Optimal End-of-Life Care

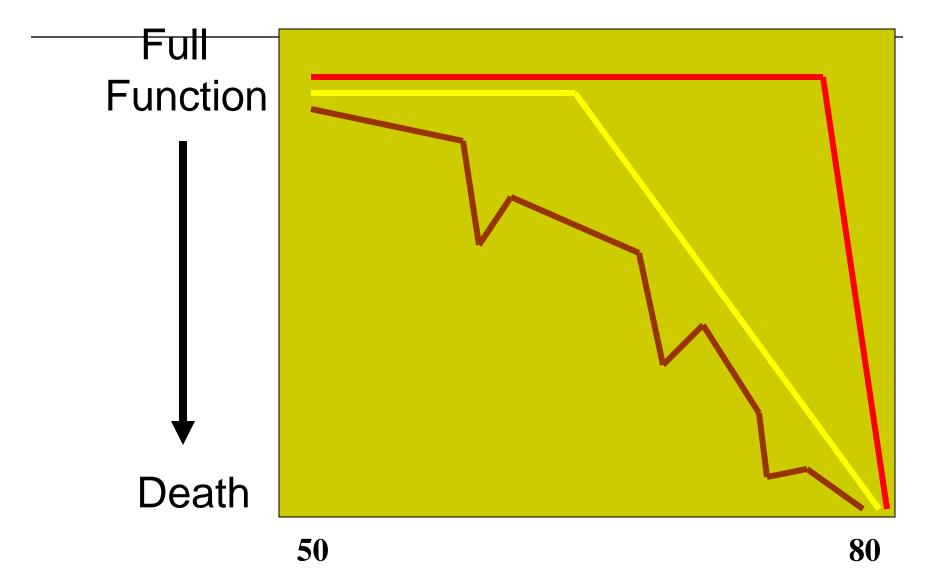
Ken Brummel-Smith, MD
Charlotte Edwards Maguire Professor of
Geriatrics

FSU College of Medicine



"In my day, people died."

Disease Trajectory



Palliative Care

Cure

Hospice

Cure

Palliate

Informed Consent

- □ What is informed consent?
 - Helping you to make the best decision for you
 - Understanding your desires and goals
- □ What informed consent isn't
 - Getting you to sign a consent form
 - Getting you to agree to something you don't want

Informed Consent

The doctor should:

- □ Provide enough information to allow you make a decision
- ☐ Give a recommendation
- □ Discuss the alternatives
 - Including not doing anything
- □ Ask for your decision
- □ Ask if you have questions

Reasons to Plan Ahead

- □ The future is known
- □ Things happen that people do not like
- □ You can control the future
- ☐ These decisions are something everybody should talk more about

Advanced Directives

- □ Deciding on medical treatments you want or don't want in advance
- □ Informing your loved ones what is important to you
- □ Informing the doctor what your values and desires are
- □ Ensuring legal protections if you can't make decisions for yourself later

Advance Care Planning

- □ A process over time
- Discussing desires and wishes for future medical care
- □ Used when patient can't make his/her own decisions
- □ A routine part of medical care

ACP - Goals

- □ Name a surrogate decision maker
- □ Clarify goals and values
- □ Identify care the patient wants and doesn't want
- □ Have forms documenting this
- □ Prevent later family or legal battles

Ultimate goal: support the patient's self-determination

Advance Care Plans

- □ Health Care Surrogate
- □ Advance Directive
 - Living will, or
 - 5 Wishes, or
 - Advance Care Planning Document
- □ Drs. Orders

These will be discussed in more detail

Surrogate Decisions

- Must name a surrogate
- □ Must tell the surrogate what you want or don't want
- □ The job of the surrogate
 - To communicate known wishes of the patient
 - To act in the patient's "best interest"
- □ Wishes may change when the situation changes
 - Be ready to "re-discuss"

Health Care Surrogate

- □ Name someone you can trust
- □ Someone who can "live without you"
- □ Someone who is available
- □ Tell them what you want

Florida Definitions

- □ Health care surrogate someone expressly named to make health care decisions for you
- □ Proxy someone who has <u>not</u> been <u>expressly</u> named
- □ Durable power of attorney for health care -essentially the same as a surrogate

Who's the Proxy?

- 1. Legal guardian
- 2. Spouse
- 3. Adult child
- 4. Parent

- 5. Adult sibling
- 6. Adult relative
- 7. Close friend
- 8. Clinical SW

Living Will

- □ A expression of wish to die naturally if:
 - Terminal condition
 - End-stage condition
 - Persistent vegetative state
- □ No reasonable hope for recovery
- □ Problems:
 - Vague terms
 - Two physicians must document state

5 Wishes

- □ Combines forms
 - Name a surrogate
 - Medical directives
 - Values history/end-of-life wishes
- □ Problems
 - **■** Cost (\$5)
 - Witness restrictions more strict than FL law
 - Medical directives vague

Advance Care Plan Document

- □ Name a surrogate
- □ Specific choices on medical treatments
 - CPR
 - Life support
 - Surgery, antibiotics
 - "Tube feeding"
- □ Problems:
 - Vague terms
 - Only conditions listed

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Physician Orders

- □ Do Not Resuscitate Order ¹
 - "DNRO form"
 - the "Yellow Form"
 - Used in FL
- □ Physician Orders for Life-Sustaining Treatment ²
 - "POLST form"
 - the "Pink Form"
 - Used in 13 states, 20 more evaluating

DNRO vs. POLST

- □ DNRO
 - CPR
 - DNR

- □ POLST
 - CPR
 - DNAR
 - Level of care
 - Artificial nutrition or hydration

POLST*

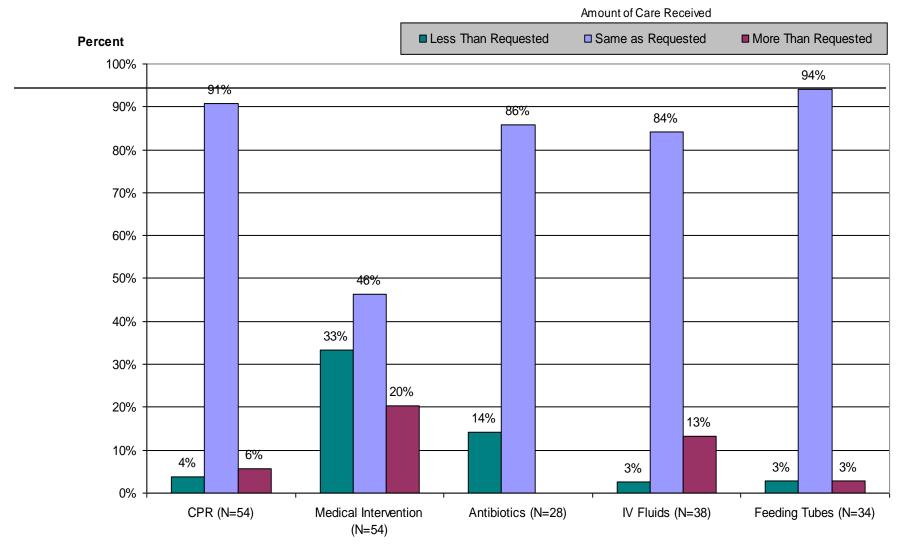
- □ CPR or DNAR
- □ Level of care intensity
 - Comfort (no hospitalization)
 - Limited advanced interventions (no ICU)
 - Full treatment (ICU)
- □ Artificial nutrition

Physician Orders for Life Sustaining Treatment

SEND FORM WITH PATIENT/RESIDENT WHENEVER TRANSFERRED OR DISCHARGED Last Name of Patient/Resident **Physician Orders** for Life-Sustaining Treatment (POLST) First Name/Middle Initial of Patient/Resident This is a Physician Order Sheet. It is based on patient/resident medical condition and wishes. It summarizes any Advance Directive. Patient/Resident Date of Birth Any section not completed indicates full treatment for that section. When the need occurs, first follow these orders, then contact physician. Section RESUSCITATION. Patient/resident has no pulse and is not breathing. Resuscitate Do Not Resuscitate (DNR) Check One Box Only When not in cardiopulmonary arrest, follow orders in Sections B, C and D. MEDICAL INTERVENTIONS, Patient/resident has pulse and/or is breathing. Section Comfort Measures Only. The patient/resident is treated with dignity, respect and kept clean, в warm and dry. Reasonable measures are made to offer food and fluids by mouth, and attention is paid to hygiene. Medication, positioning, wound care and other measures are used to relieve pain and suffering. Oxygen, suction and manual treatment of airway obstruction may be used as needed for comfort. These measures are to be used where the patient/resident lives. Check The patient/resident is not to be hospitalized unless comfort measures fail. One Box Only Limited Additional Interventions, Includes care above. May include cardiac monitor and oral/IV medications. Transfer to hospital if indicated, but no endotracheal intubation or long term life support measures. Usually no intensive care. Full Treatment. Includes care above plus endotracheal intubation and cardioversion. Other Instructions. Section ANTIBIOTICS. Comfort measures are always provided. С No antibiotics Check Antibiotics One Box Other Instructions Only ARTIFICIALLY ADMINISTERED FLUIDS AND NUTRITION. Comfort measures are always provided. Section No feeding tube/IV fluids D Defined trial period of feeding tube/IV fluids Check Long term feeding tube/IV fluids One Box Only Other Instructions: Summarize Medical Condition Discussed with: Section Patient/Resident Е Parent of Minor Health Care Representative Court-Appointed Guardian Spouse Other: Physician/ NP Phone Number Physician/ Nurse Practitioner Name (print) Office Use Only EVE Physician/ NP Signature (mandatory) Date

SEND FORM WITH PATIENT/RESIDENT WHENEVER TRANSFERRED OR DISCHARGED

Percentage of Participants Who Received Less, Same, or More Care than Requested 1.



Areas of Care and Valid Reponses

¹Percentages exclude participants for whom care was not applicable.

Advance Decisions

- □ CPR
 - Sudden, unexpected death
- □ Tube feeding
 - Temporary provision of nutrition and hydration

Problems arise when these are used for other purposes

Cardiopulmonary Resuscitation "CPR"

- Developed to prevent sudden, unexpected death
- □ Best when instituted immediately
- Best outcome when administered by trained personnel
- □ Best outcomes when patient responds within 5 minutes of initiation

CPR in Hospitals

- 14% overall survival in hospitals
- 3% on general medical wards
- 80% of those with restored rhythm are comatose
- 50% of survivors do not want CPR again
- 50% of survivors develop major depression or functional decline

CPR in NH

- □ 0%-3% survival rates in NH
- □ 1 CPR attempt per 166 beds/yr
- □ 4% of facilities have "No CPR" policies
- □ 23% never initiate call EMT
- □ DNR older, more ADL dependent, long stay, dementia, adv directives

Artificial Nutrition

- Old term" "tube feeding"
- □ Delivered as:
 - Intravenous needle with IV tubing and bag
 - Enteral (into the stomach or intestine) tube:
 - □ Nasogastric tube goes through nostril
 - □ Gastric tube through surgical opening in abdominal wall into stomach
 - Jejunostomy tube through surgical opening in abdominal wall into intestine

Artificial Nutrition Myths

In the setting of end-stage disease or advanced, progressive neurologic conditions, does it...

- □ Prolong life?
- □ Reduce suffering?
- □ Decrease aspiration?
- □ Provide ordinary care?

Prolong Life?

- □ 50%-68% 1 year mortality (Cowen, Callahan, Dharmarajan)
 - dementia
 - stroke
 - CHF
- □ Survival same as hand fed (Mitchell)
- ☐ Improvement in nutritional measures do not affect survival rates (Golden, Kaw, Mitchel)

15% - 16% die before the assessment is completed!

Decrease Aspiration?

- □ NG tube -
 - 67% aspirated
 - 43% developed pneumonia
 - 66% pulled out
- □ G tube
 - 44% aspirated
 - 56% developed pneumonia
 - 56% pulled out

Aspiration risk is increased with both NG and G tubes

(Ciocon, Pick)

Reduce Suffering?

- □ Complication rate 32% 70% (Taylor)
- Those without hunger or thirst have increased pain with ANH (McCann)
- Increased use of restraints
 - Up to 90% (Peck)
 - NOT significantly different with G tubes (Ciocon)
- □ 70% had no improvement in function or subjective health status (Callahan)

Ordinary Care?

- Decreased human contact (Slovenka)
- Supreme Court ruling in Nancy Cruzan
- Religious stands
 - Catholic burdens and benefits
 - Jewish impediments to dying

Benefits of Dehydration

- □ Lack of thirst
- Decreased sputum production
- □ Decreased urine production
- Euphoria
- □ Analgesia
- □ Anaesthetic effect

These effects apply to patients in hospice care or at the end of life.

(McCann)

What Next?

- □ Get the forms
- □ Try filling them out
- Discuss them with confidants
- □ Once decided, talk it over with doctor
- ☐ Give him or her copies
- □ Ask for a DNRO form if desired