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Our Aging Patients

How to Handle End-of Life
Conversations with Patients and
Their Families

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Learner Objectives

After this course, participants will be able to:

- Identify ethical considerations for therapists working with patients nearing end of life.
- List at least 3 opportunities within the scope of practice for SLPs working with patients at end of life.
- Describe how to implement cultural diversity for effective patient and family education.

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**“Somebody should tell us,
Right at the start of our lives, that we are
dying.
That we might live life to the limit,
Every minute of every day.
Do it! I say.
Whatever you want to do, do it now!
There are only so many tomorrows.”
-Pope Paul IV**

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End of Life- Ethical Considerations

- University of Washington- Dept of Bioethics states that there are 4 topics by which every ethical problem should be judged
 1. Medical Indications- Purpose of the intervention
 2. Patient Preferences- What does the patient want?
 3. Quality of Life- How will this improve QOL?
 4. Contextual Features (social, economical, legal)

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Basic Ethical Principles

- Nonmaleficence- “do no harm”
- Beneficence- “do good”
- Respect for Autonomy- “patient has a right to choose”

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End of Life Decisions Right to Refuse Life-Sustaining Treatments

Cases such as:

- Karen Ann Quinlan (1975)
 - Hospital refused to remove vent though parents requested
- Nancy Cruzan (1983)
 - In persistent vegetative 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
- Dax’s Case

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Advanced Directives- Planning for Healthcare Decisions

May include:

- **Living Will**
 - Establishes a framework for an individual's wishes in different scenarios
 - May state patient wishes on ANH, Life support, etc.
- **Healthcare Power of Attorney (POA)**
 - Person appointed to make medical decisions in case of incapacitation
- **HIPAA Authorization**
 - Who can obtain records/information
- **Do Not Resuscitate Order (DNR)**
 - No resuscitation efforts made if respiratory failure or cardiac arrest occur

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Estate Planning- Financial and Material Possessions

Not related to SLP, but may include:

- **Financial POA**
 - Person who acts on behalf of another's financial interests (with or without incapacity, according to paperwork)
 - Durable POA- in event of incapacitation
- **Last Will and Testament**
 - Who administers the estate (executor)
 - Passing Property, finances, stocks, etc. to persons or charities of one's choice
- **Appointment of Agent to Control Disposition of Remains**
 - Since wills may take a month or more to go through probate court, this allows a person to be deemed responsible for burial, cremation, etc.

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Role of Healthcare Professionals in EOL Decisions

- Abide by patients' directives
- Support families emotionally, while continuing to abide by patients' wishes
- If questions exist, educate families on choices within boundaries
- Be an essential part of the TEAM that looks at the whole picture
- At end of life, help with comfort and quality

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Hospice

- "Death with Dignity"
- Holistic care for patients with terminal illness and their families
- Patient admitted to hospice is re-evaluated in 6-month intervals and may be discharge if improved or prognosis is no longer 6 months or less
- Focus is on medical service, tending to disease processes, pain management, comfort care, bereavement support for families
- May be provided at home, SNF, AL, hospital, or hospice facility

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Role of SLP- PEG tubes

- Controversial whether they are effective or not
- In most settings, SLPs cannot write an order for NPO. Why?
- Are we considering the patient's cultural background and expectations?
- What alternatives are we providing (strategies to decrease aspiration risk, etc.)?

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Artificial Nutrition/Hydration (ANH) in the form of PEG Tubes- Ethnicity

- African Americans have higher rates of ANH than non-minorities (1.5 to 9.4 times as high, depending on the study)
- Hispanic and Asian Americans also have higher rates of ANH
- American Indians and European Americans (Non-Hispanic Whites) are about equal

(See reference section for additional resources)

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ANH- Other Factors

Teno et. al (2010) reported that additional factors leading to an increased prevalence of feeding tubes included:

- Larger size hospitals
- For-profit institutions
- Urban areas
- Associated with a medical school
- More critical care units (ICU)

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Counseling....as the SLP

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Counseling Patients and Families

Families with loved ones nearing end-of-life may experience:

- Fear of the Unknown
- Anticipatory Loss and Grief
 - Grieving before death
- Sociocultural Pressures
 - Stigmas, stereotypes, cultural beliefs

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Counseling or Instruction?

- Instruction- telling
- Counseling- speaking and listening (exchange)
- Guidance- educational process in which advice, suggestions, information given (how to communicate with patient, feed patient, etc.)

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Guidelines for Clinical Interaction (Toner and Colleagues)

- Use Clinical Interaction Time Wisely
- Know what's normal
- Learn about the individuals involved
- Create therapeutic partnership
- Develop and maintain trust
- Adapt to needs and concerns as they evolve
- Adjust and support communication

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Cultural Diversity and Counseling

- Ethnicity
- Socioeconomic status/ social class
- Religion/spirituality
- Geographic (urban/rural)
- Sexual orientation
- Ability status

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How Do We Become Culturally Competent Counselors?

1. *Remove the "invisible veil."* Recognize that there are differences, and no culture is superior. Confront your own bias, potential stereotypes, and values.
2. *Cultural Knowledge-* Familiarize with key historical events and social movements that may have impacted attitudes and values of different groups
3. Commit to lifelong learning to recognize and value cultural differences
4. Form relationships with sources valued by the culture in order to gain help. Refrain from being culturally encapsulated.
5. *Cultural Skills-* use individualized interventions based on patient/family needs

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Qualities of a Good Counselor

- Credibility
- Expertness
- Trustworthiness
- Validating

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Cultural Expectations (Payne, 2015)

Ethnic Group	Expectations
Non-Hispanic Whites	Assertiveness in counseling needs and effective verbal communication. Caregiver will confront clinician if they do not agree.
African Americans	Expect it to take time to build trust in order to become more personal. Respect is important. Omissive approach to handling caregiver stress
Hispanic Americans	Burden is "God's will" Counseling is for lazy or inept. Limited-time education or counseling to focus on problem at hand.
Native Americans/Alaskans	Expect caregivers to be passive. May avoid revealing personal information. Silence indicates disagreement.
Asian Americans	Expect to build a personal relationship and trust. Extremely private about information. Clinician uses authoritative manner to build confidence
Middle Eastern Americans/Muslims	Gender may be an issue. Same-gender counselors preferred. Woman may defer to husbands. Avoid direct contact with opposite gender. Personal problems are taken care of in the family. Negative information should be presented carefully and in stages.

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Culturally Competent Counseling at End of Life

- Validate the patient/family's feelings
 - Affirm their right to those feelings, whether you believe they are right or wrong.
- Provide an educated overview of options pertinent to your scope of practice
- Respect the decision made by the patient/family (autonomy)
 - Understand that cultural considerations are significant, and we may not always understand those

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“There are only four kinds of people in this world—those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who need caregivers.”-
Former First Lady Rosalyn Carter

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