Ethics, end of life & decision making:

*no-one told me there’s no right answer*

Paula Leslie

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**Ethics & Decisions**

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**Participants will be able to:**

- Explain differences: values, morals, ethics
- Discuss medical ethical principles
- Integrate frameworks that support robust & ethically sound decision making

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**Frameworks**

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Why?

- Ethics
  - ethics, morals & values
- Evidence
  - why ebp?
- Compliance
  - why do people refuse to listen to our wisdom?

Values

- Individual rules for decisions
- Right & wrong
- Should & shouldn't
- Good & bad
- Rank importance
  - Trade meeting one value or another

Morals

- Society's standards: right & wrong
  - More about good & bad than other values
- Judge others on morals
- “Immoral” person
  - Tend to be externally imposed
Ethics

- “Professional morals”?
- Formal system or rules
- Explicitly adopted by group
- Internally defined & adopted

Medical ethical principles

- Autonomy
- Beneficence
- Nonmaleficence
- Justice

Autonomy

Respect another’s worth & right to make choices
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**Beneficence**  
Take positive action to do good for others  
AND act to prevent or remove harm

**Nonmaleficence**  
Avoid causing harm

**Justice**  
Provide what patients need in fair & equitable manner
Evidence Based Practice

- Clinical Expertise
- Patient Preference
- Best Evidence

Best evidence

- Not always randomized control trials
- Some evidence is better than others
  - [http://www.asha.org/members/ebp/assessing](http://www.asha.org/members/ebp/assessing)
- Get trained in how to judge papers
- How robust was study?
- Are participants like my patients?
- Was there bias?

Evidence Based Practice

- Combine knowledge of
  - best available evidence
  - with informed clinical judgment
  - with patient’s values & expectations
- Relative benefit of chosen clinical method
- Conducting evidence based practice results in us adhering to ethical guidelines
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ASHA resources

- Discuss ethical concerns
  - with supervisors
  - with peers
- ASHA help
- Policy documents & specific guidelines
- Ethics forum
- Special interest group communication

ASHA support

- Code of ethics
- Issues in ethics statements
  - http://www.asha.org/practice/ethics/ethics_issues_index.htm
- ASHA sanctions for violations
  - http://www.asha.org/practice/ethics/sanctions.htm

Documentation

- Poor clinical record keeping is unethical
- Clinical documentation in speech-language pathology

OSLHA Conference
March 2016
**ASHA Principle II**

“Individuals shall evaluate the effectiveness of services rendered and of products dispensed and they shall provide services or dispense products only when benefit can reasonably be expected.”

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**Feeding tubes: saints or sinners?**

- What’s the evidence?
  - robust?
  - participant?
  - bias?
- What problems does patient have?
- Have I checked *advanced directives*?
- TALK TO PATIENT, FAMILY, TEAM

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**Why worry about nutrition?**

- If people can’t eat enough
- Protein energy malnutrition
- Muscle changes
- Muscles affect swallowing

Veldee & Peth (1992)
Do tube feeds help?

- Swallow recovery (Lee et al., 2004 letter)
  - need nutrition AND exercise
- Texture modified diet (Wright et al., 2005)
  - patients on modified diets are susceptible to protein & energy deficit
  - consult dietitian in case patient needs tube feed supplementation
- Think about specifics of your case

Tubes & dementia?

- Historically against gastrostomy tube feeds
- Poor outcomes “does not prolong survival” (Mitchell, 1998)
- “Lack of benefit” (Meier, 2001)
- What does prolonging survival mean?
- What is benefit?

What can tubes do?

- Nutrition
- Hydration
- Aspiration
- Quality of life?
- Patient perception (Anis et al., 2006)
  - families & patients felt it helped with nutrition
  - BUT still need evidence on real nutrition benefit & quality of life
Select for right patient

- Stroke  *(FOOD Trial, 2005)*
  - early feeding increase survival but worse outcome
  - supplement malnourished
- Does this simply mean that sicker patients are more likely to have tube feeds?
- This is associated *not* causative!

Dementia: think again

- Comorbidities?
- Prognosis?
- Patient wishes?
- SLP: what is your role
  - palliative?
  - rehabilitative?

Evidence Based Practice

- Informed Clinical Expertise
- Informed Patient Preference
- Best Evidence

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End of Life

What’s Really Important?

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Evidence Based Practice

Informed
Patient Preference

Koffman (2008)

Culture & pain

- Two groups agreed
  - pain is ‘challenge’
  - mastered by patient - not necessarily by drugs
  - pain is ‘enemy’ - an unfair attack
- But also one group felt pain is
  - ‘test of faith’
  - ‘punishment’
Trial by God

- Patient’s perspective affects
  - how patients can deal with distress
  - clinical assessment
  - perceived “compliance” with treatment

Patient values & beliefs

- Whose perspective are we thinking about?
- Understand patient’s knowledge base
- Understand their values
- Consider whole situation

Patient Wishes

Koffman (2008)
Advance directive

- You must check your State Laws
  - http://www.caringinfo.org/stateaddownload
- Establish if your patient made advanced health intervention instructions
- Discuss them with caregivers & clinical team

Types of advance directive

- Living Will
- Durable Power of Attorney
- Federal law provision
- US Living Will Registry
- PBS
- American Bar Tool Kit

Do Not Resuscitate

- On hospital admission
- In charts
- Specific to heart or respiration stopping
- Reality – proxy decides
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### Living will

- 50 states accept but each state has conditions
- Instructions to medical team
- Treatment
  - discontinuation - coma
  - suspension - artificial nutrition
  - maintenance - pain killers
- Organ donation

### Durable power of attorney

- Written by *grantor*
- To make legal decisions
- Including health care
- Names *designee*

### Values History

- Medical decisions are based on *personal*
  - beliefs
  - preferences
  - values
- Not a legal document but structured to help
  - advance discussion for end of life care
  - support proxy(ies) - they know patient’s views

*University of New Mexico (2008)*
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Five Wishes

- The person I want to make health care decisions for me when I can't
- The kind of medical treatment I want or don’t want
- How comfortable I want to be
- How I want people to treat me
- What I want my loved ones to know

Health care proxy

- Health care power of attorney
- State specific
- Named proxies
- May be restrictions on who

National Institutes of Health

- NIH resource advanced healthcare directives
  
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<table>
<thead>
<tr>
<th>Advance directives &amp; dementia</th>
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<tbody>
<tr>
<td>• Who makes advance directives (ADs)?</td>
</tr>
<tr>
<td>• Which medical conditions?</td>
</tr>
<tr>
<td>• To restrict or request intervention?</td>
</tr>
<tr>
<td>• Factors in dementia?</td>
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<tr>
<td>• 81 of 123 nursing home residents had ADs</td>
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<tr>
<td>• 70 named proxy</td>
</tr>
<tr>
<td>• 45 deferred decision to proxy</td>
</tr>
<tr>
<td>• 1 gave power to physician</td>
</tr>
<tr>
<td>• 8 shared thoughts of process</td>
</tr>
<tr>
<td>• DNR not linked to those with ADs</td>
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</tbody>
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<tr>
<td>• White &amp; well educated</td>
</tr>
<tr>
<td>• Cancer more than dementia</td>
</tr>
<tr>
<td>• Restrictions rather than requesting more</td>
</tr>
<tr>
<td>• Dementia is interesting</td>
</tr>
<tr>
<td>• PROGRESSIVE decline to point where patient can’t express view</td>
</tr>
<tr>
<td>• AND patient becomes medically more fragile</td>
</tr>
<tr>
<td>• SO more decisions need making</td>
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Caregiver involvement

- When patient can’t communicate wishes
- Must involve caregivers
- What pressure are they under?
- How are we communicating?

Patient & surrogate disagreement

- Proxy projection
- What influences disagreement?
- Academic exercise vs coalface
- 144 pairs CPR/DNR
- 294 pairs extend life/relieve pain

Surrogate disagree with Pt but agree with self = Projection

Marks & Arkes (2008)

Patient & surrogate disagreement

- CPR
  - 90 of 144 projected
- Pain relief
  - 260 of those 294 projected
- No correlation: age/SES/culture

Marks & Arkes (2008)
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**Carergiver Burden**

**Sensitivity**
- This is my fifth case of MND this month!
- Our excitement & patient fear
- Empathy & experience

**Diagnosis & caregivers**
- Denial
- Loss
- Social stigma
- Isolation
Pressures on caregivers

- Depression
- Anxiety
- Fear
- Financial hardship
- Link to poor health outcomes

Pochard et al. (2005)

Caregiving for the dying can often help professional caregivers learn more about their patients and their profession. Dr. Pat Caralis sees her job as helping people take control of their dying. She believes that the first step is good communication. For professional caregivers in hospitals and other institutions, she says, the process begins with listening carefully to patients and their families who often face agonizing choices they may not fully understand.

PBS

What causes pressure?

- Amount of care
- Patient age
- More than 1 bed in room
- Physical burden
- Degree of impairment
- TBI, cancer

Haley et al. (2003)
Stancin et al. (2008)
Pochard et al. (2005)
Communication

- People are different
- Crisis affects understanding
- Quality affects right or wrong
- Must be broad based
- Clinicians must negotiate information giving
  - how much?
  - when?


Guilt & regret

- Explain surrogate decision making - again…
- No one person – team decides together
- Caregivers involved often carry guilt
- Even when clear clinical team made decision
- Then patient dies despite decision

Cox (2009)

Letting go

- Saying goodbye
- Having a voice
- Relief of physical symptoms
- Companionship

Fine & Peterson (2002)
Seedhouse Grid


Cox, J. (2009). Making the healing difference: guilt and regret. American Journal of Hospice & Palliative Medicine, 26(1), 64-65


