REFUSAL OF CARE AND DECISION MAKING CAPACITY

“Don’t wanna
……Ain’t gonna” Syndrome

Ed Vandenberg MD CMD
OVAMC
Section of Geriatrics
&
Asst Prof. Geriatrics
981320 UNMC
Omaha NE 68198-1320
evandenb@unmc.edu
Web: geriatrics.unmc.edu
Future advice as of 7-14-08

- Reduce redundancy on topic of informed consent (you cover at initially and then it gets repeated in the portion on assessing capacity)

- Reduce redundancy on the documentation of consent (you cover initially and then gets repeated in portion on assessing capacity)
Supports and disclaimers

Co-Director

“NEBGEC: The Nebraska Geriatric Education Center”

DHHS Health Resources and Services Administration
(Other Disclaimers)
Why you should never chew bubblegum and exercise
Objectives

Upon completion the learner will be able to:

✓ Describe the process of evaluation of patients refusing appropriate care.
✓ Perform an assessment for capacity to make medical decisions
✓ Describe the various types of surrogate decision-makers and their qualifications
✓ Apply the process to assist surrogate decision-makers to make best estimates of patient's wishes.
Areas to cover

- Basic approach to patients refusing care
- Assessing capacity to make decisions
- Review types of alternate/surrogate decision-makers
Informed Consent And Refusal Treatment

Informed consent is:
- a fundamental moral and legal right
- enhances well-being
- respects autonomy

Refusal of care extends from this right.

Vol. report . Washington, DC (DC): Presidents Commission For The Study Of Ethical Problems In Medicine And Biomedical And Behavioral Research; 1982
Effective Informed Consent And Refusal Treatment

Three essential features;

1. Patient has mental capacity
2. Sufficient information provided to patient
3. Patient’s decision made freely

“This ain’t Mr. Roger’s neighborhood”

78-y.o.
First home health visit by R.N.
Eccentric, lives independently
Fall with only injury-laceration head
O; awake, alert, answers appropriately
Alcohol on breath
Refuses home nursing request to be seen for suturing and evaluation
What do you do?
Process of evaluation for refusal of care

Patient refuses treatment or care

Assess patient’s capacity to make this decision.

Assess potential harm from refusal

Adapted from the National Institute For Health And Clinical Excellence 2004 Guidelines CG 16, NICE, London
Process of evaluation for refusal of care

**Insufficient capacity**
- Surrogate Decision maker?

**Sufficient capacity**
- Emergency Medical detention?
- Adult protective services?
- Reengage, Review, Document and Release

Adapted from the National Institute For Health And Clinical Excellence 2004 Guidelines CG 16, NICE, London
Sufficient capacity—still refusing

- Regard as opportunity to continue dialogue
- Seek & examine reasons for refusal
- Is refusal consistent with patients stated goals?
- Can autonomy and pt’s welfare be reconciled?
- Are the Healthcare Providers, personal/professional values violated?

Carrese JA. Refusal of Care: Patient’s Well-Being and Physician’s Ethical Obligations, JAMA, August 9, 2006, vol. 296, No. 6, pages 691-695
Documentation

- Information provided to patient
- All efforts to persuade patient to accept treatment *(must be noncoercive)*
- Alternative treatments considered
- Patient’s decision-making process
- All other efforts involving additional healthcare providers.
- Efforts to involve family/friends in decisions *(within bounds of maintaining confidentiality)*
- Opportunities for patient to reconsider or return.

Adapted from the National Institute For Health And Clinical Excellence 2004 Guidelines CG 16, NICE, London
Information provided

- Proposed interventions
- Consequences of use or non-use of interventions

Against Medical Advice Discharges

Prior to discharge perform & document;
- Careful, well documented exam
- Assess/document severity of illness & risk
- Constructive dialogue; focus- grievances
- Perform, document discussion-risks, benefits and alternatives
- Documenting specific advice given to patients is most important

Emergency Medical detention?
Against Medical Advice Forums

- Not all AMA forms protective (1)
- Sample forms available (2)
- If refusal leads to serious consequences—form signed by patient and witnessed (3)

**Best protection:**
- evaluate
- counsel
- document

---

(2) Johnson LJ; Malpractice Consult: Medical Economics 2002; 79:143
(3) Seigel DM. Emergency Medical Clinics, North America 1993; 11:833-840
Informational overload?

See how “great leaders” handled this
Assessing Capacity To Make Medical Decisions
WE WILL COVER

- Background of the concept
- Elements of informed consent
- How much information to disclose?
- Who should do the assessment?
- Actually doing the assessment: 4 domains
- Some additional tips
- Making the judgment
- When surrogates decide
CLINICAL VS. LEGAL DISTINCTION

- "Competence" is a legal determination left to courts
- "Decision-making capacity" is a clinical assessment
- The higher the stakes, the higher the capacity needed

Roth I. Meisel A. Lidz C. Am. J. of Psychiatry, 1977; 134:279-84
Decision-Making Capacity definition

The ability to;

• “understand and appreciate the nature and consequences of a health decision” and

• “to formulate and communicate decisions concerning health care”
3 ELEMENTS OF **INFORMED CONSENT**

- ✔ Disclosure of information
- ✔ Voluntary choice
- ✔ Decision-making capacity
When Should Capacity Be Assessed?

- Subconsciously and informally, we are doing it all the time.
- Formally:
  - Always when the risk of proposed medical intervention is relatively high in comparison to expected benefits.
  - Any diagnosis or condition that implies cognitive impairment (delirium, dementia, schizophrenia).

Ganzini L et al. JAMDA, May/June, 2005 pages S100-S104
INFORMATION TO BE DISCLOSED

- Nature and purpose of proposed treatment
- Its potential benefits and risks
- Alternative approaches, and their benefits and risks

Amount and degree of detail?
(based on what an ordinary, reasonable person would wish to know)

VOLUNTARY

- No coercion
- HCP can’t threaten to withdraw from patient’s care if patient disagrees with proposed treatment
- Making a recommendation is NOT coercion
WHO SHOULD MAKE THE ASSESSMENT of CAPACITY?

- Physician—not necessary that it be a psychiatrist
- Courts receptive to non-psychiatric attendings
- Capacity best assessed by clinician responsible for care

Consider consultant when:
- Pressed for time
- You lack the skill
- You don’t want to be “the bad guy”
- Difficult/tricky/hazardous case

Markson LJ et al.. Physician assessment of patient competence. JAGS, 1994; 42:1074-1080
BEFORE STARTING THE ASSESSMENT

Alert the patient:

“Some of us involved in your care have concerns about how well you are able to make decisions about your treatment”
DOING THE ASSESSMENT: THE 4 ELEMENTS

1. Ability to **Express** a Choice
2. Ability to **Understand** the Information
3. Ability to **Reason** with the Information
4. Ability to **Appreciate** the **Situation** and Its Consequences
How do I remember these things?

Mnemonics:

EURAS

The story behind the mnemonic: ...........
1: EXPRESS A CHOICE

Not just ability to communicate; consider also consistency vs. ambivalence or vacillation

“Have you decided whether to go along with our suggestions for treatment?”

“Can you tell me what your decision is?”

Consider letter boards, eye blinks, yes/no questions, translators
“Please tell me, in your own words, what you have been told about…

...the nature of your condition,
...the recommended treatment,
...the possible benefits of this,
...the possible risks,
...benefits and risks of alternatives
...and benefits and risks of no treatment?”
2: **UNDERSTAND RELEVANT INFORMATION**

- Decision capacity is question specific
- Even with lack of capacity, patient can still sometimes participate in decision.

Ganzini L et al. JAMDA, May/June, 2005 pages S100-S104
3: **REASON WITH THE INFORMATION**

- Look for irrationality in processing the information
- Eccentric is different from irrational
- Do the patient’s choices flow logically from the premises, values, and views of the consequences?

Caresses JA. JAMA 2006; tonight 6:691-695
3: REASONING, cont’d

“Can you tell me how you reached the decision that you did?”

“What factors were important to you in thinking about this?”

“How did you balance those factors?”
4: **APPRECIATE THE SITUATION AND CONSEQUENCES**

Patient should acknowledge:
- …suffering from disorder diagnosed, and
- …the consequences in own personal situation
4. APPRECIATE SITUATION, cont’d

“Tell me what you believe is wrong with your health now”

“Do you believe you need some kind of treatment?”

“What is treatment likely to do for you?”

“What do you believe will happen if you are not treated?”
ADDED TIPS

- Don’t rush; consider reassessing later

For patients with sensory impairments or limited cognition
- Try: written disclosures, illustrations, models, videotapes

- Consider stopping drugs that may cause somnolence or confusion; or starting drugs to treat distracting symptoms
ADDED TIPS, cont’d

- Involve family, friends, clergy, members of same ethnic group
- It may be OK for patient to turn over the decision to a friend or family member
- Many cultures traditionally utilize their families or certain family members to make decisions.

Adler RN. Doorway thoughts. American Geriatrics Society. Jones and Bartlett publishers 2004
MAKING THE JUDGMENT

Does this patient have sufficient ability to make a meaningful decision, given the circumstances?

Weight autonomy vs. protection (former gets more weight)

Persons are presumed capable/competent; the burden of proving otherwise rests on those who would overturn decision
As risk of harm rises, degree of impairment in DMC that is required to overturn the decision decreases.

Capacity is therefore decision-specific.
DOCUMENTATION

- Two or three paragraphs
- Document:
  - Patient informed of purpose of evaluation
  - Patient’s mental status at time of evaluation
  - Describe information conveyed
  - Patient’s performance on the 4 standards
  - Autonomy vs. protection; your opinion.

HOW DO CLINICIANS DO AT DETERMINING CAPACITY?

- N = 302 consecutive medical inpatients over 18 months; of these, 159 could be interviewed.
- Assessed by MacArthur competence tool
- Patients with capacity: n = 109
  Clinical team in complete agreement.
- Patients lacking capacity: n = 50
  Clinical team identified 24%
- Physicians usually fail to identify patients with significant cognitive impairment lack capacity

Questions?
The Good Things About Dementia

적이 수입을 구매하고자 할 수 있습니다!

물론이, 이는 항상 새로운 사람들과 만난다!

당신은 자신의 부활절 계란을 숨길 수 있습니다!

과하고, 이것은 항상 처음의 경험을 마진다!!!!
Surrogate Decision-Makers

- Durable Powers of Attorney
  - healthcare
  - financial
- Guardian
- Conservator
## Surrogate decision-makers

<table>
<thead>
<tr>
<th>Decision-Maker</th>
<th>Who chooses?</th>
<th>Who can change?</th>
<th>Who activates?</th>
</tr>
</thead>
<tbody>
<tr>
<td>DPOA</td>
<td>Patient</td>
<td>Patient while still capable</td>
<td>Physician (in writing)</td>
</tr>
<tr>
<td>Guardian</td>
<td>The court</td>
<td>The court</td>
<td>Active immediately</td>
</tr>
<tr>
<td>Conservator</td>
<td>The court</td>
<td>The court</td>
<td>Active immediately</td>
</tr>
</tbody>
</table>
Helping Surrogates Make Decisions

What if a patient lacks decision-making capacity and a surrogate must decide?

Standards to apply:
- 1st step: patient’s prior explicit choice
- 2nd step: Substituted judgment (proxy chooses what patient would have, based on known values)
- 3rd step: “Patient’s best interests”
Assisting surrogate decision-makers

1. Establish surrogates
   - groups; review positions/relationships
   - single person; establish position/relationship

2. Request their knowledge of patients condition

3. “Backfill” additional information needed

4. Review patients prior wishes (Living Will?)

5. Use Substituted Judgment principles & techniques

6. Provide professional opinion
   (prognoses, EVB information)

Always with patient’s “best interests” as foundation
What if there are no DPOAs?

1. Spouse
2. Adult child
3. Parent, or the written nominee of a deceased parent
4. Any relative of the incapacitated person with whom he or she has resided for more than six months.
5. Adult sibling
6. Significant others who have a current sustained relationship with the patient and can present the patient's preferences.

Also they must be; Available, willing and have the capacity to serve as a responsible surrogate

Lyons W. Practical Ethics: Assessing Decision-making Capacity

AMDA website, white paper on decision-making capacity at; http://www.amda.com/governance/whitepapers/surrogate/index.cfm
ANYWAY

People are unreasonable, illogical, and self-centered,

- LOVE THEM ANYWAY

If you do good, people will accuse you of selfish, ulterior motives,

- DO GOOD ANYWAY

If you are successful, you win false friends and true enemies,

- SUCCEED ANYWAY
The good you do will be forgotten tomorrow,
- **DO GOOD ANYWAY**

Honesty and frankness makes you vulnerable,
- **BE HONEST AND FRANK ANYWAY**

What you spent years building may be destroyed overnight,
- **BUILD ANYWAY**

People really need help but may attack you if you help them,
- **HELP PEOPLE ANYWAY**

Give the world the best you have and you’ll get kicked in the teeth,
- **GIVE THE WORLD THE BEST YOU’VE GOT ANYWAY.**

From a sign on the wall of Shishu Bhavan, the children’s home in Calcutta
What do I think about “same sex marriage”?  

Fact: Those of us who have been married for some time know that…………………………………………

It’s the “same sex” over and over again!!!

Robin Williams
Thank You
for
your kind attention!
RESOURCES

• Surrogate decision-making in Nebraska; Nebraska Department of Health and Human Services
  http://www.nhima.org/surdec.pdf