Difficult Decisions in Dementia:
how to reduce suffering & harm

ALMDA Annual Conference

Dr. Rob Webb
Medical Director, Supportive/Palliative Care,
North Alabama Medical Center, Florence, AL

July 28, 2019

Difficult Decisions Objectives

- Recognize that dementia is a LLD
- Understand goal-focused care and the goals of medicine to relieve suffering and prevent harm
- Learn how to help a patient/family & staff make decisions based on their goals
- Understand what *Comfort Care Only* means

Decisions in Dementia - Outline

1. Why is dementia a LLD
2. What is goal-focused care
   - What are the goals of medicine
3. What options does a patient/family have
   - What is CCO

1. What is Dementia*

- **Dementia** is *the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person's daily life and activities.*

** NIA/NIH*

Why is Dementia a LLD

- **Life Limiting Disease**: one which will eventually lead to death if nothing else causes death prior to that.
- Dementia has no cure & will be fatal
  - therefore, it is a LLD
- Acceptable on *Death Certificate*
  - *E.g. 1)Terminal hypovolemia, due to*
    2)Alzheimers Dementia

2. What is Goal-Focused Care

- Health care based on achievable goals chosen by patient/family and physician/team together
  - Based on best evidence available

Goals

- What are 'goals'?
  - A result or end we want to reach.
- Why set goals of the medical care?
  - Care goals shape expectations & priorities
  - Improves quality of care
  - Improves patient, family & staff satisfaction

Goals - a spectrum of choices

From:
"DO EVERYTHING"
- CPR
- Dialysis/transplants
- Tx all conditions
  - Even if pain worsens or cause suffering

To:
COMFORT ONLY
- A.N.D. / DNAR
- Control symptoms
- Tx any discomforting symptom aggressively & Prevent suffering & AVOID HARM

Choices for Dementia?

Dementia will worsen: so what to choose?
- *Do everything?*
- *Comfort only*?
- Something in-between? – a spectrum of choices available [should document in Advance Directive]

'*Do Everything*' Options

Do Everything can include:

- CPR. Vent/trach. BiPap. O2'
- Dialysis. PEG. Surgery.
- Disease-specific Drugs. [HTN, CHF, etc.]

What/How to decide: choice easier when keep GOALS and prognosis in mind…

Choosing Goals

- General goals - e.g. Cure vs Comfort
  - General or philosophical guide
  - Can change as illness progresses
- Specific goals - e.g. abx for UTI
  - Discuss as need arises
  - Change with situation
  - Anticipate situations and plan response (e.g. wt.loss, not eating - ?PEG)

Goal setting questions

- What's the initial general healthcare goal?
- What are current health problems?
- What's the prognosis for each problem?
- How will goals & actions 'today' impact QOL & QOD later?
  - Will today's actions interfere in a 'natural' process, cause harm & more suffering, and unintentionally prolong dying?

Case Example – Ms. Abigail

- 82 yof, Alzheimer's x 4 years
- HTN, PVD, OAB, OA, OP, GERD
- TIA's, CAD w/ stents, CHF
- Taking many prescriptions
- Widow, in ALF, 3 kids
- Walks with a cane

Goals Process - Ms.Abigail

1. What's the initial general healthcare goal?
   - **What's most important to her (and her family)?**
   - "Do Everything" vs "Comfort only"

   vs "In between (stabilize function)" ?

Often, to answer that, need to know their understanding of her condition?

…Goals Process…

2. What's her current health status?

- She has two Life-Limiting Diseases*
  - CHF & Alzheimer's
- Will 'curative' treatments of these improve or worsen her memory and her QOL?

* CHF, Alz.Dem, Cancers, ESLD, ESRD, AIDS, ALS

…Goals Process…

3. What's the prognosis (life expectancy) for each?
   CHF = 5 years Alzheimer's = 5 years avg.

4. *How will decisions/actions today impact QOL later*? !!
   - How do we rationalize the different choices for treating all her problems…?

Summary - Setting Goals [again !]

1) What's the initial Goal ?
   E.g. "Philosophically", which is preferred: comfort or longevity.

Goals may change once given more info !
E.g. Once told that major surgery may impair memory, patient may choose to not have it.

…Setting Goals…

2) What's the current health status &
3) the prognosis for each problem?
   * **People need to know, if LLD present, cure no longer reasonable expectation**
4) How will decisions 'today' impact QOL later?
   – Could choices interfere and ultimately cause more harm & suffering?

…Setting Goals

Goals should be patient-driven !

Goals require regular review, in a *collaborative partnership* between patient/family/providers

Goals process should result in appropriate advance directive instructions

GFC is supported by Goals of Medicine…

The Goals of Medicine

1) To prevent & relieve suffering.

Cassell. *The nature of suffering.*

2) To *Do No HARM.*

Maxim: *Primum non nocere = first, do no harm.*
[from ?Hippocrates – "to abstain from doing harm"]
Gwande – Being Mortal

What is suffering?

- *Suffering*: *"a state of severe distress associated with events that threaten the intactness of person".* [Cassell. P.32]
  = Distress w/ no end in sight!
- *Physician's goal*: *"The mandate for the existence of a profession of medicine in society is its obligation to relieve the suffering caused by human sickness."* [Cassell. P.61]

…What is 'Do No Harm'?

- [by focusing on only the dx and tx of disease, physicians…] *"may fail to prevent or treat suffering adequately or even inadvertently cause it as a result of treatment…in part because doctors are not trained to the belief that one of their primary tasks is the relief of suffering."*

[Cassell. The nature of suffering. 2004. P.61]

Collaborative Partnership: What Do Patients & Families with Serious Illnesses Want?

- Pain and symptom control
- *Avoid prolongation of the dying process*
- A sense of control & honor wishes
- *Included in decisions & to be listened to*
- *Honest information*

Singer et al. JAMA 1999;281(2):163-168.
Tolle et al. Oregon report card.1999 www.ohsu.edu/ethics

What is Comfort Care Only [CCO]

- What's included when order CCO?
- Why was PNA called "old person's friend"?
  - Is PNA painful?
- Why choose CCO?
  - Escape from unwanted situation
  - Avoiding worse suffering later
  - When is it appropriate…

CCO means:

Choosing Goals which prevent suffering

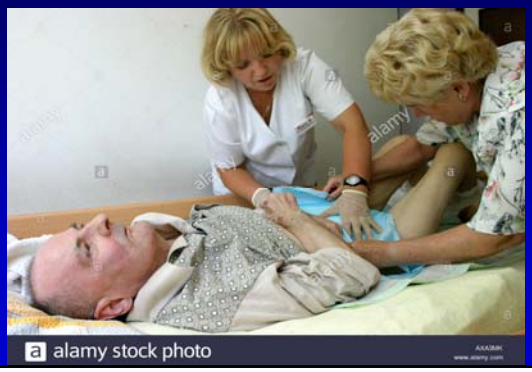
* Using only tx/drugs that improve comfort
* Choose to avoid 'harms', such as:
  CPR, Vent, Dialysis, PEG,
  ORIF/surgery, Transfusions
  Which drugs…?

CCO & the *Old Person's Friend*

- What was the 'Old person's friend'? *[Osler]*
  = Pneumonia in pre-abx times
  - tired, worn out, pain, 'burden' – suffering!
- When to choose "No Antibiotics" in LTC
  – Infections – PNA, UTI/pyelitis, etc.

'Old Person's Friend' Candidate?

‘Old Man’s BFCandidate’



Why Choose CCO?

- Dementia has terrible prognosis: BB, total care, risk of PU/infections/pain/falls/fx + loss of dignity?
- Who would choose such an EOL?
  - Example pt/family [AD w/ 1 seagull]
- If anticipated situation ‘intolerable’, what can one do to prevent it and/or allow an escape?

Ms. A.’s decision dilemma

- How do we rationalize the different choices for treating all her problems?
  - **GOALS, GOALS, GOALS**
- What has she told family in past ?!

  [never keep me alive on a machine]

  Is she ready for CCO?

…Ms. A.'s dilemma

- Based on info given:
  - A.D. is incurable, made worse by many meds
  - CHF is incurable

  They choose comfort ! [but not CCO yet]
- Therefore, they choose "A.N.D." & to reduce as many meds as possible?

On 14 $$$ Medications ($900+/mo.)

- Digoxin ($10/mo) - Lasix ($11/mo)
- Plavix ($120) - Toprol ($25)
- Asa - Amiodarone ($150)
- Lipitor ($103) - Paxil ($79)
- Altace ($75) - Detrol ($85)
- Aricept ($150) - Vitamins, Calcium
- Nexium ($120) - Fosamax ($66)

Based on her goals, how many can she stop?

Can she stop all/most meds?

- Which ones are <u>not</u> comfort focused or have the most side effects?
- Will that help her reach her goals?
- <u>Can she and her family live with the decision</u> !!??
- This leads to an important part: How to make an informed decision…

Informed Decisions

Important principles about decision making:

- To make decisions, people need credible and adequate information; because…
- Knowledge about the condition and prognoses usually affects decisions; and…
- Information combined w/ skillful guidance may avoid non-beneficial interventions and improve Quality Of Life

Informed Consent – Ms. A.

Should Ms. A. have a Knee Replacement?
What's the process to make a decision?

1. Current Condition: OA of most joints, knees worse
2. Other Conditions: A.D.; CHF; CAD
3. Prognosis: < 5yrs [at best]
4. Goal: control pain and enjoy family (comfort)

Ms. Abigail - preOp

…Informed Consent

5. Surgeon recommends Knee Replacement

Questions to ask:

Will surgery help?

Any risks? - Will memory decline?

Can her pain be controlled w/o surgery?

This leads to "What's Comfort"?

[Chooses to have operation: pain initially better; memory much worse.]

"Comfort Care" Comments

- Comfort for me, may be uncomfortable for you; may change with situation
- Pain (comfort) includes: physical, emotional, social, spiritual
- Each person must decide what's tolerable and best for their own circumstances
  - Coping with own family's unrealistic expectations

Comfort-focused Care is …Palliative Care

- PC helps people (and families) with any life-limiting disease live comfortably as long as possible; AND
- when they are at the very end of life, PC helps them to die comfortably.
- Thus, LTC/NH should be PC oriented !

Ms. Abigail – 1 year later

- Now requires walker and 1 assist all ADL's
- Falls & admitted to hospital w/ fx hip
- Delirium develops
- Surgeon says, "we need to fix her hip to control her pain and help walk again"
- Family says, "do everything necessary"
  - What does that really mean ??

Ms. Abigail post-fall

Truly Informed Decisions – will avoid non-beneficial care

- Approaching EOL, we [providers and family] may be primary cause of suffering or, we can be primary cause of its relief !
- Only 10% people die suddenly
- 90% need some form of terminal care
- We must face decisions of "how many and what kind of interventions are needed"

Defining Non-beneficial Care

- "clinical care that has a <5% chance of survival", or
- "when desired goals not met or desired results cannot be achieved"

Non-beneficial Care is **NOT** Quality Care

- Having more care and more expensive care doesn't = quality care necessarily
- Quality means the care:
  - Must be appropriate for the condition in light of patient's values and goals
  - Must maximize benefits, minimize risks
  - Must be cost-efficient

Reasons for Non-beneficial Care

- Poorly defined
- Decision processes faulty
  - Goals are not made known
  - Patients/families have insufficient info
  - Choices may not be clear
  - Leads to incongruity between patient goals and physician's offered choices
  - Results in mutual misunderstanding

  e.g. Ms. Abigail

The Non-beneficial or Futile "Do Everything"

- Doctor's assumption: provide all surgery & drugs & tests to keep alive
- Patient's assumption: doctor will only do those things known to be effective in reaching their goals
- "Do Everything" really means "Do everything that will help reach goals"

Avoiding Non-beneficial care

1) What information should the surgeon and the family have?
2) What are her/their goals?
3) What are the chances of her walking again?
4) Can her pain be controlled w/o surgery?
5) What's the chance of her worsening, or dying, w/ the surgery vs w/o it?
6) Will this intervention only ultimately enable more suffering?

How to Make Informed Decisions & Avoid Futile Care - Summary

1) Discuss status of conditions and prognosis
2) Clarify goals
3) Understand all the options (read relevant information if possible)

…How to Make Informed Decisions & Avoid Futile Care

4) Ideally, physician recommends one option based on Goals – "we should do what's necessary to keep her comfortable"
   - encourage the 'old person's best friend' option
5) Formulate a plan, including response to crises
6) "Can you live with the decision?"

…Avoiding Futile Care

- Explain why we should NOT do a specific treatment [*avoid harm*!]
- Should Never Hear "There's nothing more we can do" !!!!
- Reinforce the link between Goal & Options
- Never lose HOPE – that good will come from decisions; that no one will be abandoned

What we can do: Preserve Hope while Avoiding Futile Care

Our Traditional/Palliative Role

To cure sometimes

To relieve often

To comfort always…[the '*art*']

- anonymous 16th century aphorism

…Art of Medicine

- *"The art of medicine consists in amusing the patient while nature cures the disease."*
  - Voltaire
- Unfortunately, today our expensive drugs and unnecessary treatments are prescribed to cure things which are incurable, resulting in all too often iatrogenic disease [harm]!
  - Gwande: *Being Mortal*

Some Harmful EOL Myths…

1) Dehydration is painful
2) We cannot allow someone to starve to death
3) Feeding tubes prevent aspiration
4) CPR will resurrect most patients

… Realities

1) Dehydration improves comfort
2) People do not "starve to death"
   We allow them to die naturally from the disease !
3) PEG's increase aspiration risk x 4
4) CPR only 5 % successful in those w/ LLD

McCann. Comfort care for terminally ill patients. JAMA. 1994
Christakis. BMJ 2000;320][Benkendorf. Prehosp EmCare 1997

… CPR

- What is the success rate of CPR on TV?
  - 67% !!
- What is it in real life?
  - 0-10% ! (for those >70 years of age)
- Is CPR a dignified procedure for elders?
- Why isn't it very successful?

What can be done?

- Determine goals: yours & your patient's
- Be comfortable with your own mortality & philosophy of care – have an Adv.Directive
- Don't be afraid to recommend CCO !!
  - and the 'old person's friend' option
- Be knowledgeable about Medical Myths
  - Don't hesitate to advise "AND, No PEG" !
- Read the suggested references

Suggested Readings

- Hank Dunn. *Hard Choices for Loving People*. 2001. A&A Publishers. [www.hardchoices.com]
- Ira Byock. *Dying Well*.
- Gwande's *Being Mortal*.
- His Holiness the Dalai Lama's "*Advice on Dying and Living a Better Life*"

Success & Aging

Hope is eternal. Life is a circle.

- At age 4, success is…not peeing your pants
- At age 12, success is…having friends
- At age 16, success is…a driver's license
- At age 20, it's…having sex
- At age 35, it's having money

Success cont'd

- At age 50, success is…having money
- At age 60, it's…having sex
- At age 70, it's…having a driver's license
- At age 75, it's…having friends
- At age 80, success is not peeing your pants!

"Growin' old ain't for sissies"

- Bette Davis

THANK YOU !