


## Changing American Beliefs about Death: Is it OK to Die?

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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 problem: the 90-70 dilemma
- American beliefs and practices that have created this dilemma
- Solving the problem: You and I
- Creating a "Good Death"
- Facts and Figures
- Social transitions already under way
- Please join with me: [www.oktodie.com](http://www.oktodie.com)




### 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

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Increasing dependence on scientific technology to fight death

### 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


- 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...)
- 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

Increasing dependence on scientific technology to fight death

- Death has become a "medicalized" event
- Medical events are controlled by doctors/nurses/healthcare providers and occur in ambulances, helicopters, hospitals or skilled nursing facilities
- Doctors/nurses/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'
  - 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

Increasing cultural knowledge of death and how to manage it




Regaining intimacy and obtaining emotional closure

- 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

### 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?


- Doctors/nurses honestly educating patients about mortality
- Highlight the loss of quality time with inappropriate use of *high technology at the end of life*
- Highlight the increase of quality time with appropriate use of *high touch* medicine at the end of life
- Touch the referring doctor's heart-letters from patient/families
- Improved End-of-Life decision tools:
  - ADs and the POLST
  - Who makes decisions?
  - New Tool for Surrogate Decision Makers
  - 5 Questions to "own" your end-of-life path

### Medical Decision-Making: Does my patient have decision-making capacity?

Chow G V et al. Chest 2010;137:421-427

Does the patient have decision-making capacity?	<b>Choose and Communicate</b> - Can the patient communicate a choice?
	<b>Understand</b> - Does the patient understand the risks, benefits, alternatives, and consequences of the decision?
	<b>Reason</b> - Is the patient able to reason and provide logical explanations for the decision?
Can emergency treatment without informed consent be provided?	<b>Value</b> - Is the decision in accordance with the patient's value system?
	<b>Emergency</b> - Is there a serious and imminent risk to the patient's well-being?
	<b>Surrogate</b> - Is there a surrogate decision-maker available?

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### 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?

### 5 Questions to "own" your end-of-life path

- 1. How do people typically die from \_\_\_(stroke, heart attack, etc. or any disease)\_\_\_ ?
- 2. If this was your mother, father or yourself what would you do next?
- 3. How will we know when to ask for hospice care?
- 4. What are the signs of dying?
- 5. Can you support us in trying to take our loved one home?


*If your doctor is unwilling to engage you in answering these questions, or is unable to support you, then find another doctor who will. The whole quality of the end of your life depends on it.*

### 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 impending death
- Honoring the dying person's beliefs and values
- Physical contact\*\*

### The Facts and *the Future*....



Medicare Payment Advisory Commission, Med PAC, 2013. June 2013. A Data Book, Health Care Spending and the Medicare Program. Internet: <http://www.medpac.gov/documents/Jun13DataBookEntireReport.pdf>

## The Facts and *the Future*.....



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## Other Social Factors Working to Create a Better End-of-Life...

- A national conversation on death and dying costs and ethics is already occurring. Expect it to gain momentum because:
  - Baby Boomers began turning 65 recently
  - Generational attitudes differ from previous. Example: responsible for the natural birth movement, they will also push for the "de-medicalization of death" to view it as a natural phenomenon again.
  - The sheer numbers of aging baby boomers facing end of life issues will pressure the system to change and accommodate.



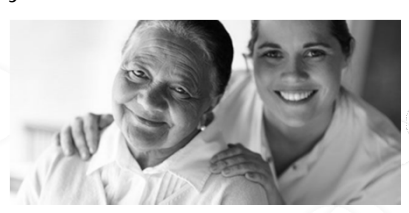
## Other Social Factors Working to Create a Better End-of-Life...

- Changes within the American Healthcare Model:
  - Accountable care organizational (ACO) model will replace traditional service and reimbursement models
  - ACOs will emphasize palliative services upstream in health care delivery, naturally feeding more patients into hospice care sooner, and in larger proportions



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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