“Death and Dying” at a Psychiatry Conference????

Let me explain.....

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“You’ll experience denial, anger, bargaining, depression, acceptance, and finally, stuffing.”
“To help you overcome your fear of death, I want you to hug the Mr. Death doll, then take him home and snuggle with him...”
COULDN'T YOU AT LEAST
PRETEND TO HAVE A PROBLEM?

SHRINKS IN HEAVEN

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American Beliefs about the End of Life: The Importance of Advanced Care Planning

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Disclosure of Conflict:

I disclose a potential financial conflict of interest in relation to the listing of the “It’s OK to Die” website in my presentation and subsequent book sales this could generate. This potential conflict of interest has been resolved by the activity directors for this conference.
Outline

The “Big Picture”
end-of-life crisis: the 90-70 dilemma

American beliefs and practices that have created this dilemma

Solving the problem:
You and I

Creating a “Good Death” and Advance Care Planning
The Present End-of-Life Problem: *The 90-70 Dilemma*

- Huge GAP between what people want for end-of-life care and what they actually receive:
  - 90% of people wish to die at home
  - 70% of people actually die in institutions
  - Only 20-30% of Americans have Advance Directives
3 Variables of the 90-70 Dilemma

- Cultural knowledge of the features of death and dying
- Quality of human relationships
- Beliefs that drive the utilization of advanced scientific technology
Cultural Beliefs and Practices that have created *the 90-70 Dilemma*

- Decreasing knowledge of death and how to manage it
- Loss of intimacy and emotional connections
- Increasing dependence on scientific technology to fight death
Cultural Beliefs and Practices that have created the 90-70 Dilemma

- Generational changes in knowledge of death
- Death expelled from societal dialogue
  - Doctors do not explain it
  - No one talks about it socially (but nurses would like to...)
  - Social workers/case managers/clergy left out on a limb
- Changes in society that have decreased intimacy and emotional connections
  - Industrial Era
  - City Dwellers/Commuters
  - Computers
Cultural Beliefs and Practices that have created the 90-70 Dilemma

- Death has become a “medicalized” event
- Medical events are controlled by doctors/nurses/social workers/healthcare providers and occur in ambulances, helicopters, hospitals or skilled nursing facilities
- Doctors/nurses/social workers/other healthcare providers use advancing medical technology to fight and cure illness, disease, delaying death.
- People have become deluded by the perceived promises of advanced scientific technology, that it can buy extra ‘time’
  - “Hollywood”
  - Quantity vs Quality
How do you and I solve the 90-70 dilemma?

We flip the equation...
How do we solve the **90-70 dilemma**?

Making, Documenting and Discussing Conscious Choices

- Increasing knowledge of death and how to manage it
- Regaining intimacy and obtaining emotional closure
- Decreasing dependence on scientific technology at the end of life
Solving the 90-70 dilemma by consciously changing American Beliefs and Practices

- Re-introducing death into public dialogue
- Death and Dying Education
- Find ways to harness the power and gifts inherent in the end of life that are limited at other times of life:
  - Heightened emotional availability
  - Relationship healing
    - Closure that cannot be obtained at any other time of living: *Six things that must be said*
  - Summarizing life lessons and leaving a legacy
    - Ethical Wills
    - “Dignity Therapy”
    - Physical Legacy: Organ Donation
This study examined a novel intervention, *dignity therapy, designed to address psychosocial and existential distress among terminally ill patients*. Dignity therapy invites patients to discuss issues that matter most or that they would most want remembered. Sessions are transcribed and edited, with a returned final version that they can bequeath to a friend or family member.

Terminally ill inpatients were asked to complete pre- and post intervention measures of sense of dignity, depression, suffering, and hopelessness; sense of purpose, sense of meaning, desire for death, will to live, and suicidality.

**Results** Ninety-one percent of participants reported being satisfied with dignity therapy; 76% reported a heightened sense of dignity; 68% reported an increased sense of purpose; 67% reported a heightened sense of meaning; 47% reported an increased will to live; and 81% reported that it had been or would be of help to their family.

**Postintervention measures of suffering** showed significant improvement (*P* = .023) and reduced depressive symptoms (*P* = .05). Finding dignity therapy helpful to their family correlated with life feeling more meaningful (*r* = 0.480; *P* = .000) and having a sense of purpose (*r* = 0.562; *P* = .000), accompanied by a lessened sense of suffering (*r* = 0.327; *P* = .001) and increased will to live (*r* = 0.387; *P* = .000).

**Conclusion** Dignity therapy shows promise as a novel therapeutic intervention for suffering and distress at the end of life.

Solving the 90-70 dilemma by consciously changing American Beliefs and Practices

- Decreasing dependence on scientific technology at the end of life
- Moving from High Tech to High Touch Medicine at the end of life...
  - From Cure-focused to Comfort-focused medicine
  - From Artificial Life support to Natural Death support (AND)
  - From hospital to hospice and home (then keep them there)
  - We must define and seek to create a “good death”
  - Then, document and support these conscious choices
How do we help people move from *High Tech* to *High Touch* Medicine at the End of Life?

- Understand the best practices care patterns at the end of life

- Improved End-of-Life decision tools:
  - Advance Directives and Mental Health
  - DNR forms
  - Decisional Capacity: Who makes decisions?
  - Tool for Surrogate Decision Makers
The Map for the Best Care Possible

Adapted from:
Toolbox for Advanced Care Decisions

- “Normalize” the conversation...
- The Conversation Starter Kit
- Living Will/Healthcare POA
- DNR orders or Portable Orders for Patient End of Life Preferences
“Your Alabama advance directive for health care goes into effect when your doctor determines that you are no longer able to understand, appreciate and direct your medical treatment, and your doctor and one other doctor experienced in making the diagnosis determine that you are permanently unconscious or terminally ill.”

“This form does not expressly address mental illness. If you would like to make advance care plans involving mental illness, you should talk to your physician and an attorney about a durable power of attorney.”

“Your (healthcare) proxy, if you appoint one, does not have authority to authorize psychosurgery, sterilization, or abortion—unless it is necessary to save your life—or to have you involuntarily hospitalized or treated for mental illness.”

ALABAMA
Emergency Medical Services
Do Not Attempt Resuscitation Order

Patient’s Full Name

Attending/Treating Physician’s Order

I, the undersigned, a physician licensed in Alabama, state that I am the attending physician; or a physician providing medical treatment to the patient named above. It is my determination that [must check 1 or 2, below]:

1. The patient is an adult (eighteen years of age or older) and is capable of making an informed decision regarding consent about providing, withholding, or withdrawing specific medical treatment or course of treatment, and the patient has decided that he or she does not wish to be provided resuscitative measure in the prehospital setting. (Signature of patient required on reverse side).

2. The patient is an adult (eighteen years of age or older) and is NOT capable of making an informed decision regarding consent about providing, withholding, or withdrawing specific medical treatment or course of treatment.
Overview of a Portable DNAR

- Patients’ detailed healthcare wishes become doctor’s orders - recognized by the entire medical system
- PORTABLE document that goes with the patient and stored online for electronic access
- Will be a brightly colored, standardized form for entire state of Alabama
- Based on POLST paradigm, see www.polst.org

*Sample document*
Medical Decision-Making: Does my patient have decision-making capacity?


Choose and Communicate - Can the patient communicate a choice?

Understand - Does the patient understand the risks, benefits, alternatives, and consequences of the decision?

Reason - Is the patient able to reason and provide logical explanations for the decision?

Value - Is the decision in accordance with the patient’s value system?

Emergency - Is there a serious and imminent risk to the patient's well-being?

Surrogate - Is there a surrogate decision-maker available?

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Pop Quiz: How often is a surrogate needed?

Multiple Choice Question

____% of us (total population) will be unable to make medical decisions for ourselves near the end of our lives.

A. 25%
B. 35%
C. 50%
D. None of the above

(David Wendler PhD, Director of Vulnerable Populations at the National Institutes of Health’s Department of Bioethics.)
Fierro’s Four R’s: A Tool for Surrogate Medical Decision Making

- You (the surrogate medical decision-maker) do not have to decide what to do by yourself. Let (name) decide for himself/herself, here is how:
  1) **Reflect:**
     - Think back and imagine (name) when he or she could still make his/her own decisions.
  2) **Reconstruct preferences:**
     - Answer the following questions: What are his/her favorite things? His/her favorite color? What are his/her hobbies? What is his/her favorite meal? What things did he/she dislike?
  3) **Reconstruct values:**
     - Think about whom he/she was, his/her opinions, his/her beliefs and how he/she chose to live his/her life. What are his/her values?
  4) **Review medical options and decide:**
     - Now, imagine that (name) is standing here beside you, looking at him/herself here in this hospital bed. (She hears the diagnosis and the available options the doctor has given.) What does he/she want us to do, or not do next?
A Good Death

- A sense of control including knowing and honoring the wishes of the one who is dying
- Assuring comfort and dignity
- A sense of closure including words of “goodbye”
- Affirming the unique qualities of the person who is dying
- Trust in the health care providers
- Recognition and acceptance of impeding death
- Honoring the dying person’s beliefs and values
- Physical contact
But ultimately all of these changes will begin with you.
You hold great power. If you will take a stand and educate those within your influence, a better end-of-life can be created for all Americans--for your patients, for your family and ultimately, for yourself.
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