Thinking “Inside the Box”: The Four Box Method for Facilitating Ethical Decision Making

Christine Westphal NP MSN ACNS ACHPN®
Director/Nurse Practitioner
Beaumont Health, Beaumont Hospital-Dearborn
Disclosures

• No conflicts of interest to disclose

• No discussion of off-label drugs

• Case study information is based upon actual cases, but names are fictional.

• Photographs are from internet public domain
Objectives

• Describe the elements of the Four Box Method and related ethical principles.

• Demonstrate how the Four Box Method can be applied to facilitating ethical decision making using case examples.
Codes of Ethics

- American Dietetics Association, 2009
- American Medical Association, 2001
- American Nurses Association, 2001
- American Pharmacists Association, 1994
- Association of Professional Chaplains, 2000
- American Speech-Language-Hearing Assoc., 2010
- Code of Ethics for the Profession of Dietetics, 2009
- National Association of Social Workers, 1999
Western Ethical Principles

• Autonomy: Respect for rights of the individual

• Beneficence: “Do good”

• Non-maleficence: “Do no harm”

• Dignity: All persons deserve to be treated with dignity/respect

• Fidelity: Keep promises, be true

• Veracity (Truthfulness): Basis of informed consent

• Justice: Stewardship in allocation of resources; fairness
Ethically speaking...

• No distinction between withholding and withdrawing

• No distinction among therapies

• Ethical principals and a systematic approach should be used to facilitate decision-making
  • Beauchamp & Childress, 2008
Ethical v Legal

- What “ought” to be
  - Shapes morality
    - Social/personal rules
    - Behaviors
    - Judgments
- Violation may elicit
  - Disapproval
  - Removal from group
  - Condemnation

- Created to maintain social order
- Statutes, case law
- Minimum standard for social behavior
- Violation results in enforceable punishment

Beauchamp & Childress, 2008
Shared Decision Making

• Collaborative process
• Best scientific evidence
• Patient’s values, beliefs, preferences
• Process
  – Introduce choice
  – Describe options: Benefits/harms, medical evidence
  – Explore patient preferences
  – Make decisions
  – “Touch back”

• Elwyn et al, 2012; Rubin, 2014; Fink-Samnick 2016
The Four Box Method

- Clinical Indications
- Patient Preferences
- Quality of Life
- Contextual Features

Jonsen et al 2010
Bonnie

- 85 YO with advanced dementia
- Resides in NH
- Bed/chair bound, limited verbal, dependent all ADL
- Aspiration pneumonia
- Albumin 2.1; 75% of IBW
- Failed modified barium swallow
- PEG?
Clinical Indications

Jonsen et al 2010
Questions to Consider

• What is the goal?

• What is evidence that the therapy may achieve goal?

• What is the potential harm of providing/not providing the therapy?

• What are the alternatives? Is a time-limited trial warranted?
Beneficence and Non-malfeasance

• Obligation of clinicians to determine what is medically indicated (beneficial).

• No obligation to provide non-beneficial ("futile") treatment.
  – "physicians should not accede to demands for treatment that are inconsistent with sound medical practice." AMA Council on Scientific Affairs, 2000
Definitions of Futility

Physiological (Medical)
Cannot achieve a medical physiological aim

Quantitative
Less than 1% chance of treatment success

Lethal condition
The patient has an underlying condition that will not be affected by the intervention and death will occur within weeks to months

Qualitative
Cannot achieve an acceptable quality of life. Only preserves unconsciousness and/or fails to relieve total dependence on intensive medical care

Likely Beneficial

• Physiologic support for reversible problems
  – Dysphagia related to CVA
  – Post-operative ileus
  – Critical illness

• Nutritional support during oncology treatment
  – Chemotherapy mucositis
  – Optimizing nutrition for therapy
  – Good performance status with slow growing malignancy

• Allow time for accurate assessment of recovery
  – Traumatic brain injury

• Chronic disabilities with ANH providing quality
  – Parkinson’s disease
No Meaningful Benefit in Advanced Dementia

— No

• Increased survival compared to hand feeding
• Difference in survival between early and later insertion of feeding tubes
• Lower risk of aspiration
• Increased healing of pressure ulcers
• Difference in weight loss
• Evidence of increased comfort, functional status or quality of life

Finucane TE et al, 1999; Sampson et al, 2009; Teno et al, 2011; Teno et al, 2012
Feeding Tubes and NH Residents

- 5266 NH residents
- Patients with feeding tubes died significantly faster (1.44) than those without
  - Mitchell et al, 1998

- Nationwide NH survey severe brain impairment
- Use of feeding tubes varies widely use across the country (3.8-44.8%), but no difference in mortality between high use and low use states
  - Teno et al, 2002
Suffering

• Small studies suggest most dying patients do not experience hunger/thirst
• Hunger/thirst relieved with small amounts of food and ice chips, not ANH
  • Ellershaw JE, 1995; McCann et al, 1994; Fine RL, 2006

• Terminally ill patients who refused food/water do not demonstrate signs of discomfort
  • Ganzini L et al, 2003; Pasman HRW et al, 2005
Potential Harm

- Nausea/vomiting
- Diarrhea
- Pulmonary congestion
- Edema
- Increased urination
- Infection
- Immobility/Use of restraints
- Trauma due to dislodgement
- Bleeding
- Earlier death?
  - Monturo C & Hook K, 2009
Questions to Consider

• What is the medical/clinical goal?

• What benefit will ANH provide toward the goal? What is likelihood of success?

• What is the potential harm of providing or not providing ANH?

• What are the alternatives? Is a time-limited trial warranted?
Clinical Indications

Quality of Life

Jonsen et al 2010
Quality of Life

• What constitutes quality? Whose definition?
  – “Qualitative Futility”

Only preserves unconsciousness and/or fails to relieve total dependence on intensive medical care

• Expected QOL with and without treatment: physical, emotional, social, spiritual.

• Additional resources to optimize quality?
Autonomy

- Right to choose and refuse
- Does not entitle person to treatment that is not clinically indicated
- Religious and cultural views may influence individual choices
Legal Right to Choose and Refuse

- Constitution guarantees of liberty and privacy

- The right to refuse end-of-life care was guaranteed with the passage of the federal Patient Self-Determination Act (PSDA)

- Decisions must be based upon the elements of informed consent (veracity)
Informed Consent

- What?
- Why?
- How?
- Who?
- Benefits?
- Risks of proceeding and declining?
- Alternatives?
Informed Consent and PEG

• N= 154 dementia patients
• Only 1 record included risks and benefits
• 7/18 Surrogates signed for competent patients
• Inadequate quality of informed consent
  – Brett AS & Rosenberg, 2001

• N=238 advanced/metastatic CA died 2-15 mo after dx
• No documentation of discussion related to life expectancy before initiating ANH
  – Dy SM et al, 2011
Capacity

- Clinical evaluation of patient’s ability to:
  - Receive information (e.g. awake, but not necessarily oriented x 3),
  - Evaluate, deliberate, and mentally manipulate information
  - Communicate treatment preference

- May vary depending upon complexity of the decision and timing

Competency

- An assessment made by a mental health professional that may lead to a legal declaration about the ability to make decisions.

- **Never competent**
  - Individuals who were never able to exercise decision-making capacity

- **Formerly competent**
  - Adults and minors of sufficient age and maturity who were able to make decisions previously

- Personal Communication. JK Felt JD Dykema Gossett PLLC
Advance Directives

- Advance directives protect the right to choose/refuse in the event the individual loses decision-making capacity
  - Designation of Patient Advocate
  - Power of Attorney for Healthcare
  - Living Wills
  - DNR documents

Alternate Decision-Makers

- Designated patient advocates
- Guardians
- Parents of minors
- Next-of-Kin for adults
  - “Order of authority” statutes in some states
## Standards for Decision-Making

<table>
<thead>
<tr>
<th><strong>Substituted Judgment</strong></th>
<th><strong>Best Interest</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of the incapacitated person’s values, beliefs and past choices</td>
<td>No/ very little knowledge of the patient</td>
</tr>
<tr>
<td>Choice reflects what decision-maker believes patient would choose.</td>
<td>Also used for people who were never competent</td>
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<tr>
<td></td>
<td>Greatest “benefit” and least consequences</td>
</tr>
<tr>
<td></td>
<td>“Reasonable person” determination</td>
</tr>
</tbody>
</table>
Questions to Consider

• Can the patient make decisions and/or able to express preferences?

• If not, is there evidence of previously expressed preferences? Who is the appropriate decision-maker?

• If no known preferences, then consider beneficence, non-malefiecence, best interest.
Quality of Life

Clinical Indications

Patient Preferences

Contextual Features

Jonsen et al 2010
Contextual Features

- Influencing family factors
- Cultural views
- Religious/spiritual views
- Provider/System concerns
Family Issues

- Acceptance of diagnosis
- Immobilized decision-making
- Concern about “giving up”, guilt
- Conflict
- Anticipated family life changes
- Financial concerns
- Anticipatory grief
Resources for Patients/Families

- Alzheimer’s Association
- http://www.webmd.com/healthy-aging/should-i-receive-artificial-hydration-and-nutrition
Cultural Issues

• Autonomy and decision-making

• Symbolism of food and eating

• Social significance “Cruel” not to feed

• Healing related to foods
Religious Views

• Catholic
  – 2004 “Papal allocution” regarding ANH and PVS
  – Food and water, by any means, is ordinary “in principle”. Removal is euthanasia by omission
  – *Debate regarding application to other conditions*

• Judaism
  – Adherence to the Halakha (Jewish law) Sanctity of life as foremost
  – Various views: Orthodox, Reform Conservative, Reconstructionist
  – Most view food and water as essential to life and must be offered
  – Some would differentiate “ordinary” and “extraordinary”

• Islam
  – Nutritional support is considered basic care and not medical treatment.
  – Hastening of death by the withdrawal of food and drink is forbidden
  – Withdrawal of futile, death-delaying treatment, including life support, may vary with the school of thought

Provider/System Concerns

- Justice: nondiscriminatory decisions
- Time for discussion with patients/families
- Lack of knowledge about alternatives
- Avoidance of controversy
- Fear of litigation
- Reimbursement for procedures
- Unreimbursed care
- Conflicts of interest
- Fear of sanctions (i.e. CMS)
- Time/staffing to hand feed
Legal Issues

• Common law and constitutional guarantees of liberty and privacy protect right to refuse

• ANH is equivalent to other therapies
  – 1993 Uniform Health Care Decisions Act

• Clarity of advance directives

• Patient’s with no decision-makers

• Scope of guardian authority
• 68 YO female
• PMH: CAD, MI X 2, Ejection fraction 20% diastolic and systolic heart failure IV D
• PSH: Angioplasty/stenting to 3 vessels, BiVentricular PPM/internal cardioverter defibrillator
• Two admissions/3 months. Presented to ED:
  – Dyspnea
  – BLE edema
  – Weight Gain
  – Several ICD firings
  – Dx: Heart Failure
Diane

• Psycho-social
  – Divorced for many years
  – Sole wage earner
  – Cares for a 35 YO daughter with Down’s syndrome
  – Support system is her sister

• Wants to discontinue pacemaker and ICD
Clinical Indications

Jonsen et al 2010
Cardiac Resynchronization Therapy (CRT)

• Goal: Restore LV synchrony in patients with dilated cardiomyopathy and a widened QRS to improve the mechanical functioning of the LV

• Bi-Ventricular pacing of right ventricle (RV) and the left ventricle (LV).

• Leads are placed on the RV endocardium and through coronary sinus for LV

• Lead may also be placed in right atrial (RA) for AV sequential pacing
P wave spike

Sequential QRS spikes
Internal Cardioverter Defibrillator

• Prevention of sudden cardiac death
  – Primary Prevention: patient has not had a life-threatening arrhythmia. Accounts for the majority of all implants
    • Low EF with post MI, cardiomyopathy
    • Sustained VT with structural disease
  – Secondary prevention: survivor of cardiac arrest secondary to ventricular fibrillation or ventricular
Internal Cardioverter Defibrillator (ICD)  
Cardiac Resynchronization Therapy (CRT)

• ICD reduce likelihood of death  
  – As disease progresses, more shocks may occur  
  – Need to discuss deactivation  

• CRT has been shown to improve quality of life and reduce symptoms  
  – Slaughter MS et al 2009; Stewart GC & Givertz MM 2012; Broglio K et al 2015.
Shock therapy from an ICD

ECG

EGM

18 joules
Dual Chamber Pacemaker

CRT with ICD
Quality of Life
Clinical Indications

Jonsen et al 2010
Clinical Indications

Patient Preferences

Quality of Life

Contextual Features

Jonsen et al 2010
Physician Assisted Suicide?

- Differences between “ending one’s life” and decision to discontinue therapies
- Religious/spiritual considerations
- Concept of intent
  - Ending life
  - Allowing natural death
- Predictability of death with discontinuation
  - Gordon & Grossman, 2015
  - Broglio et al, 2015
Recommendations

- Advance care planning/medical directives
- Early and on-going shared decision-making
- Interdisciplinary approach and engage religious leaders if needed
- Apply a systematic method to analyze the dilemma
- Consider alternatives and time-limited trials
- Use available resources
  - Evidence and best practices
  - Educational materials
  - Ethics consultations
Christine.Westphal@beaumont.org
313-593-8614

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References


• Applebaum P. Assessment of patients’ competence to consent to treatment. NEJM. 2007; 357: 8134-1840.


• Slaughter MS, Rogers JG, Milano CA et al. Advanced heart failure flow left ventricular assist device NEJM 2009; 361(23): 2241-51.


