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Ethical Practice in Aging Care

Amber B. Heape, ClinScD, CCC-SLP, CDP

Moderated by: Amy Natho, MS, CCC-SLP, CEU Administrator, SpeechPathology.com

continued

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continued

Ethical Practice in Aging Care

Amber Heape, ClinScD, CCC-SLP, CDP



Learner Outcomes

- Identify major principles of bioethics and how they apply to clinical practice.
- Explain each principle of bioethics in order to apply them to the practice of speech-language pathology.
- Describe how to apply ethical principles to everyday practice situations.

continued

What are Ethics?

- "A moral philosophy and/or a set of moral principles that determine what is right, good, virtuous, true, and just, as defined by a culture or society" (Kummer et.al, 2011)
- The "invisible line" that healthcare professionals keep as the boundaries of acceptable behavior (Hasselkus, 1997)



continued History of Ethics in Healthcare

- Dax Cowart (1973)
 - Burned in an accident and asked for treatment removal multiple times
 - Decision making abilities were questioned
 - Became an attorney to advocate for patient right to refuse treatment
- Karen Ann Quinlan (1975)
 - Hospital refused to remove vent though parents requested
- Nancy Cruzan (1983)
 - In persistent vegitative state, parents wanted artificial nutrition removed.
 Supreme Court refused stating there was insufficient evidence on the patient's wishes
- Terri Schiavo (2005)
 - Husband vs. Parents
- Andrea Rubin (2014)
 - Burned in accident. Father was surrogate decision-maker and ordered treatment to continue, despite Andrea's request not to.
 - After recovery, Andrea acknowledged that her decision-making capacity was limited by the extreme circumstances and that the team did right by continuing treatment. (Gerrek, 2018)

continued

Questions We Ask...

- Is what I am facing an ethical dilemma?
- How do SLPs know what is right for every ethical dilemma?



First Step....

- Gather all the facts!
 - Includes facts, risks, patient beliefs...
- Person centered care ...consider contextual factors

continued

Ethical Considerations in Aging

- There are 4 areas in which every ethical problem in healthcare should be judged using the principles of bioethics:
 - Medical Indications
 - Patient Preferences
 - Quality of Life
 - Contextual Features (social, economical, legal)

(Mueller et.al, 2004; University of Washington, n.d.)

continued

Medical Indications

- Medical Facts
 - Diagnosis
 - Prognosis
 - Interventions indicated
- Always ask the question.....what is the purpose of the medical intervention?

continued

Patient Preferences

- What does the patient want?
 - Goals
 - Personal assessment of benefit vs. burden
 - Cultural factors often influence
- Ethical Questions
 - Is the patient competent to make a decision?
 - Does the patient truly understand the options?
 - Is the patient being coerced?
 - Who makes the decision if the patient can't



Quality of Life

- What does QOL mean?
 - Different for different patients
- Ethical Questions
 - Is our perception of QOL the same as the patient's?
 - Is there bias or prejudice in our decision-making?

continued

Contextual Features

- Patient care may be influenced (positively or negatively) by contextual features
 - Financial constraints
 - Social factors
 - Emotional involvement
 - Legal ramifications
 - Scientific practice
 - Religious beliefs
 - Cultural factors



Let's judge a scenario using these 4 factors

Dementia and dysphagia

continued

Scenario

Sandra is a 80 year-old female living in a long-term care setting. She has a diagnosis of end-stage Alzheimer's Disease and has drastically decreased PO intake over the course of the past 3-4 months. Her weight loss is not yet considered severe, but is on a steady downward trend. Sandra's family tries to visit daily and constantly pushes her to eat, even when she refuses. In a family meeting, Sandra's son expresses that he's worried that his mom will starve and wants to have a feeding tube inserted to give her nutrition. Her daughter isn't so thrilled about this idea, worrying that Sandra will not survive a procedure like this. Sandra has a DNR but does not have a living will stating her wishes, nor does she have a designated medical POA. The son and daughter are both considered next-of-kin.



Medical Indications- Questions to ask...

- What is the purpose of the tube?
 - Is it to prolong life?
 - Does scientific evidence actually support this?
- What risks increase with the use of the PEG?
- Do the risks outweigh the benefits?

continued

Patient Preferences-

- Sandra doesn't have a living will, so who makes that decision?
- Is Sandra capable of giving any input?
- Can either child recall a conversation with Sandra before her decline on this topic?



Quality of Life

- Will this feeding tube increase quality of life, or will it even prolong life?
- Will placing this tube make staff less likely to encourage PO intake, including pleasure foods?
- How does this affect her relationship with her children?

continued

Contextual Features

- Financial- Is the facility pushing the PEG placement for reimbursement purposes?
- Resource allocation (Walker, 2016; Mueller et.al, 2004)
- Neither child has a POA, so what occurs when they disagree?
- Does the patient's cultural, religious, or social background have a specific belief system on feeding tubes?



What could change our answer to the scenario?

- Different disease process or stage of AD
- Advance directive present
- Younger patient? (Ageism?)
- Desires of family
- Religious/cultural values

continued

Limit Personal Opinions

- Present all options
- Assess risk vs. benefit
- Ask about QOL
- Be sure that family knows their decision is supported, whatever it may be
 - Approximately 66% of feeding tube decisions in patients with advanced dementia are influenced by the interaction with the SLP (Waters et.al, 2012; Shega et.al, 2003)



Principles of Ethics

- Nonmaleficence
- Beneficence
- Respect for Autonomy
- Justice
- Dignity

continued

Nonmaleficence- "Do No Harm"

- How can SLPs harm patients?
- "Principle of Double Effect"
 - A single action may have more than one effect (positive or negative), so choose the lesser of 2 evils (good outweighs bad)
 - Painful procedures may prolong life
 - DNR for patients with terminal conditions
 - Non-recommended diet and patient quality of life



Violation of Maleficence

• A therapist is new to her current role, and has not yet had training in NMES, nor has she ever used this modality. An order from the MD for that is written that specifically states NMES is included, because the family heard it may help from a family friend. The therapist provides the NMES, despite not having training demonstrated competence, and causes skin breakdown on the patient.

continued

Beneficence- "Do Good"

This may include:

- EBP
- Treating when there is a disorder
- Always remembering the patient's best interests
- Removing the patient from harm, reporting abuse/neglect/poor care

At what point do efforts become futile and non-beneficial? (Leslie et.al, 2014)



Violation of Beneficence

A patient presents with severe Broca's aphasia post-stroke. You have never treated a patient with this severity, so you use your normal workbooks and try to make the best of the treatment time.

continued

Respect for Autonomy

- Patients' right to choose
 - Name they are called
 - Clothes they wear
 - Life-saving procedures
 - Diets
 - Communication modality
 - Refusing medical care



Violation of Respect for Autonomy

• The SLP is working with a patient who often refuses to consume the recommended diet. The patient understands the risks of his choice, and the interdisciplinary team meets to discuss. They allow the patient to make a choice to consume specific foods, understanding the risk involved. The facility, however, refuses to provide the patient with his chosen diet. They say the patient can only have those foods if the family brings them in.

continued

Justice

- Providing what our patients are owed, or what they deserve
- Treating all people fairly, equally, and impartially
 - Allocation of resources
- Treatment provided by students?



Violation of Justice

 A Speech-Language Pathologist is told by her administrator that she is only allowed to treat a patient who has a certain type of insurance once per week, and only for 15 minutes.

continued

Dignity

- Patient right to be treated with dignity is a major focus of many organizations.
- HIPAA plays a major role in dignity!
- Do we recognize that our patients are people?
- We work where they live!
- Dignity can be influenced by seemingly small actions



Violation of Dignity

• Viola is a 65 year old woman with Parkinson's disease. She has tremors in her hands, but prefers to be as independent as possible with her ADLs. Viola is often the last person in the dining room, as meals frequently take her 45 minutes or more to complete. One day, you see a staff member go over to Viola and say "Here, just let me feed you. It will take less time for you to eat that way."

continued

Interactive Case Studies

You will see a scenario related to SLP, and will be asked to check any/all ethical principles that apply to this situation.



Interactive Case Study 1

Tracy is a 40 year-old female admitted to your rehab center after an accident with resulting traumatic brain injury. She is not eligible for Medicare rehabilitation and does not have private insurance. Therefore, the facility will have to absorb any cost of therapy. The administrator has made it clear that the patient is to get as little therapy as possible, since it will cost the facility. Tracy has severe dysarthria and is unable to express wants/needs or pain verbally. She also has pragmatic language difficulties which affects her social interactions with other residents.

Your rehab manager tells you that you must provide Tracy therapy only in group format, since you will not be reimbursed. This will be limited to twice per week.

continued

Which Principle(s) of ethics are involved in this scenario? (check all that apply)

- Nonmaleficence
- Beneficence
- Respect for Autonomy
- Justice
- Dignity



Principles of Ethics-Questions to Ask

- Nonmaleficence- Will this patient be harmed by not having individual therapy?
- Beneficence- Are we doing the right thing with treating a specific number of times per week?
- Respect for Autonomy- Does the patient want therapy?
- Justice- Do we treat this patient any differently due to payer type?
- Dignity- Will treatment make a difference in the patient's dignity or social ability?

continued

Interactive Case Study 2

You are a SLP in a skilled-nursing facility that also admits patients for Medicare Part A rehab. With PDPM approaching and the increased revenue potential if patients are on altered diets, nursing has begun to automatically place every new admission on mechanical soft until speech therapy evaluates the patient (capturing the altered diet even if you upgrade on eval). You speak to the director of nursing, but she justifies their actions by saying that they are just looking out for patient safety.



Which Principle(s) of ethics are involved in this scenario? (check all that apply)

- Nonmaleficence
- Beneficence
- Respect for Autonomy
- Justice
- Dignity

continued

Principles of Ethics-Questions to Ask

- Nonmaleficence- Will patients be harmed by having an altered diet?
- Beneficence- Are we doing the right thing by placing every patient on altered diets?
- Respect for Autonomy- Did the resident choose to have this downgrade with no dysphagia present?
- Justice- What is the motivation behind this?
- Dignity- Will being on an altered diet make a difference in the patient's dignity?



Interactive Case Study 3

Juan is a 60 year old male with recent CVA. His primary language is Spanish, and English proficiency is limited, more so since the CVA. Juan has been diagnosed with oral-pharyngeal dysphagia and is currently on a puree diet with honey thickened liquids. You cannot find a report of an instrumental evaluation in his discharge summary paperwork, so you do not know the exact deficits Juan has. He is non-compliant with this diet, as nursing has reported finding him at the water fountain between meals.

continued

Which Principle(s) of ethics are involved in this scenario? (check all that apply)

- Nonmaleficence
- Beneficence
- Respect for Autonomy
- Justice
- Dignity



Principles of Ethics-Questions to Ask

- Nonmaleficence- Will water between meals harm Juan? Does the facility have a free water protocol? Do we even know that the diet is the best for Juan?
- Beneficence- What is best for Juan, physically, socially and emotionally? Will this altered diet have a positive effect?
- Respect for Autonomy- What are Juan's wishes? Have the risks and benefits been explained to him in his native language? How do we go about that?
- Justice- Has Juan been provided with a translator in his native language? If not, why?
- Dignity- When Juan's family comes to visit and eat in front of him, what does that do for his dignity?

continued

What Ethical/Professional Codes or Guidelines Do We Adhere To?

- ASHA Code of Ethics
- State Boards- Practice Acts
- Organizational Codes of Conduct within our Employers
- Guidelines from Payer sources



Consequences?

- Education, Probation, Suspension, Termination
- Loss of License
- Censure/Revocation of CCC
- Legal consequences
- Fines
- Criminal charges

continued

Final Thought...

"How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving and tolerant of the weak and strong. Because someday in your life you will have been all of these."

-George Washington Carver



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