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ONLINE CONTINUING EDUCATION FOR THE LIFE OF YOUR CAREER

End-of-Life Care for the SLP Part 1: How and where we die

Amanda Stead, PhD, CCC-SLP

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

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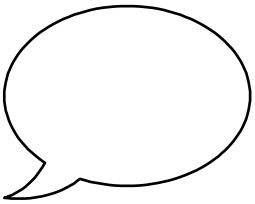
End-of-Life Care for the SLP Part 1: How and Where We Die

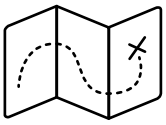


Hello!

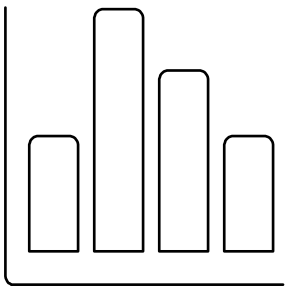
Amanda Stead, Ph.D., CCC-SLP,
Associate Professor CSD
Pacific University

Learner Outcomes

- Describe major physiological changes at the end of life.
- List similarities and differences between hospice and palliative care.
- Describe issues related to providing quality end-of-life care.
- Identify goals of care for the dying patient.
- Describe how and where people die in the US.



Dying in America



Average life expectancy 78.6 years
Up from 70 years in 1980 & 51 years a century ago

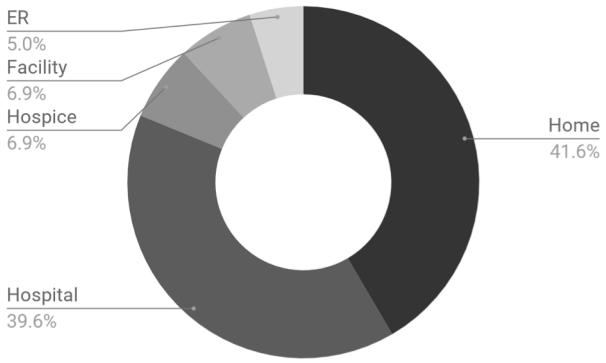
Leading Cause of Death is Heart Disease
Accounting for nearly 600,000 deaths in 2016

For the past 3 years life expectancy in the US has declined
A trend driven by Drug Overdoses and Suicide

National Center for Health Statistics. (2019, April 22). Retrieved April 24, 2019, from https://www.cdc.gov/nchs/

´“The medicalization of dying has shifted the experience of aging and dying, bringing therapeutic professionals in close contact with those that need support communicating their end of life wishes.” -Pollens

Where we Die



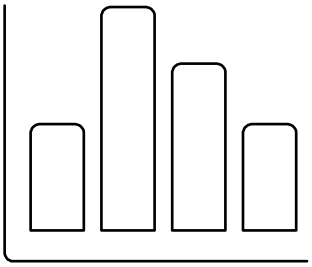
The Final Year: Visualizing End of Life. (2018, July 30). Retrieved April 21, 2019, from https://www.arcadia.io/final-year-visualizing-end-life/

Where we Die

- Many patients move from home to hospice to hospitals and back during the last 30 days of life.
- Some end up in the hospital because their pain or symptoms weren't adequately controlled at home.

The Final Year: Visualizing End of Life. (2018, July 30). Retrieved April 21, 2019, from https://www.arcadia.io/final-year-visualizing-end-life/

"Your chances of avoiding the nursing home are directly related to the number of children you have,"
— Atul Gawande, Being Mortal: Medicine and What Matters in the End



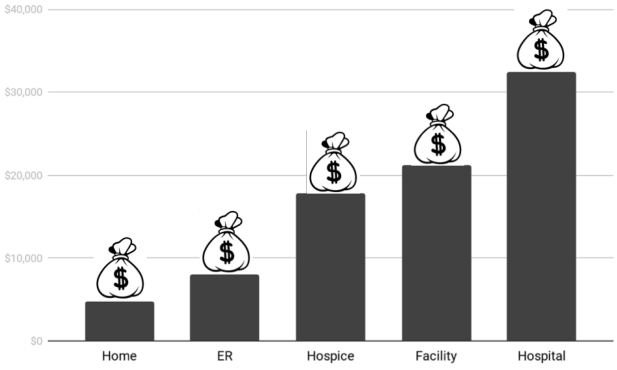
4 of 5 People Who Die in the United States are covered by Medicare
2.1 of 2.6 million deaths

14% of Total Medicare Expenditures are spent on EOLC in 2016
A decrease from 19%

$10.4 Billion spent on Medicare Hospice Benefit
An increase from $2.3 Billion

Source: Kaiser Family Foundation analysis. Original data and detailed source information are available at kff.org/JAMA_11-01-2016.
Please cite as: *JAMA*. 2016;316(17):1754. 10.1001/jama.2016.15577

Cost of Where We Die



The Final Year: Visualizing End of Life. (2018, July 30). Retrieved April 21, 2019, from https://www.arcadia.io/final-year-visualizing-end-life/

30%

The number of families impoverished in the dying process

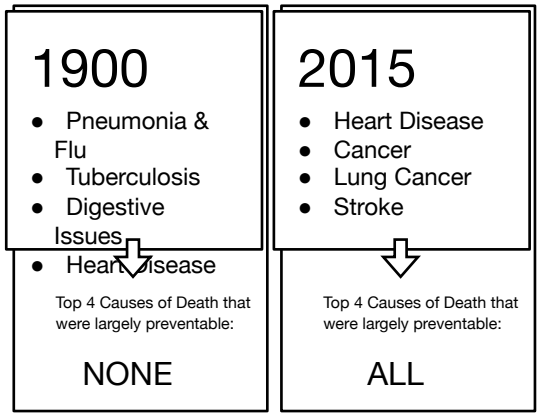
How we die

Number of deaths for leading causes of death (2017)

- Heart disease: 635,260
- Cancer: 598,038
- Accidents (unintentional injuries): 161,374
- Chronic lower respiratory diseases: 154,596
- Stroke (cerebrovascular diseases): 142,142
- Alzheimer's disease: 116,103

National Center for Health Statistics. (2019, April 22). Retrieved April 24, 2019, from https://www.cdc.gov/nchs/

Things Have Changed



Physiology of the Dying

What's Happening?

- The body is shutting down
- People begin to sleep more and more
- People need less nourishment
- People can because nauseous or have incontinence as their body is less able to process food and waste.

**The most common symptom of dying is fatigue

Pre-Active Dying

- Increased restlessness, confusion, agitation, inability to stay content in one position and insisting on changing positions frequently (exhausting family and caregivers)
- Withdrawal from active participation in social activities
- Increased periods of sleep, lethargy
- Decreased intake of food and liquids
- Beginning to show periods of pausing in the breathing (apnea) whether awake or sleeping

SIGNS AND SYMPTOMS OF APPROACHING DEATH. (n.d.). Retrieved April 21, 2019, from https://hospicepatients.org/hospic60.html

Pre-Active Dying

- Patient reports seeing persons who had already died
- Patient states that he or she is dying
- Patient requests family visit to settle "unfinished business" and tie up "loose ends"
- Inability to heal or recover from wounds or infections
- Increased swelling (edema) of either the extremities or the entire body

SIGNS AND SYMPTOMS OF APPROACHING DEATH. (n.d.). Retrieved April 21, 2019, from https://hospicepatients.org/hospic60.html

Active Dying

- Inability to arouse patient at all (coma) or, ability to only arouse patient with great effort but patient quickly returns to severely unresponsive state (semi-coma)
- Severe agitation in patient, hallucinations, acting "crazy" and not in patient's normal manner or personality
- Much longer periods of pausing in the breathing (apnea)
- Dramatic changes in the breathing pattern including apnea, but also including very rapid breathing or cyclic changes in the patterns of breathing
- Severely increased respiratory congestion or fluid buildup in lungs
- Inability to swallow any fluids at all (not taking any food by mouth voluntarily as well)
- Patient states that he or she is going to die

SIGNS AND SYMPTOMS OF APPROACHING DEATH. (n.d.). Retrieved April 21, 2019, from https://hospicepatients.org/hospic60.html

Active Dying

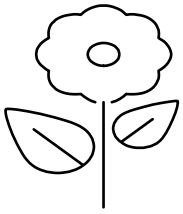
- Patient breathing through wide open mouth continuously and no longer can speak even if awake
- Urinary or bowel incontinence in a patient who was not incontinent before
- Marked decrease in urine output and darkening color of urine or very abnormal colors
- Blood pressure dropping dramatically from patient's normal
- Patient's extremities (such as hands, arms, feet and legs) feel very cold to touch
- Patient complains that his or her legs/feet are numb and cannot be felt at all
- Patient's body is held in rigid unchanging position

SIGNS AND SYMPTOMS OF APPROACHING DEATH. (n.d.). Retrieved April 21, 2019, from https://hospicepatients.org/hospic60.html

"A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives." - Atul Gawande, Being Mortal: Medicine and What Matters in the End

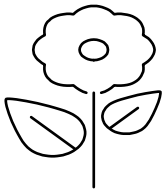
Goals of Patient Care at End-of-Life

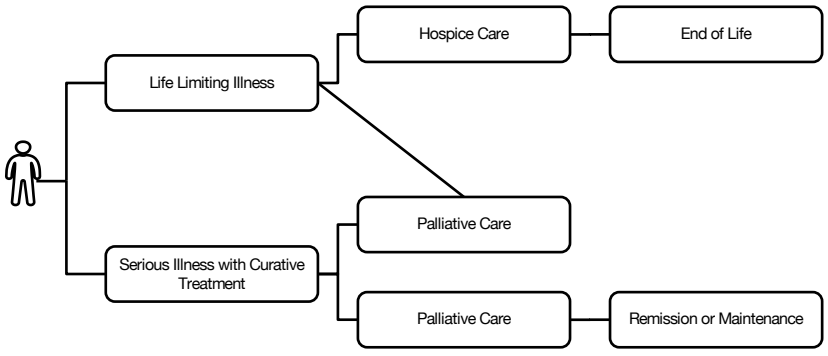
- Cure of disease
- Avoidance of premature death
- Maintenance or improvement of function
- Prolongation of life
- Relief of suffering
- Optimized quality of life
- Maintenance of control
- A good death
- Support for families and loved ones
- A Review of one's life



Hospice and Palliative Care

The hospice and palliative care movement has helped people come to terms with their terminal illness, impending death, and the importance of spiritual issues and needs.

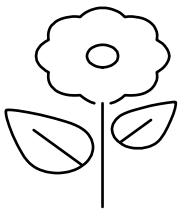




Palliative and Hospice Care Pathways

Palliative Care

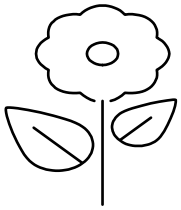
Palliative care is essentially adopting a plan of care that aims to control symptoms and provide physical, psychosocial, and spiritual support to patients as opposed to pursuing aggressive treatment that can often worsen symptoms and pain.



Focus on quality of life

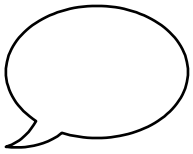
Palliative Care

- The GOAL of palliative whenever possible is to identify the underlying cause of the symptoms
- This care is frequently administered in Hospitals but conditions depending, can be prominent in outpatient settings



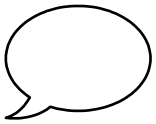
Language Matters: Bad Examples

- Do you want us to do everything possible?
- Will you agree to discontinue care?
- It's time we talk about pulling back.
- I think we should stop aggressive therapy.
- I'm going to make it so he won't suffer.



Language Matters: Good Examples

- I'm going to give the best care possible until the day you die.
- We will concentrate on improving the quality of your child's life.
- We want to help you live meaningfully in the time you have left.
- I'll do everything I can to help you maintain your independence.
- I want to ensure that your father receives the kind of treatment he wants.
- Your child's comfort and dignity will be my top priority.
- I will focus my efforts on treating your symptoms.
- Let's discuss what we can do to fulfill your wish to stay at home.



Case Study

Dolores' Story

Choosing hospice does not have to be a permanent decision. For example, Dolores was 82 when she learned that her kidneys were failing. She thought that she had lived a long, good life and didn't want to go through dialysis, so Dolores began hospice care. A week later, she learned that her granddaughter was pregnant. After talking with her husband, Dolores changed her mind about using hospice care and left to begin dialysis, hoping to one day hold her first great-grandchild. Shortly after the baby was born, the doctors said Dolores' blood pressure was too low. At that point, she decided to re-enroll in hospice.

What Are Palliative Care and Hospice Care? (n.d.). Retrieved April 24, 2019, from https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#palliative-vs-hospice

CONTINUED

Case Study

Tom's Story

Tom, who retired from the U.S. Air Force, was diagnosed with lung cancer at age 70. As his disease progressed and breathing became more difficult, he wanted to explore experimental treatments to slow the disease. Through the palliative care provided by the Veterans Health Administration, Tom got treatment for his disease and was able to receive the care and emotional support he needed to cope with his health problems. The palliative care program also helped arrange for assistance around the house and other support for Tom's wife, making it easier for her to care for him at home. When the experimental treatments were no longer helping, Tom enrolled in hospice. He died comfortably at home 3 months later.

What Are Palliative Care and Hospice Care? (n.d.). Retrieved April 24, 2019, from https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#palliative-vs-hospice

CONTINUED

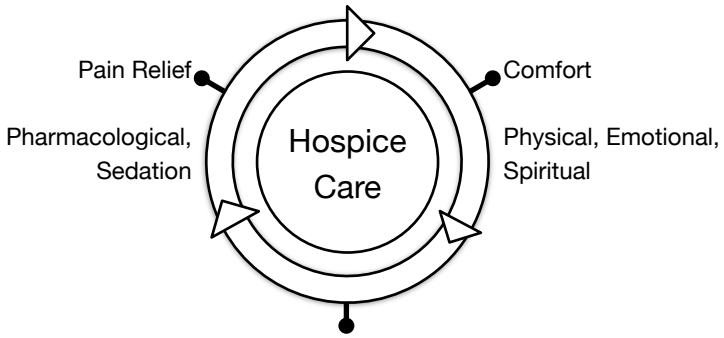
"Modernization did not demote the elderly. It demoted the family. It gave people—the young and the old—a way of life with more liberty and control, including the liberty to be less beholden to other generations. The veneration of elders may be gone, but not because it has been replaced by veneration of youth. It's been replaced by veneration of the independent self. ***" -Atul Gawande, Being Mortal: Medicine and What Matters in the End

Hospice Care

Hospice care enables a person to retain his or her dignity and maintain quality of life during the end of life. Hospice care encompasses the support given to the patient and the family during the illness and through their bereavement.

Hospice Care

- Addressing the patient's emotional, physical, psychological, and spiritual needs
- Managing the patient's pain and symptoms
- Providing need drugs, medical supplies, and equipment
- Delivering special services like speech and physical therapy when needed
- Enabling a person to live the last weeks and months of life as fully and comfortably as possible, with dignity, at home, or in a homelike setting
- Making short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
- Accepting death as a natural part of life, seeking neither to hasten nor prolong the dying process
- Providing bereavement care and counseling to surviving family and friends



Hospice Care

Medicare usually covers these hospice services and pays almost all of the costs

(Centers for Medicare & Medicaid)

- Physician services
- Nursing care
- Medical equipment (wheelchairs, walkers, hospital beds, etc)
- Medical supplies (bandages, catheters, ostomy supplies, etc.)
- Medications for symptom control and pain relief
- Social work services
- Short-term care in the hospital, including respite and inpatient care for pain and symptom management
- Home health aide and homemaker services
- Physical and occupational therapy
- Speech therapy
- Dietary counseling
- Grief support for the patient and family

Case Study

Annie and Maria's Story

Eighty-year-old Annie had advanced metastatic melanoma and asked for help through a hospice program so she could stay in the home she had lived in for more than 40 years. After Annie died, hospice continued to support her family, offering bereavement counseling for a year. Hospice services greatly reduced the stress of caregiving for Annie's family. This was especially true for Annie's wife, Maria, who weathered the sadness of her loss without her own health declining.

What Are Palliative Care and Hospice Care? (n.d.). Retrieved April 24, 2019, from https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care#palliative-vs-hospice

End Game

A Netflix Documentary

YouTube Link:
https://www.youtube.com/watch?v=FgJD6ksdkWY

Goals of the Dying Patient

Dying Patients Bill of Rights

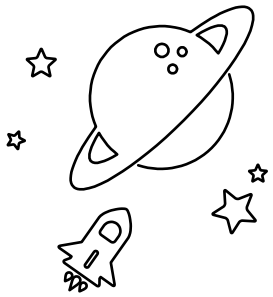
- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness however changing its focus may be.
- I have the right to be cared for by those who can maintain a sense of hopefulness however changing that may be.
- I have the right to express my feelings and emotions about my approaching death in my own way.
- I have the right to expect continuing medical and nursing attention even though 'cure' goals must be changed to 'comfort' goals.
- I have the right not to die alone.

Dying Patients Bill of Rights

- I have the right to be free from pain.
- I have the right to have my questions answered honestly.
- I have the right not to be deceived.
- I have the right to die in peace and dignity.
- I have the right to participate in decisions concerning my care.
- I have the right to have help from and for my family in accepting my death.

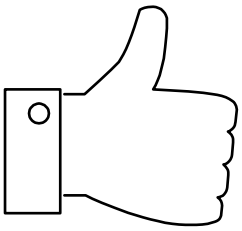
Dying Patients Bill of Rights

- I have the right to retain my individuality and not be judged for my decisions which may be contrary to the beliefs of others.
- I have the right to discuss and enlarge my religious and/or spiritual experience whatever these may mean to others.
- I have the right to expect that the sanctity of the human body will be respected after death.
- I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.



Your Own Personal Experience Matters

"Man is fallible, but maybe men are less so."
— Atul Gawande, The Checklist Manifesto: How to Get Things Right



Thanks!

Any questions?
You can find me at
amanda.stead@pacificu.edu

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