Drugs & Myths in Hospice & Palliative Care

Part II: Common Myths

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Florence, AL

Feb. 8, 2011

REMINDERS

- Turn off cell phones & pagers
- Ask questions at any time

II. Common Myths: EOLC &…

1. Hospice & Palliative Care Myths
   - PC & Hospice
2. EOLC Myths
   - CPR
   - Starvation & Dehydration
   - Feeding Tubes
   - Time of death
3. The Myth of 'Informed Consent'
   and the Ethics of Dying

1. Palliative Care's Myths

What's a myth?

A popular belief which is not based on facts

- NB for pharmacists to help educate patients
- Myth: PC is only for those about to die!
- Myth: PC accelerates dying by putting a patient on morphine!
- Myth: PC "gives up" too soon and does nothing but 'let you die' !

…What is PC?

Be Careful when Judging Others

Palliative Care – formal definition

Interdisciplinary care that aims to relieve suffering and improve quality of life for patients with advanced illness and their families.

It is offered simultaneously with all other appropriate medical treatment.

- *[CAPC – Center to Advance PC}*

Palliative Care is Comfort-focused

1) Helps them clarify their goals in the face of a LLD*, to make informed decisions and avoid non-beneficial treatments;
2) Helps those with life-limiting disease live comfortably (soothing symptoms) as long as possible; plus
3) when they are at the very end of life, PC ensures a natural death w/ comfort and dignity.

*LLD = Dementias, cancers, end-stage organ disease (e.g. lung/ heart/renal/liver), ALS, AIDS

Palliative Care Realities

– PC is a philosophy of care and approach to living available, at any time, to anyone with a chronic/ incurable illness, who wants mostly to be comfortable

* It is NOT care only for those nearing death or the end of life !

– "Letting Go" and "Giving Up" are different !
  - Giving up lives out of fear
  - Letting go lives out of grace and trust !

…PC Realities…

- PC does NOT accelerate dying
  - Cost Savings Impact Study 2009 at ECM
    - 97% of patients in both the control group and the PC consult group died in the same 6 mo.

and…

- PC improves survival & QOL in lung cancer
  - Patients receiving chemotherapy and PC lived 3mo longer (11.6mo v 8.9mo) than those on just chemoRx. *[Temel. NEJM 2010.]*

…PC Realities

- Cancer pts who discuss EOLC wishes w/ MD have better QOL and lower costs in final wk of life
  - Less aggressive care/admissions to hospital
  - Improved QOL w/ more peaceful death

  ** Zhang B. Health care costs in the last week of life. Arch Intern Med. 2009*
- Pts who choose hospice live ~29 days longer than those not in hospice

  * Connor S. Comparing hospice & non-hospice patient survival among patients who die within a three-yr window. J Pain Symptom Manage 2007

Historically, always had PC:

Physician's Traditional Role = PC

- To cure sometimes
- To relieve often
- To comfort always

- anonymous 16th century aphorism [?Hippocrates]

Hospice

Definition: a Medicare benefit for anyone with a physician-certified life expectancy of <6mo if the disease runs its usual course.

- It's PC for the final six months of life

Myths:

i. There are 'two' kinds of hospice
ii. Patient must have DNR [AND]
iii. Cannot be admitted to hospital
iv. Patients must be discharged if they don't die in <6mo.

Hospice Realities

i. Only ‘one’ kind of treatment hospice
   - there are “Not-for-profit” & “For-profit”
ii. Patients do not need a DNR/AND
iii. Patients can be admitted to hospital
iv. After the initial 6 mo. certification, if the doctors believe death will still occur within the next six months, patients can continue in hospice

2. End-of-Life Care Myths & Realities

1) CPR
2) Starvation & Dehydration
3) Feeding tubes
4) Time of death
5) No one can predict death/outcome

1) CPR & "No Heroics"- Myths & Reality

What is CPR:

- **C**ardio **P**ulmonary **R**esuscitation
- Initiated when the heart stops
  - Chest compressions & 'shocking' begin
  - Mouth-to-mouth breathing is started
  - A tube for a breathing machine is placed
  - It may continue for over 30 minutes

CPR & “No Heroics”

CPR **Myth**:

- Most people recover with CPR and ‘shocking’ the heart
  - (TV success rate is 67%)

Diem SJ, et al. NEJM 1996 Jun 13

CPR & "No Heroics"

…CPR **Reality**:

- Only 2-17% over the age of 70 survive CPR
- Seniors' bodies have little reserve and rarely return to pre-CPR health status

  [See Emma Thompson in movie "Wit"]

Tribble BT. DNAR: More than code or no code. AAHPM bulletin. 2008

CPR & “No Heroics”

CPR **Reality**:

- Usually considered “heroic measures”
- Incompatible with a peaceful death
- Ribs break & pneumonia often develops
- CPR in seniors often ends in traumatic death or placement on machines

CPR & "No Heroics"-
How to avoid CPR

What is an AND/DNR Order:

- It means "**D**o **N**ot attempt **R**esuscitation (with CPR)"
- A doctor must write "AND" or "DNR" order in a medical record
- You will receive CPR unless order written !!!

What is “A.N.D.” ?

A.N.D. means:

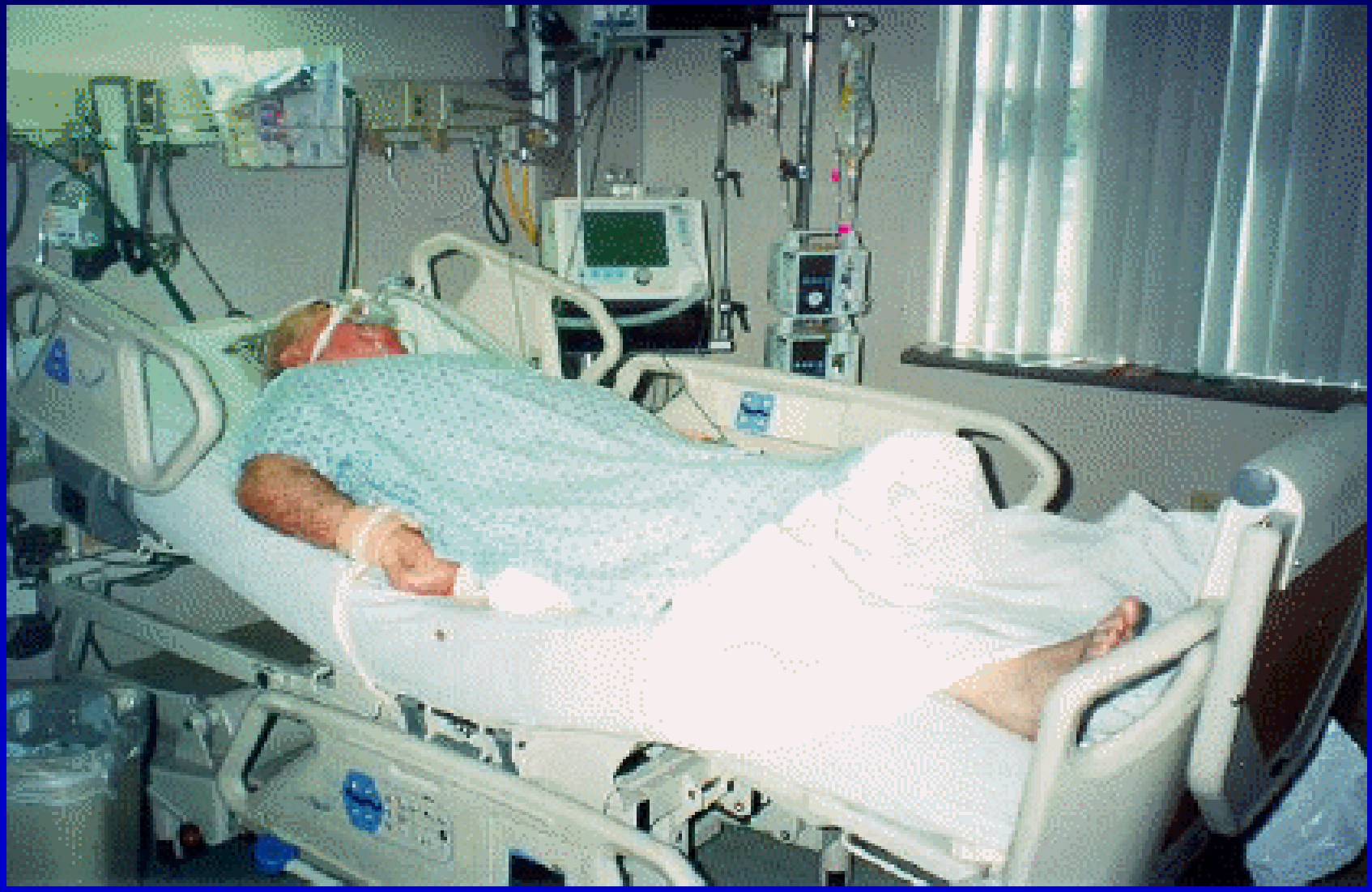
- Allow Natural Death
- “keep me comfortable when it’s time to die”
- Allows the dying process to occur naturally
- Permits withdrawal of artificial nutrition and hydration

A.N.D.=
"Allow Natural Death"

Why Use "A.N.D." ?

- Avoids negative term "DNR" –
  "Do Not Resuscitate" perceived as withholding
- Avoid misinterpretations of DNR
  - Do everything but CPR ?
  - Don't do anything "since she's dying" ?
- **Avoid <u>futile</u> undignified resuscitation attempt**
  - How do you want to die…or watch a loved one die…

Futility – how do you want to die?



2) Dehydration & Starvation - Myths & Realities

Facts:

- Healthy people who do not eat or drink become hungry
- Food and water are symbols of caring
- Because they are symbols of caring, it is hard to consider stopping them…

Dehydration & Starvation

…Facts:

- The brain depends on sugar and water for awareness/thinking
- Dehydration makes the brain less aware of pain/discomfort (endorphins produced)
- Providing fluids when dying, makes the brain more aware of pain

Dehydration & Starvation

Myths:

1) Dehydration and starvation are painful
2) We cannot allow someone to starve to death
3) Providing IV (intravenous) fluids will make a terminally ill person more comfortable.

Dehydration & Starvation

Reality:

- "Pain" of dry mouth can be treated
- Dying people who don't eat or drink are more comfortable due to chemical changes in the brain (endorphins)
- The disease causes terminally ill people to die
  - Not Starvation !

Dehydration & Starvation

…**Reality**:

- IV fluids delay death & prolong suffering
  - Days may become weeks of suffering
  - The brain is more aware of pain & hunger
  - The bladder fills more frequently
  - Lungs fill with more fluids
  - IV's convert a 'dry' death into a 'wet & miserable' one

Dehydration & Starvation

…**Reality**:

Prior to IV's and feeding tubes, people usually died of "natural causes"

- Natural causes are not starvation

3) Feeding Tubes - Myths & Realities

Feeding Tube **Facts**:

- They artificially provide nutrition
- They usually artificially prevent dehydration and starvation
- They are inserted through the nose or through an abdominal incision (PEG)

Feeding Tubes

Myths:

- Feeding tubes prevent aspiration pneumonia
- They prevent malnutrition
- They improve survival
- They reduce pressure sores
- They reduce risk of infection
- They improve functional status & comfort

Feeding Tubes

Reality:

- None of the myths is accurate !!
- Risk of aspiration pneumonia is 4 times greater
  [increases from frequency of 15% to 60%]

Koretz et al. Am J Gastro.2007

4) Time of Death Myths

- Myth: It doesn't matter what we do because people will die 'when God decides'
- Reality: Medical technology:
  - has created situations which keep people alive;
  - often causes suffering and prolongs dying;
  - now requires us to make decisions re medical 'interventions':
    - IV's, PEG's, Vents, abx, ICD's,
  - Are families and doctors 'playing God' by interfering?

…And 5)

- Myth: doctors cannot predict death or outcome with any reasonable certainty
- Reality: for many patients, an educated estimate can provide helpful guidance
  - Cancers example

…why is prognosis important?

When Cancer has <6mo Prognosis

- Metastatic [i.e. Stage IV] and failed chemoRx
- When ECOG Stage 3 reached:

  (Eastern Cooperative Oncology Group)

  – Stg I - ambulatory, active, mild symptoms
  – Stg II - in bed <50% of day, more symptoms
  – Stg III – in bed >50% of day [= 3-6mo.survival]
  – Stg IV – bedridden, total care [= <3wks avg survival]
- Usual Symptoms: losing wt, dysphagia, anorexia, dyspnea, dry mouth

…Why Prognosis is Important

- Prognosis: forecasting the outcome of a disease
  - A traditional duty of a doctor
    - diagnosis, etiology, treatment, prognosis
- Prognosis:
  - provides context to make informed medical decisions
  - helps clarify ‘goals’
  - Helps change focus to ‘whole person’ – not just a diagnosis for one damaged organ

…Knowing Prognosis may avoid Non-Beneficial or Futile Care

- Only 10% people die suddenly
- 90% need some form of terminal care
- Providers must face decisions of "how many and what kind of interventions are needed"
- During EOLC, we can be primary cause of suffering or, primary cause of its relief !

3. The Myth of Informed Consent & the Ethics of Dying

- Myth: patients make informed decisions.

  …but, do they?

- Ethical Question: Is the "road to death" undignified and more costly because patients [and their doctors], lacking relevant information (particularly on risks & benefits), make "un-informed" decisions which often result in futile interventions?

  …what do patients want to know?

What do Patients & Families with Serious Illnesses Want [their goals?]

- Pain and symptom control
- ***Avoid inappropriate prolongation of the dying process***
- Achieve a sense of control
- ***Included in decisions & to be listened to***
- ***Honest information***
  - Everyone wants adverse event info [1/100,000 - Ziegler. Arch Intern Med 2001]

** Singer et al. JAMA 1999;281(2):163-168.*

** Tolle et al. Oregon report card.1999 www.ohsu.edu/ethics*

Identifying Patient Goals

What are ‘goals’?

- A result or end we want to reach.

Why set goals of the medical care?

- Care goals shape expectations & priorities
- Goals often dependent on understanding risks & benefits of options and on prognosis

If we haven’t discussed the goal and prognosis, how can we establish an appropriate plan of care and obtain an informed consent?

How to Make Informed Decisions

1) Clarify status & prognosis of condition & treatment options
2) Help patient/family identify their goals !!

   E.g. Is it comfort, longevity, or mixture of both?

3) Point out & accept that goals may change w/ more info or as disease progresses !

   i.e. Learning new risks/ benefits of **available options** may affect a decision.

Goals & Communicating Risk:
What is an **Informed** Decision

A. Legal Requirements for informed decision
   - Information – credible, accurate, understood
   - Capacity to make decision

B. **Communicating Risk**
   - Understanding what's "Risk"
   - Risk in perspective
   - Emotions v Facts in decisions

C. Treatment Limitations

A. Informed Consent Requirements

Elements of Information in Informed Consent:

- nature of procedure
- benefits
- risks, common or severe
- alternatives

For Consent to be Valid:

- Voluntary – must be free to choose
- Patient must understand what's to be done
  - Capacity to understand?

B. Communicating Risk & Informed Consent

- Some people want "Illusion of Certainty"
  - Don't want to know!! ??
- Illusion (Myth) of Certainty: the belief that an event is absolutely certain although may not be ! Examples:
  - Treatments have only benefits but no harm
  - There's only one best treatment
  - A diagnostic test is absolutely certain

But, in reality…

- "In this life, nothing is certain but death & taxes"- Franklin's Law
- All real world events are uncertain
- Every healthcare decision is one between two risks, not between a certainty and a risk
  - ***All attempts to do good, also generate unwelcome side-effects (unintended consequences)!!***
  - ***NB for pharmacists & doctors***

Communicating Risk …

- **"Risk"** [*the possibility of harm*] is an uncertainty that can be expressed numerically (via probabilities & frequencies)

- **Forms of Risk Communication**:
  - Probabilities [confusing]
    - Single event probability
    - Conditional Probabilities
  - Frequencies [less confusing]


whatever happened to our sexual relations?
I don't know. I don't even think we got a Christmas card from them this year.
parodyville.com

Communicating & Common Sense:

- Public has right to clear information
- If guidelines being debated, that usually indicates ***uncertainty*** !! e.g. HR Therapy

- Use ‘natural frequencies’ to explain risks via
  - ARR & NNT
  - Frequency Tree
  - Population Visual aid [Paling Palette]

How NOT* to represent benefits & risks…

- Relative Risk Reduction (RRR): measure (as a %) of effect of treatment relative to number people improved/saved [typical in journal & newspaper articles]
  - RRR amplifies small differences and makes the insignificant appear significant
  - RRR doesn't reflect the baseline risk of outcome events

[Henley, 2000. Edwards, 2002. Paling 2006]*

…How to represent benefits & risks

- Absolute Risk Reduction (ARR): measure of effect of treatment in terms of absolute number people improved/saved
- Number Needed to Treat (NNT): number of people who need to be treated to improve/save one

Real World Example:
Benefits & Risks of Treatments to Reduce CVA Risk in A.Fib.

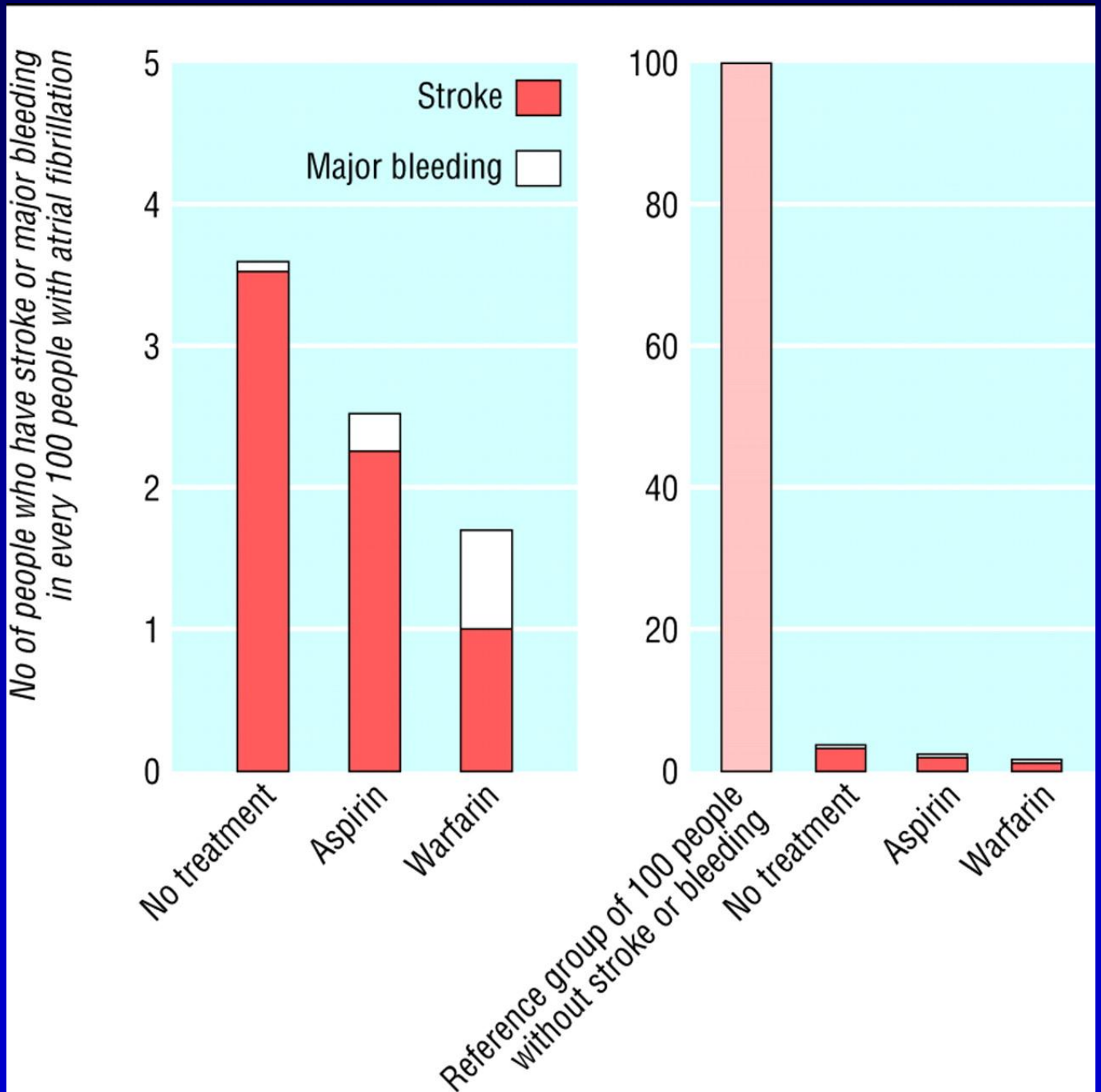
How much does a treatment actually reduce the risk of having a stroke or cause a major bleed from the drug used?

Data followed by different perspectives / representations (which is better?)

Benefits of Warfarin v. ASA (in A.Fib)

Treatment	Risk of CVA
• No treatment:	3.5% (1-18%: CHAD2 risk score 0-6)
• ASA:	RRR = 37% (2.5/3.5 x100)
	decreases ~1% (ARR)
	NNT = 100 (100/1)
• Warfarin:	RRR = 71% (1.3/3.5 x100)
	decreases ~2% (ARR)
	NNT = 50 (100/2)

but, increases Bleeding Risk ~1%


No of people who have stroke or major bleeding in every 100 people with atrial fibrillation
Stroke
Major bleeding
5
4
3
2
1
0
100
80
60
40
20
0
No treatment
Aspirin
Warfarin
Reference group of 100 people without stroke or bleeding
No treatment
Aspirin
Warfarin

Risk & Benefit *Mis*-Communication

- It's how we present the information !
- "There are three kinds of lies: lies, damn lies, and statistics!"
  - Benjamin Disraeli
- Use visual aids – provide POS & NEG info
  - Paling Palettes – 1000 people
  - Dr. Chris Cates website – Visual Rx

C. Treatment limitation at the end of life?

- Right to refuse any intervention
- All patients have rights, even incapacitated
- Withholding / withdrawing
  - not homicide or suicide
- Patient/family does NOT have right to demand a “futile” treatment
- Courts need not be involved

The Ethics of Dying & Stewardship in Healthcare

- Stewardship: "A [fiduciary & ethical] responsibility to take care of something one does not own."
- Stewardship implies avoiding things which are non-beneficial/futile for another person !

[Futile Care: care which will not help a patient reach their goal.]

Stewardship

- 5% of Medicare beneficiaries die each year
- 30% of budget [total = $482B in ‘05] is for last year of life
- Of those dying, 50% of costs spent on last 2 mo. of life [w/ no “gain in quality”]
- Do we (providers **&** patients) not have a stewardship responsibility to avoid futile or non-beneficial care?
  - What’s the goal of medicine??

* 1. USA Today; 2. J. Lubitz, DHHS, report to US Congress 2004

Does stewardship imply not abandoning him to the system?

"… they saw finally that in their attempt to help they had not helped but only complicated his disease beyond their power to help. … Loving him, wanting to help him, they had given him over to "the best of modern medical care"—which meant, as they now saw, that they had abandoned him."

– Wendell Berry, *Fidelity*, 1992

How to Improve QOL & Dying: Be informed

- Internet information – Understand Risk
  - Cardiovascular Risk Calculator – University of Edinburgh – cvrisk.mvm.ed.ac.uk/calculator
  - Bandolier - www.medicine.ox.ac.uk/bandolier/
  - Paling Perspective Scale – www. trci.info
  - Visual Rx - www.nntonline.net/

- Advance Directives & Discussions
  - OneSlideProject – engagewithgrace.org
  - ParentsWish.com

…Avoid Futile Care: Be informed

- Other information
  - Risk Charts for Men/Women – J Nat'l Ca Inst
  - **Comfortcarechoices.com** – R.Webb's website w/ info about EOLC and palliative care choices
  - Gerd Gigerenzer. *Calculated Risks. 2002*
  - *InfoPOEMS – website & daily service* www.essentialevidenceplus.com/

Summary & Pearls

- Palliative/hospice care is comfort-focused
- Drug doses/routes are often different
  - MD not always a ‘doofus’
- Methadone may become the gold std?!
- Make decisions based on good information, not myths !
  - CPR is usually a futile, undignified procedure
  - Dehydration is not uncomfortable when dying
  - People die naturally – not from starvation

Summary & Pearls…

- PC is NOT only for those about to die!
- PC does NOT accelerate dying !
- ‘Giving up’ is not same as ‘letting go’ !

- In Hospice:
  - There are NOT ‘two’ kinds of hospice
  - Patient do NOT have to have DNR [AND]
  - Patients can be admitted to hospital
  - Patients do NOT have to be discharged in <6mo.

…Summary & Pearls

- Clarify goals and the prognoses of each condition before making decisions
- Provide relevant risks & benefits perspectives
- Discuss goal-focused choices
  - "Can you live w/ your decision?"
- Encourage others to be assertive – avoid abandoning a loved one to the "system."

Thank You !

As you slide down the banister of life, may all the slivers point down!

- *Maxine*

Grow'n old ain't for sissies !

- *Betty Davis*

So, enjoy yourself while you can !