Dysphagia Management in Hospice: Continuum of Care by the SLP and Related Professionals

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Financial Disclosure

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▪ We declare that we do not have any financial relationship in any amount, occurring in the last 12 months with a commercial interest whose products or services are disclosed in this presentation.

Learner Outcomes

▪ Describe hospice and the classification for speech language services.
▪ Discuss how patients are eligible for hospice services.
▪ Discuss the role of the speech language pathologists in hospice.
▪ Describe an SLP hospice plan of care for service.
▪ Describe biopsychosocial assessment.

Quote

You matter because you are you, and you matter to the end of your life.

-Dame Cicely Saunders, Founder of the Hospice Movement
**Presentation Highlights**

1. Steps in Intervention
   - Views of hospice care
   - Who is responsible?

2. End of life issues
   - Pleasure eating
   - Dysphagia and Hospice Care
   - Hospice eligibility and Care Plans

3. Biopsychosocial Assessment
   - 4 levels of care for better outcomes for treatment

**What is hospice?**

A philosophy of care that provides comfort as life nears its end, rather than heroic lifesaving measures when they no longer offer any promising outcomes.

**Hospice Care**

- Goal is comfort at the end of life for those with a terminal illness for whom there is little to no curative alternatives.

**The Hospice Team**

- Patient and Family
- Volunteers
- Clinical social Workers
- Chaplains
- Physicians
The Facts

Although a large majority of Americans say they would like to die at home...a majority of deaths still occur in hospitals.

Profession of Speech Language Pathology

•The SLP

Quote

“People are like stained-glass windows. They sparkle and shine when the sun is out, but when the darkness sets in, their true beauty is revealed only if there is a light from within.”

—Dr. Elizabeth Kubler-Ross

Dr. Elizabeth Kubler-Ross

•Dr. Ross Foundational Approach
Goals of Hospice

- Is to provide non-curative pain control and symptom management utilizing a patient-centered, community-based, multi-disciplinary approach which seeks to avoid inappropriate prolongation of the dying process

(Singer, Marks, & Kalter, 1999)

Palliative versus Curative Care

- Hospice care is appropriate when active treatment is no longer effective and supportive measures are needed to assist the terminally ill patient through the dying process.
- It offers the patient a supported and safe passage from life to death in a way that preserves dignity and important relationships.
**Hospice vs. Palliative Care**

**Hospice**
- You must generally be considered to be terminal or within six months of death to be eligible for most hospice programs or to receive hospice benefits from your insurance.
- Focus on comfort care
- Medicare hospice benefit

**Palliative Care**
- Any time during illness
- May be combined with curative care
- Independent of payer
- Complimentary therapies

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**8 Domains of Care**

- **Structure and Processes of Care**
- **Physical Aspects of Care**
- **Psychological and Psychiatric Aspects**
- **Social Aspects of Care**
- **Cultural Aspects of Care**
- **Psychological and Psychiatric Aspects**
- **Ethical and Legal Aspects of Care**
- **Patient and Family**
- **Community**

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**Hospice**

**Hospice philosophy**

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**Influential Factors to Consider for Dysphagia and Hospice Management**

- Disease
- Religion
- Culture
### Cultural Diversity and Dysphagia/Hospice Care

#### European American
- Favor directives
- Limit treatment at EOL
- Primarily future oriented
- Prefer direct eye contact
- Prefer large amount of personal space
- Value privacy
- Low to moderate amount of touching

#### Asian/Middle Eastern
- Protect pt. from bad news
- Family makes decisions
- Primarily present oriented
- Not likely to make direct eye contact with those perceived to be in authoritative positions
- Low volume
- Small amount of personal space
- Little touching in public

#### African Americans
- Object to limiting treatment
- Prefer aggressive treatment
- More likely dc’d to extended care
- When death inevitable, 2X as likely as Caucasians to request life sustaining treatment

#### Older African Americans
- May distrust healthcare system based on hx of segregation/discrimination
- Strong religious beliefs
- “Fictive kin” – people considered family but not linked by blood ties
- Primarily present oriented
- Not likely to make direct eye contact w those perceived to be authoritative
- Small amount of personal space

#### Native Americans
- Reject directives
- Tribal leader
- Self fulfilling prophecy
- Primarily present oriented
- Not likely to make direct eye contact w those perceived to be authoritative
- Small amount of personal space
- Use touch lightly

#### Hispanics
- Less likely to institutionalize, value touching
- More likely to use CPR, intubation, ANH than Caucasians
- Dr. knows best – Mexican Americans
- Religious – heavily influenced by Catholic beliefs
- Family makes decisions to spare pt. unnecessary pain
- Less likely to use hospice - denotes giving up
- Not likely to make direct eye contact w those perceived to be authoritative
- Small amount of personal space

#### Japanese
- May agree to ANH based on wishes of families/dr.
- Preference for natural death & fighting cancer valued as important
- 40% pts in survey prefer not being informed of bad news
- 1 study – 30-50% general public said ANH is minimum standard of care
- 30% believed ANH relieves symptoms
- 32% allowing pt. to die under dehydrated conditions is ethically impermissible

#### Chinese
- Eating is as important as the emperor
- Worry pt. will starve to death and become a “starving soul” after death
- Utilize TCM = traditional Chinese medicine
- Herbal remedies
- Eldest male child is primary decision maker
- Decision inclined toward family’s best interest, but perhaps not pt.’s.
- Provision of food/water is basic act of caring
- Feeding has powerful symbols & social significance
- Many believe ANH prevents dehydration/starvation
Living with Grief: Ethical Dilemmas at the End of Life

- Hospice Foundation of America
- Asians/Latinos living in US want everything done
- 6 yr. study in N. California: ANH at death in Hispanic/Asian/Pacific Islanders 5.2 times that of non-Hispanic Caucasian group
- In North America, withholding diagnosis from pt. may be grounds for legal action
- Chinese, East Indian, Filippino, Hmong, Iranian, Korean, Latino, Russian, Vietnamese prefer family spokesperson be informed first before pt. is told

Standards of Care

SLPs question
- Lack of outcomes data for other options
- Continued hand feeding
- Time limited trial and withdrawal of PEG
- Forgoing food and fluid
- Uncertain outcomes w/peg > certain death
- Discomfort w/letting pt. die
- Uncertainty w/role in suggesting palliation

Pt. Preferences
- If there is something to fix, fix it
- Must consider
- Culture
- Religion
- Individual differences in perception about feeding

4 Levels of Care

- Routine Care
- Inpatient Care
- Continuous Care
- Respite Care

Utilization of Therapy Services, cont.

Hospice
- SLPs obtain orders and make arrangements for therapy services.

- Therapy services, goals, duration, and interventions will be included in the integrated plan of care and in the hospice progress notes.
Utilization of Therapy Services, cont.

**SLP and Hospice Collaboration**

- Scope and frequency of therapy services will be agreed upon and documented.
- Both will monitor the efficacy and communicate recommendations.


Responsibilities at the Time of Death

*Collaboration is critical during this time!*

Determine in advance who is responsible for notifying the physician, pharmacy, mortuary, and coroner (per county procedure).

Biopsychosocial Assessment

- Review and discuss physical and psychological stages of the dying process
- Physical and psychological manifestations of pain
- Range of psychosocial interventions that can alleviate discomfort
- Biopsychosocial needs of clients and their family members

(Borrell-Carrió, Suchman, Epstein, 2004)

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<thead>
<tr>
<th>Should address:</th>
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<tr>
<td>- Current symptoms including duration and severity</td>
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<tr>
<td>- Personal history of depression</td>
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<td>- Family history of mental illness</td>
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<td>- Quality of interpersonal relationships</td>
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<td>- Living Conditions</td>
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Five Wishes

- www.agingwithdignity.org
- 888-594-7437
- In 26 languages
- 5 Wishes
- -10 states have special requirements (may apply
- My Wishes
- -Children
- -Not legal document

Five Wishes Valid in:

- Alaska, Arizona, Arkansas, California, Colorado, Connecticut,
- Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho,
- Illinois, Iowa, Kansas, Maine, Maryland, Massachusetts,
- Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska,
- Nevada, New Jersey, New Mexico, New York, North Carolina, North
- Dakota, Oklahoma, Pennsylvania, Rhode Island, South Carolina, South
- Dakota, Tennessee, Vermont, Virginia, Washington, West Virginia,
- Wisconsin, Wyoming

- May attach it to other state’s forms - Alabama, Indiana, Kansas,
- New Hampshire, Ohio, Oregon, Texas, Utah

Let Me Decide – New Grange Press

- Dr. William Molloy
- Let Me Decide Series – book, video
- Let Me Pass Gently
- Pt. lists what unacceptable level of functioning means to them
- Additional sections to identify treatments
- -If loss of functioning Not Acceptable and Not Reversible
- -If loss of functioning acceptable and/or IS reversible
- Section to address updating directive in 12 months with new signature
  and date

Price per Book: €10

Resources

- www.capc.org – Center to Advance Palliative Care
- www.experis.mcw.edu – End of Life Physician Education Resource Center
- gerpal.com – geriatric and palliative care blog
- How and why to talk to the dying patient
- How to have difficult conversations with patients, families
- Psychosocial needs matter most at the end of life
- 5 (incorrect) reasons oncologists avoid bad news talks
References

1. ASPEN webinar: applications of ethical & legal concepts in use of nutritional support therapies, Charles Mueller, PhD, RD, CNSD and Albert Barrocas, MD, FACS. May 11, 2011.

2. Kate Krival, PhD, CCC-SLP; Anne McGrail, MS, CCC-SLP; and Lisa Kelchner, PhD, CCC-SLP, chair of the Education Committee of Special Interest Division 13 (Swallowing and Swallowing Disorders) of the American Speech-Language Hearing Association.


References


SLPs Remember…….

“We are all visitors to this time, this place. We are just passing through. Our purpose here is to observe, to learn, to grow, and to love….and then we return home.”

Australian Aboriginal Proverb
Don't forget

What to say to someone who is dying...

Show your love through words and touch.

Listen with patience and full attention.

Follow the lead of the person in meaningful conversation.

Be calm and natural.

Bring spiritual comfort according to the patient’s belief.

"Is there anything you want to talk about?"

"Is there anything you want me to take care of?"

Thank you