

Dying Healed: A Shared Quest for Wholeness

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Prognostication

- Difficult topic today...one that is often avoided and undervalued.
 - Review some research, discuss its value, discuss how to dialogue about it.
 - My hope is that you will leave VALUING giving a prognosis, as well as provide you with some elemental tools for how to do so.

Current Death Rate?

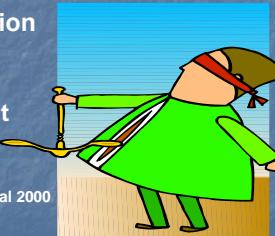
1 per
person



Death is inevitable, yet there is often a lack of timely hospice referral. Why?

**“Lack of recognition
that restorative,
rehabilitative, or
curative treatment
futility has
commenced”.**

-Travis SS. et.al 2000

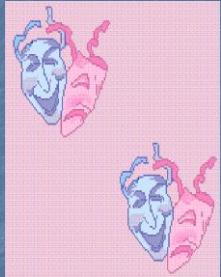


Personal Reflections



- 15% of Americans die suddenly.
 - 80% die in health care institutions.
 - 25-35% receive ICU care prior to death
 - 40-70% unnecessarily suffer significant pain
 - 50-60% are SOB
 - 96% of patients age 65 with advanced cancer had at least 1 advanced imaging study.
 - 30% express preferences about EOL care that are disregarded
 - 75% are hospitalized in the year prior to death
 - 60% see a physician at least 5 times in the last year.

What if dying isn't the worst thing that could happen?



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Prognosis is important because we live our lives differently when we are given one.

We realize that our life matters!

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Death Foretold: Prophecy and Prognosis by Nickolas Chrystakis.

Professionals: almost no training on subject.
Seldom give one.

When they do, it's overly optimistic.
The longer you know a patient, the more optimistic you will be.

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"I don't want to take their hope away."

How does lying to people increase their hope?
 Are there adverse effects to enabling denial?
 How many here hope to be prepared for your death so nothing is left unsaid or undone?
 How many here hope to die healed?
 Are these hopes legitimate?
 When someone is nearing the end of life, which is a more legitimate hope: to prepare yourself and your family for your death or to pretend that death is not going to come?

Not trying to convince you of anything.. just trying to get us to get honest with ourselves. Think about what we are doing.

■ **COLLUDING WITH ILLUSION OF NEVER GOING TO DIE.**

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Alzheimer's Association

End-Stage is marked by such features as:

- Lack of recognition of family members
- Loss of verbal communication
- Loss of mobility
- Incontinence

When one of these occurs, death can be expected within the next year or two.

Hospitalized Demented Patients

- **Hip Fracture or Pneumonia: Half died within 6 months.**

- Morrison & Siu, JAMA 2000

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Alzheimer's Association EOL Position Statement

"Hospitalization is NOT recommended, given the limited life expectancy, the significant burdens of aggressive treatment, and the limited attention given to pain control. The most compassionate decision is to eliminate hospitalization and concentrate on palliation and comfort care."

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Alzheimer's Association EOL Position Statement

"CPR, dialysis, TF, and all other invasive technologies should be avoided. The use of antibiotics usually does not prolong survival and comfort can be maintained without antibiotic usage. Physicians should recommend this less burdensome, and, therefore, more appropriate late-stage approach to family members."

Educating family on this?

Does your practice follow professional guidelines?

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Often Overlooked... 9P Assessment for Agitation/Confusion

- Pain
- Pee
- Poop
- Puffing
- PTSD
- Poly-pharmacy
- Pre-Imminent
- People (unfinished business with)
- Paranoia



Unnecessary Procedures? (or other things that may interfere with achieving a good death?)

Can some of the following be stopped or modified?

- Vital signs
 - Weights
 - Dressings
 - Glucose Monitoring
 - Labs
 - X-rays
 - Certain medications
 - Changing route of necessary meds



Take-home Points

- Bring consciousness to practice
 - At least “do no harm”: VS
 - Hearing is the last to go.
 - Practice scenario for 911 call
 - Technology is wonderful and applied in the wrong situation, it is awful.

Softening the Environment: Lighting, Music, Food

- No Fluorescent lighting
 - "Music used in therapy is meant to engage a person in interactive experiences that support life processes. Music thanatology, on the other hand, is concerned with providing music that is simply to be received, allowing a person's "unbinding" and movement toward the completion of life." –Christina Puchalski

A Time for Listening and Caring

Rx: Breathlessness in Advanced Cancer, Lung Disease, and Heart Disease

- 90% prior to death
 - Even mild breathlessness compromises QOL and function
 - Opioids first line therapy: ATC low-dose with rescue doses for breakthrough episodes.



An Evidence-Based Practice?

- American College of Chest Physicians Consensus Statement on the Management of Dyspnea in Patient with Advanced Lung or Heart Disease
 - *J.Pain & Symptom Management.* (42: No.3, 2011). Currow, et.al. Once-Daily Opioids for Chronic Dyspnea.
 - *British Medical Journal.* (vol:327, Sept.) 2003. Abernethy, et.al. Randomized, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnea.
 - *Thorax.* (vol. 57) 2002. A systematic review of the use of opioids in the management of dyspnea

Is your practice current?

Tube Feeding: What the Research Reports:

Helps Hunger/Aspiration

- Non-bedridden
 - ↑ performance status
 - Proximal GI obstructions
 - ALS
 - Reversible illness in a catabolic state
 - Non-bedridden CVA
 - Bedridden
 - Advanced Cancers
(Putting gas in a broken engine isn't going to help)

Reports:
Does not

Does Not Want Aspirations

- Bedridden
 - Advanced Cancers

is (Putting gas in a broken engine isn't going to help)

Diabetic Glucose Control?

- "There comes a time when tight glycemic control can not only prove of questionable benefit, but has the potential to cause harm." (*J.Palliative Care Medicine*. 2011 (14:1))
- Recommend treatment based on 3 trajectories:
 - Advanced Disease with stable blood sugars BEGIN DIALOGUE R/T REDUCING THE INTENSITY OF GLYCEMIC CONTROL. Pleasure-based diet, limiting concentrated carbs.)
 - Impending Organ Failure. ELIMINATE TYPE II DM GLYCEMIC MEASUREMENTS. DISCUSS GOALS OF CARE.
 - Actively Dying. STOP HYPOGLYCEMICS AND GLYCEMIC MEASUREMENTS.

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What do Patients Want?

- Information
- Empowerment to plan for and achieve a good death, free of pain, at home, with loved ones, having said good-byes and put their affairs in order.



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What are Patients Waiting For?

- For the Doctor to say, "No More."

What are Doctors Waiting For?

- For the Patient to say, "No More."

STALEMATE!

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Phrases NOT to Use

- "If your heart stopped, do you want us to start it?"
- "Do you want us to DO EVERYTHING if your heart or breathing stops?"

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DNR: INFORMED Consent

The chance of people surviving CPR with meaningful life is less than 1% if any of the following conditions are present:

- Metastatic cancer
- Age greater than 70
- Sepsis
- Prolonged CPR
- Unwitnessed arrest



AJ of H&PC Medicine. 2005. Vol.22, No:1, Jan/Feb.
Mirza, Kad, Ellison

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A 3-Tiered Approach

- "We don't usually do _____"
- Watch response.
- Educate based on their response.
- Watch response to the education.
- Provide treatment
(and re-approach differently at a later time)

"Let's sort out what will help and what will not help. That way you won't be wasting any time or energy."

At Least Get them in the Ballpark, even if you can't predict when they'll cross home plate

"I can't give you an exact time. But my guess is you might only have

- a few hours to days
- a few days to weeks
- a few weeks to months
- a few months to years"

(Also, let them know that death could come suddenly, so it's best to be prepared.

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Prognostic Indicators

- -intake (albumin)
- -adl changes (T3)
- -change in mentation/cognition
- -dead relatives

(Tell family about these indicators too)

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"No one can predict the future..."
"I'm not God..."
"I don't have a crystal ball..."



"No one can know
 for sure exactly what's
 going to happen. But it's
 possible you might only
 have a short time to live. So,
 it's important to be prepared.
 That way all the bases are
 covered and you and your
 family will be ready
WHENEVER it occurs."

Educated Guess + ambiguity = space for preparation

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**"Pretend like you
 died today,
 what would be
 left unsaid or
 undone..."**



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What would happen if you had...

- A patient with chest pain in the ER and didn't get an ECG or troponin levels and admitted them to an oncology unit?

What would happen if you were dying, and you were admitted to an ICU, received treatments that didn't help, family was limited in their visitation, and no one prepared you so you would know how to die healed?

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Shift hopes

From	To
Quantity of life	Quality of life
Cure	Heal
Treatments	Relief of s/s
"Unfinished	Completing
Emotional Business"	Business
Material Gains	Spiritual growth
Living Forever	Peaceful Death

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**7 Tasks of
Living and Dying Healed**

- Forgive me
- I forgive you
- I love you
- Thank you
- Good-bye
- Let go
- Open Up



This is the morphine of the SOUL.

Important Pamphlets...



"I had supervised Hospice for years, but I had no idea what they really did. On the outside looking in, Hospice felt like a stone I carried in my pocket, weighing me down. Then, I became the Medical Director for Hospice. What I discovered was that stone was really a precious gem. Hospice saved my life."

-John Frutchey MD
Chief Geriatrics & Extend Care
Bay Pines VAMC



You only get to die once.

Don't miss the opportunity
to be present.

-Deborah Grassman

Outcome Measures

"I'm packed up,
prayed up, and
ready to go".
- Hospice patient



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Is the Time Surrounding Death Important?



Start a Book Circle!

Stay in Touch!

Start a Veteran Circle!



Leave your business card with me
(or write email address on paper)!
Utilize www.OpusPeace.org
(Tools, Blogs)
