
- (ASK-TELL-ASK)

What is known? (ASK)

- What is being said is not always what is being heard.
- Make no assumptions. Ask what they already know, ask about the last 3-6 months. Ask about one year ago
- How have things changed?

Medical Review (TELL)

- Present medical information
- Give details and how it relates to the big picture
- Speak slowly, deliberately, clearly
- NO JARGON



Medical Review (ASK)

- Do you have questions about what I just went over?
- Now everyone can be on the same page of the same book

Question #2

- Based on that information, what is the GOAL?
Now and if your health worsens?

Make Recommendations

- Patients and families want help in making decisions
- Support the decision that is made but do not be afraid to express what concerns you about the decision

Example

- Addressing Code Status
- “WE WANT EVERYTHING DONE”

Code Status

- Most of us walk out of the room, write “full code”, shake out heads and tell a colleague “this family just does not get it”
- What is the GOAL? To have mom live...

Code Status

- “What makes you think everything hasn’t been done? I reviewed the record and I can assure you, in your mom’s situation, everything has been done”
- Now you have the opportunity to have a detailed discussion about the outcome of a code situation
- Will not change the outcome (the public thinks it will) only how the patient experiences the outcome.

Remember

- DYING is a process
- DEATH is the event

Translate Goals in to a Plan

- We have discussed that time may be short. Knowing that, what is important
- Home? Family? Comfort? Upcoming life event? (wedding, graduation? anniversary?)
- Hope is not binary (Have hope, she lives; No hope she dies)
- Mutually decide with the patient/family on the steps necessary to achieve stated goals

Goals into Plan: Common Issues

- Future hospitalizations?
- Admission to ICU?
- Tests?
- Code status?
- Artificial Nutrition and Hydration? (Know the facts)
- Antibiotics?
- Blood Products? (benefits vs burdens)
- Home support? Hospice?

Goals into Plans

- When trying to decide among the various treatment options, a good rule of thumb is that if the test, procedure will not help toward meeting stated goals then it should be discontinued, or not started



What are you
good at?

Know your strengths

- Not everyone has to be good at this
- Know who amongst your colleagues is good at this and when to refer your patients

Regardless of your Skill Set

- You must learn enough “Chinese” to throw in with your “French” so your patients have the best chance for a meaningful life and a peaceful death





Now you know “french “ and speak enough “chinese” to
help your patients and families!

Thank you!

References

- Mastering Communication with Seriously Ill Patients, Back, Arnold, Tulsky. Cambridge Univ Press, NY 2009
- Fast Facts: Family Conference Topics
- Leading a Family Meeting, David E Wasserman, MD
- The Conversation: A Revolutionary Plan for End of Life Care; Volandes 2015
- “Families Balk at Feeding Tubes for Dementia Patients”. NY Times Aug 30, 2016
- “Bereaved Caregiver Perspectives on the End of Life Experience of Patients with LVAD” JAMA-IM April 2016

References

- Dying In America: Improving Quality and Honoring Individual Preferences Near the End of Life” Institute of Medicine Report 2015
- Effect of Patient-Centered Communication...JAMA-ONC July 14, 2016
- “I Wish Someone Had Told Us the Risks and Benefits of Replacing My Father’s Defibrillator” JAMA-IM July 2016