



**Ethics in Practice:**  
what can we learn from the end of life?

Paula Leslie



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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?

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### Values

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

*ChangingMinds.org (2008)*

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### Morals

- Society's standards: right & wrong
- More about *good & bad* than other values
- Judge others on morals
- "Immoral" person
  - but no word for not respecting values
- Tend to be externally imposed

*ChangingMinds.org (2008)*

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**Ethics**

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

*ChangingMinds.org (2008)*

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**My biases**

- Racism
- Religion
- Motivation

*Do they affect my clinical care - subconsciously?*

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**Medical ethical principles**

- Autonomy
- Beneficence
- Nonmaleficence
- Justice

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**Autonomy**

*Respect another's worth & right to make choices*

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**Autonomy**

*Respect another's worth & right to make choices*

- Accept that patient may choose not to have aggressive health intervention
- Understand that patient may value eating a little with family despite risk of choking

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**Beneficence**

*Take positive action to do good for others  
AND act to prevent or remove harm*

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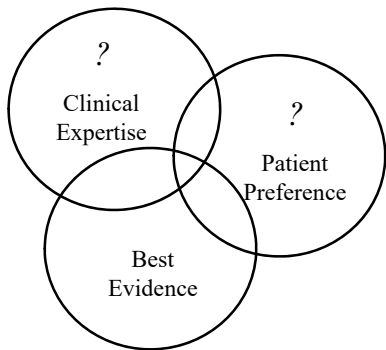
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### Evidence Based Practice



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### Best evidence

- Not always randomized control trials
- Some evidence is better than others
- Get trained in how to judge papers
- How robust was study?
- Are participants like my patients?
- Was there bias?

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### Evidence Based Practice

- Best available evidence
- Plus informed clinical judgment
- Plus patient's values & expectations

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**Evidence Based Practice**

- Patient's values & expectations
- Plus informed clinical judgment
- Plus best available evidence

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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

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**ASHA support**

- Code of ethics
- Issues in ethics statements
- ASHA sanctions for violations

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### Documentation

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

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### ASHA Principle Iκ

“Individuals... shall evaluate the *effectiveness* of services provided, technology employed, and 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 *advance directives*?
- TALK TO...

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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)*

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### 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

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### 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*?

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### What can tubes do?

- ? Nutrition
- ? Hydration
- ? Aspiration
- Quality of life?
- Patient perception *(Anis et al, 2006)*
  - families & patients felt it helped with nutrition

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### 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

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### Evidence Based Practice



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**Ethics in Practice:**  
what's really important?

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Paula Leslie


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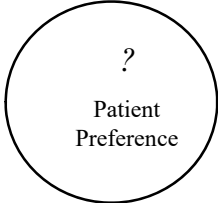
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**Evidence Based Practice**



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Patient  
Preference

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**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'

Koffman (2008)

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## **Trial by God**

- Patient's perspective affects
  - how patients can deal with distress
  - clinical assessment
  - perceived "compliance" with treatment

*Koffman (2008)*

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## **Patient values & beliefs**

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

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## **misUnderstanding**

- We talk of patient compliance
- Compliance = agreement

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Patient Wishes

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**Advance directives**

- You must check your State Laws
- [www.caringinfo.org](http://www.caringinfo.org)
- Establish if your patient made advance health intervention instructions
- Discuss with caregivers & clinical team

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**ARKANSAS  
Advance Directive  
Planning for Important Health Care Decisions**

*Caring Connections  
1731 King St., Suite 100, Alexandria, VA 22314  
[www.caringinfo.org](http://www.caringinfo.org)  
800/658-8898*

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer engagement initiative to improve care at the end of life.

**It's About How You LIVE**

*It's About How You LIVE* is a national community engagement campaign encouraging individuals to make informed decisions about end-of-life care and services. The campaign encourages people to:

- Learn about options for end-of-life services and care
- Implement plans to ensure wishes are honored
- Voice decisions to family, friends and health care providers
- Engage in personal or community efforts to improve end-of-life care

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## Types of advance directive

- Living Will
- Durable Power of Attorney
- Federal law provision

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## Living will

- 50 states each with own conditions
- Instructions to medical team
- Treatment
  - discontinuation - coma
  - suspension - artificial nutrition
  - maintenance - pain killers
- Organ donation

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## Durable power of attorney

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

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## Health care proxy

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

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## 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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## PREPARE

- [www.prepareforyourcare.org](http://www.prepareforyourcare.org)

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### Advance directives & dementia

- Who makes advance directives (ADs)?
- Which medical conditions?
- To restrict or request intervention?
- Factors in dementia?

*Triplett et al (2008)*

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### Advance directives & dementia

- 81 of 123 nursing home residents had ADs
- 70 named proxy
- 45 deferred decision to proxy
- 1 gave power to physician
- 8 shared thoughts of process
- DNR not linked to those with ADs

*Triplett et al (2008)*

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### Who & what?

- White & well educated
- Cancer more than dementia
- Restrictions rather than requesting more
- Dementia is interesting
  - PROGRESSIVE decline to point where?
  - AND patient becomes?
  - SO more decisions?

*Triplett et al (2008)*

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### **Caregiver involvement**

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

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### **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)*

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### **Patient & surrogate disagreement**

- CPR
  - ? of 144 projected
- Pain relief
  - ? of 294 projected
- No correlation: age/SES/culture

*Marks & Arkes (2008)*

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**Carergiver Burden**

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**Sensitivity**

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

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**Diagnosis & caregivers**

- Denial
- Loss
- Social stigma
- Isolation

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## **Pressures on caregivers**

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

*Pochard et al (2005)*

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## **What causes pressure?**

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

*Haley et al (2003)  
Stancin et al (2008)  
Pochard et al (2005)*

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## **Communication**

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

*Azoulay (2000) & Ethical issues in dementia care (2006)*

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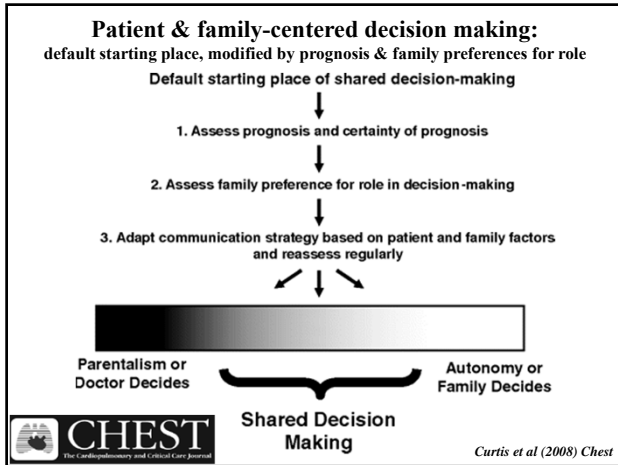
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**Guilt & regret**

- 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)*

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**Letting go**

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

*Fine & Peterson (2002)*

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# Seedhouse Grid

