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End-of-Life Care for the SLP Part 2: Roles, Responsibilities & Ethics

Amanda Stead, PhD, CCC-SLP

Moderated by:
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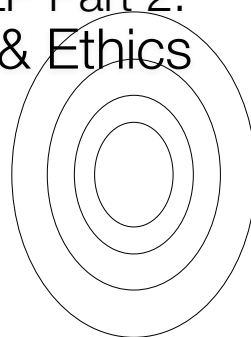
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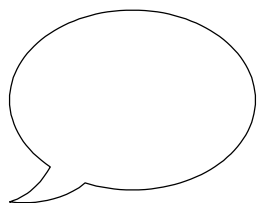
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End-of-Life Care for the SLP Part 2: Roles, Responsibilities & Ethics



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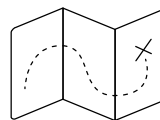
Amanda Stead, Ph.D., CCC-SLP,

Associate Professor CSD
Pacific University

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Learner Outcomes

- Explain key concepts of ethical principles as they relate to dying patients.
- Identify key components and factors in care planning documentation.
- Describe the role of the SLP and other key professionals in end-of-life care.



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Ethics in EOLC

continued

“With the availability of increasingly sophisticated health care technology, end-of-life care presents unprecedented ethical challenges for individuals, families, health care professionals, and policy makers. The role of health care professionals and the use of these technologies are changing how death, dying, and end-of-life care are viewed and managed.”

continued

Autonomy 101

There are four basic elements of autonomy (Burkhardt & Nathaniel, 2013; Jech, 2000):

1. Autonomy implies respect for the individual.
2. Individuals must be capable of determining their personal goals.
3. Individuals have the capacity to decide up on a plan of action for care. They must be able to understand the meaning of their choice, must be able to select from alternatives, and must be able to understand the consequences of their choice.
4. Individuals have the freedom to act upon the choices they have made.

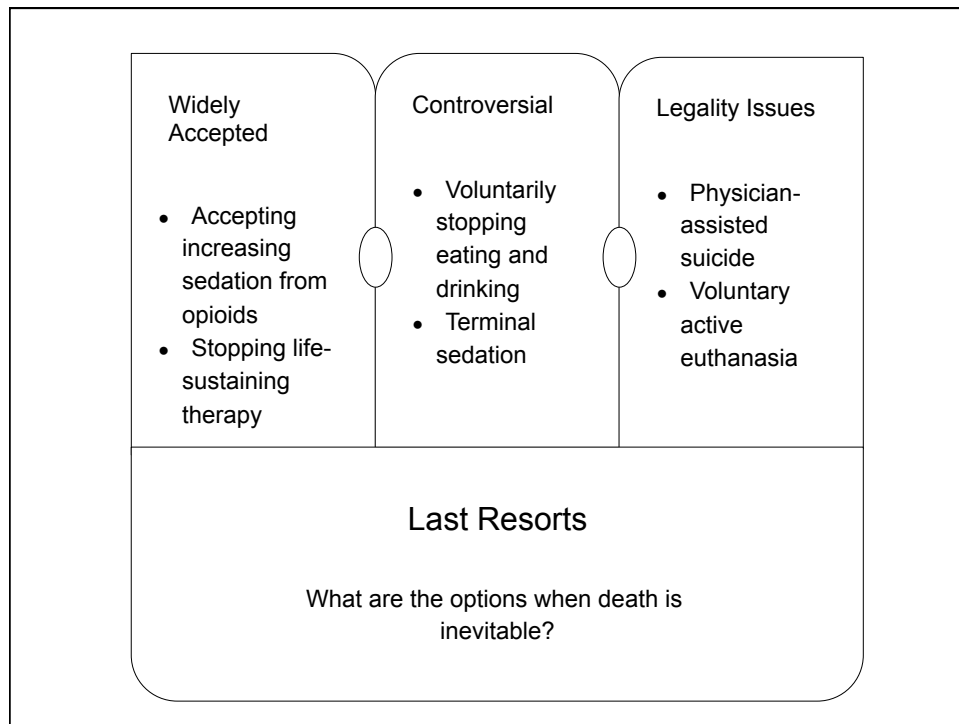


Violations of Autonomy

Health care providers can mistakenly violate a patient's autonomy when they do any or all of the following (Burkhardt & Nathaniel, 2013):

- Mistakenly assume that the patient has the same values and goals as they do
- Fail to recognize that the patient's thought processes may be different from their thought processes
- Fail to understand the patient's level of knowledge about his or her disease or illness
- Fail to treat the patient as a person instead of a "job" that has to be completed before their shift ends





Ethics Dilemmas

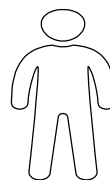
Neighbors (2011) presents many ethical dilemmas for health care providers, including the following:

- Who should be resuscitated?
- In what circumstances should life be prolonged?
- Who should make the decision to prolong life with extraordinary measures (such as feeding tubes or ventilators)?
- Who should make the decision to discontinue these extraordinary measures?
- How should healthcare professionals be involved in these decisions?
- Should decisions of such a personal and private nature be left to the courts? If not the courts, then by whom should the decisions be made?



Case Study

An elderly woman told her daughters that if she ever ended up with dementia she wouldn't want to live like that. Years later she developed senile dementia and her daughters had her move into a nursing home. Although she did not recognize family or friends, she enjoyed the company of others and the nursing home's cat. When she stopped eating, her daughters were asked whether she should receive a feeding tube



Futility

- What constitutes futile intervention remains a point of controversy in the medical literature and in clinical practice
- Use of life-sustaining or invasive interventions in patients in a persistent vegetative state or who are terminally ill may only prolong the dying process.
- These controversies arises when the patient or proxy and the physician have discrepant values or goals of care

continued

Case Study - Futility

An elderly man who lives in a nursing home is admitted to the medical ward with pneumonia. He is awake but severely demented. He can only mumble, but interacts and acknowledges family members. The admitting resident says that treating his pneumonia with antibiotics would be "futile" and suggests approaching the family with this stance



continued

Documentation

continued

The Five Wishes

The Five Wishes includes documentation on the following
(Kuebler, Berry, & Heidrich, 2002):

1. The person chosen by the patient to make care decisions for the patient when he or she cannot
2. The kind of medical treatment the patient wants or doesn't want
3. How comfortable the patient wants to be
4. How the patient wants people to treat him or her
5. What the patient wants his or her loved ones to know



Why Facilitate This Conversation

- Giving the person a sense of control in the dying process.
 - Advance care planning ensures that the patients goals will be followed should the patient become incompetent.
- Reflecting clearly the patient's personal values and goals for terminal care.
- Enabling patients to anticipate and consider aspects of the dying process that they might not have considered previously.
 - This may help patients think about goals that they otherwise might not have considered (i.e., a last trip to visit family, writing a will, etc.).



Why Facilitate This Conversation

- Facilitating communication with significant others.
 - Making sure their family is taken care of.
 - Make it easier for surrogates to act in keeping with patients' goal should they need to make decisions for them.
- Allow the identification of the patient's preferred spokesperson (health care proxy)



“I have an advanced directive
not because I have a serious
illness, but because I have a
family”

-Ira Byock MD

Advanced Directive

- Written legal documents that state your wishes if you can no longer speak for yourself.
- With these documents in place medical personnel and loved ones don't have to guess what you would prefer or make decisions you would not want for yourself.
- Since advance directives cannot predict every clinical scenario you may be part of in the future, choosing a health-care proxy in most situations is more helpful.



Advanced Directive

- | | |
|-----------------|-----------------|
| ▪ Resuscitation | ▪ Narcotic Pain |
| ▪ Ventilation | Control |
| ▪ Non-oral | ▪ Dialysis |
| feeding | ▪ Special |
| ▪ Artificial | Circumstances |
| hydration | |



Health Care Proxy

- Names someone to make medical decisions for you when you are not able to make such decisions.
- This person should be someone you trust, who knows what treatments you would want or would reject, and who will respect these preferences.
- Your proxy does not have to receive specific instructions from you and can make decisions as if he were in your situation, but conscious and able to communicate.



DNR

- A do not resuscitate order instructs medical personnel not to bring you back to life if you stop breathing or your heart stops.
- CPR can often involve more than just chest compressions and mouth-to-mouth resuscitation.
- Although CPR can save lives, it frequently does not work. Even if a person is resuscitated, they may suffer painful injuries during CPR or may be left in a worse condition than before.
- People with terminal illnesses or other serious medical conditions might not want to have CPR performed on them, even if that means they might die as a result.

continued Case Study

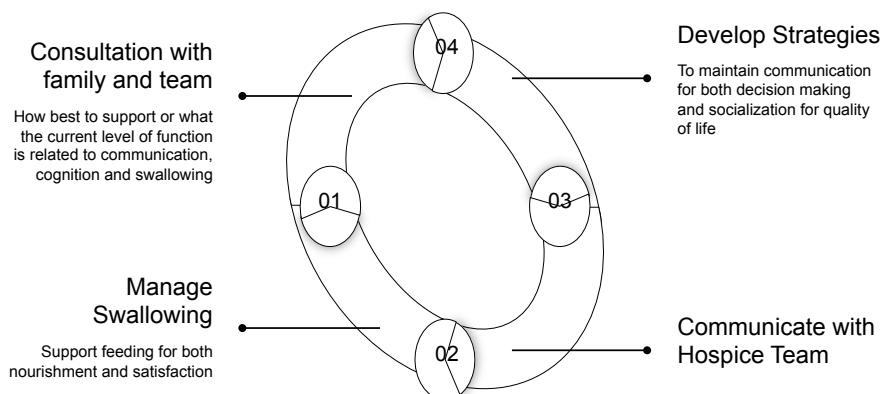
Alice is a 81-year-old who resides in an assisted living facility. When her health condition was determined to be terminal, an slp is called in to consult and support Alice in her swallowing abilities. After extensive cancer treatment Alice's swallow was impaired and she was losing weight. The slp worked with Alice to modify her diet as was acceptable to her. During the discussions and evaluations of Alice's swallow the slp got to know her well and took the opportunity to discuss her end of life decisions. Because Alice wanted to eat food that was not necessarily safe for her, the slp documented her wishes in regards to her oral intake. The slp then inquired about her wishes in regards to IV hydration and non-oral food intake. This opened the door to a more general discussion about end-of-life care. The slp recorded the wishes of Alice and made copies for her chart, her home, her family, and her doctor. The management of Alice's swallow impairment provided an opportunity to discuss and document Alice's wishes in regards to not only the management of food and water intake, but also her wishes regarding other medical decisions and proxies.

continued Case Study

Amelia is a 67-year-old woman who has recently be diagnosed with early stage Alzheimer's disease. Upon her diagnosis she sought support for her memory and cognition from her primary care physician who referred her to a speech pathologist. Upon meeting with the slp a discussion took place as to her goals for therapy and her reason for referral. The slp then asked Amelia if she had an AD in place. Initially, Amelia was shocked and angry and did not wish to discuss it. Throughout the short course of her treatment addressing living independently, Amelia became concerned with how she could remain independent across the disease course. On the last day of treatment Amelia and the slp were discussing her future plans. The slp asked what her fears were and also what her goals were. She replied that as long as she was still able to meaningfully interact with her grandchildren she would feel content. The slp then asked about her worries, and Amelia stated she was concerned about being incontinent and living in "locked-unit." The slp then asked her if she wanted to document these fears and wishes. After Amelia realized that an AD is in place to help honor her wishes she became more open to the idea of filling on out. The slp helped Amelia document her basic wishes and passed a copy onto her doctor.

Roles & Responsibilities of SLPs

Role of the SLP



Pollens (2004)

Supporting Communication

- Training Carepartners
- Supported Communication
- External Aids
- AAC
- Accessibility



Feeding & Swallowing

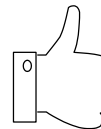
- Caregivers and family connect food with comfort and care
- Dysphagia is a poor prognostic sign
- Adherence to recommendations for safe swallowing is problematic.
- Patients often choose not to alter their diet consistency, and
- serious illness may impact their vigilance and attention to treatment recommendations
- *We are a partner in decision making



Hawksley et al., 2017; Goldsmith & Cohen, 2018

Reimbursement

- Hospice benefits include speech-language pathology services:
 - "for purposes of symptom control or to enable the individual to maintain activities of daily living and basic functional skills" (Sec. 230.1.I of the Medicare Hospice Manual).
- In addition, Medicare has alerted claims reviewers that they cannot automatically deny a claim based on a diagnosis of dementia. This allows for the provision of reasonable and necessary skilled services to those patients with dementia who can benefit from them.



Other Professionals Roles

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Primary Team

- Physician
- Nurse
- Care Coordinator
- Hospice/ Palliative
team Volunteers
- Carepartners

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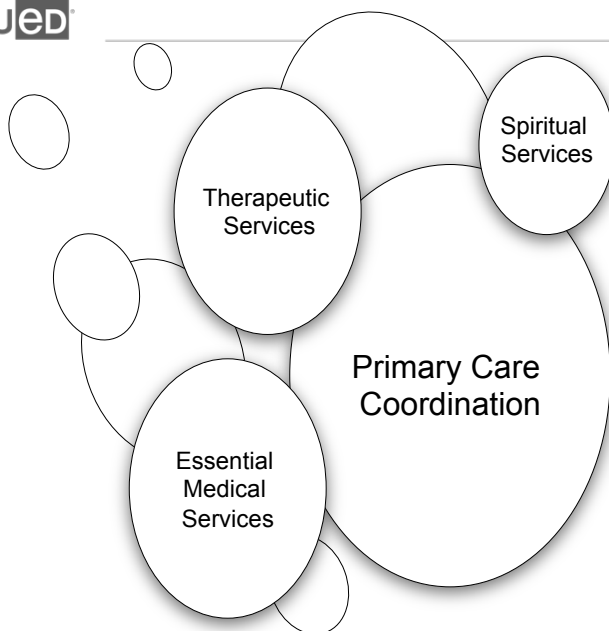
Frequent team members

- Psychologist
- Physical Therapist
- Occupational
Therapist
- Speech Therapist
- Chaplain

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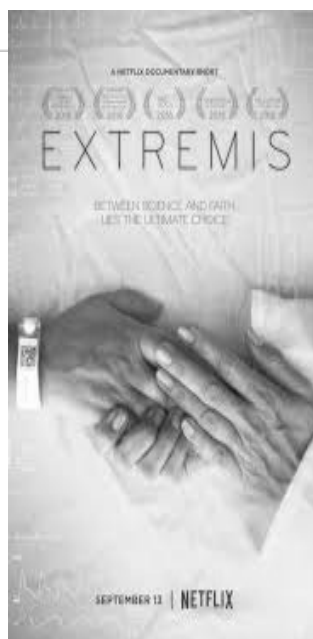
Frequent team members

- Nutritionist / Dietician
- Pharmacist
- Social Workers
- Alternative providers
- Counselors



continued

Extremis:
A Netflix
Documentary



continued



Thanks!

Any questions?

You can find me at

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continued

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