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End-of-Life Care for the SLP Part 3: Grief, Spirituality & the Good Death

Amanda Stead, PhD, CCC-SLP

Moderated by:
Amy Hansen, MA, CCC-SLP, Managing Editor, SpeechPathology.com



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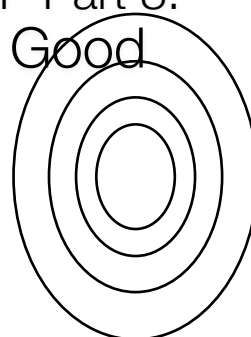
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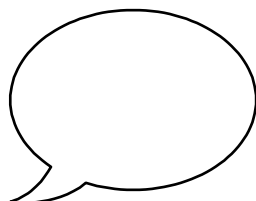


End -of-Life Care for the SLP Part 3: Grief, Spirituality & the Good Death



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Hello!

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

Associate Professor CSD
Pacific University

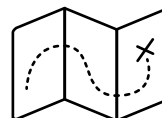
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Learner Outcomes

After this course, participants will be able to:

- Explain key aspects of the "Good Death."
- Identify institutional changes that could support patient care at the end-of-life.
- Describe the spiritual, psychological, social, and physical aspects of the process of dying.



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"We shower so much love on babies and children," she said. "But as we grow up, it stops. No one showers love on grown-ups. But I think we need more love as we get older, not less. Life gets harder, not easier, but we stop loving each other so much, just when we need love most."

— Kerry Egan, *On Living*

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The Good Death

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Fantasy Death

If you could decide when, where & how you die,
what would it look like?

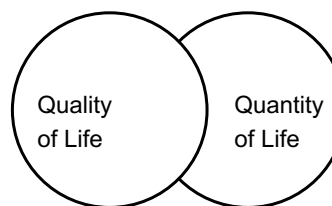
What does that tell you about your values?



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Values: Start with Good Questions

- What matters to me at the end of life is...
- Are there particular concerns that you want to be sure are talked about?



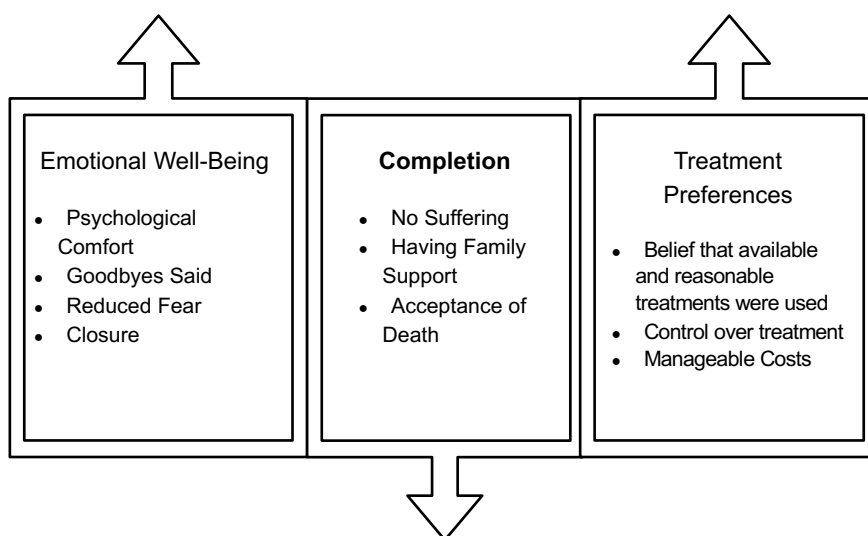
Starter Kits. The Conversation Project. (2019, May 03). Retrieved from <https://theconversationproject.org/starter-kits/#conversation-starter-kit>

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“You learn working in hospice
that a person can, in fact, live too
long.”

— Kerry Egan, *On Living*

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Location Decisions

Why People Want to Be Home

- Better environment for maximizing the life that remains and for achieving personal closure.
- The stress of traveling to and from the hospital or hospice facility is eliminated
- Dying persons often are psychologically more comfortable in a familiar environment with continuous support of family, friends, and pets.
- The ability to prepare meals makes it easier to offer what the individual likes

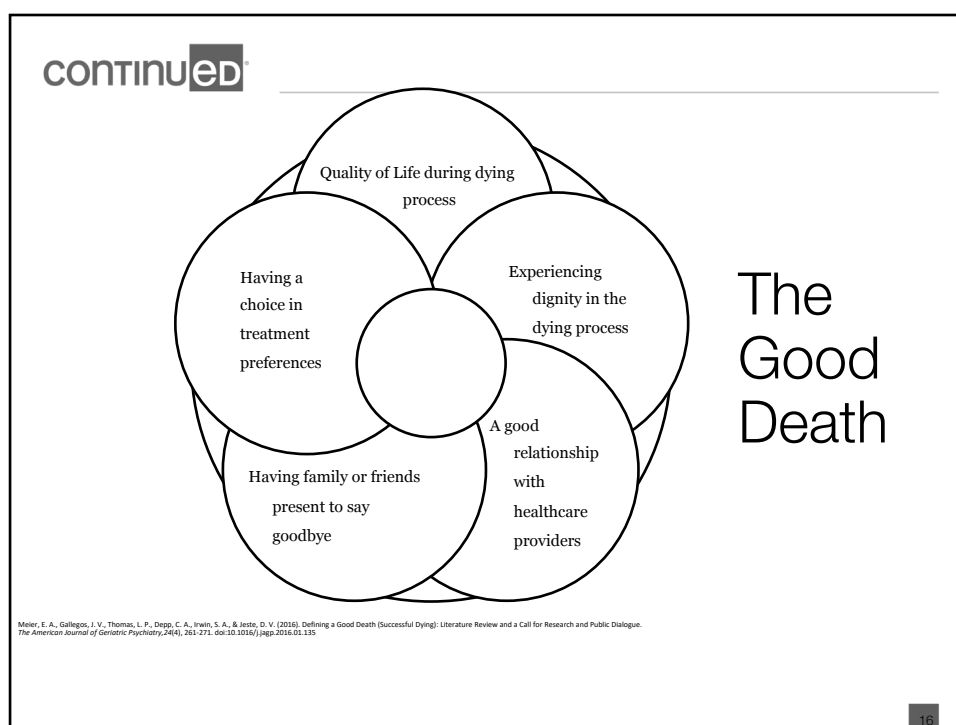
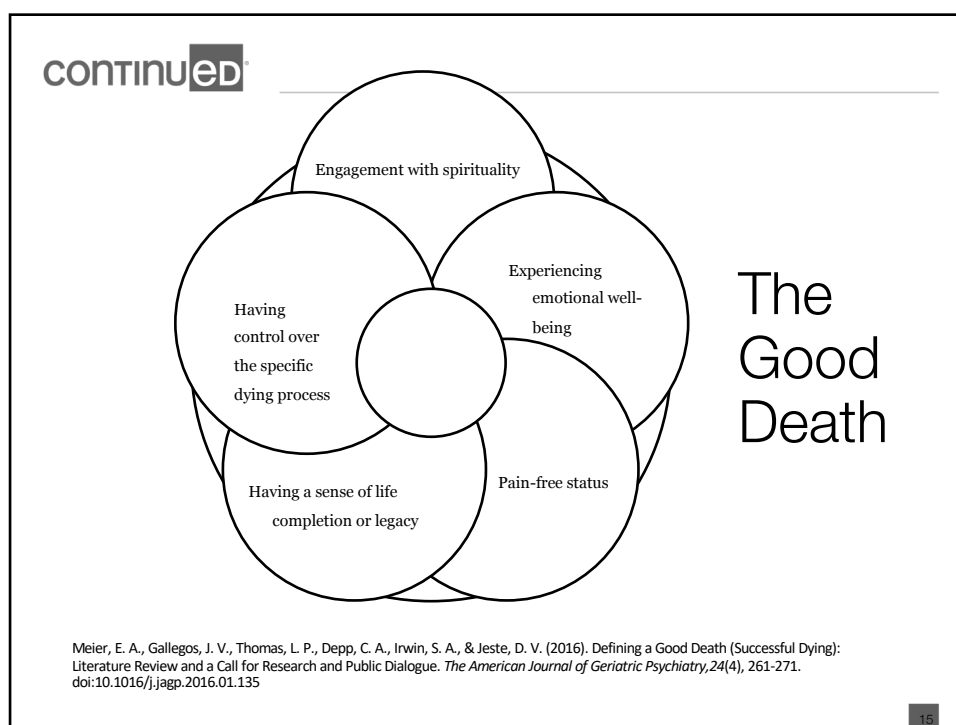
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Location Decisions

Why People **DO NOT** Want to Be Home

- There may be inadequate support for, or difficulty in coping with, care needs.
- There may be competing needs for care by small children, older adults, or other sick or disabled family members.
- The stress of caring for a dying person might be overwhelming.

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continued

"Death must be so beautiful. To lie in the soft brown earth, with the grasses waving above one's head, and listen to silence. To have no yesterday, and no to-morrow. To forget time, to forget life, to be at peace."
-Oscar Wilde, The Canterville Ghost

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continued

Grief & Spirituality

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continued

Spirituality

Spirituality in healthcare is a controversial but necessary subject.

It can present an opportunity to explore patient preferences, to communicate, and to try to understand what is important to patients.

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Spirituality

Doka (2019) identified these three spiritual needs of the dying:

1. The need to search for the meaning of life
2. The need to die appropriately
3. The need to find hope that extends beyond the grave

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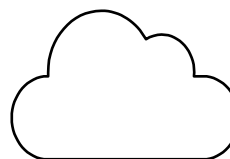


What do you think is the role of the provider in dealing with patients' spiritual or religious needs in the dying process?

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Spirituality



"Why did God do this to me?"

"What do you think will happen to me when I die?"

"Do you believe in God (or Jesus, heaven, etc.)?"

"It would feel like murder to _____"

"I know this is God's will. Only God knows when someone will die, so..." (either)

- "...keep my loved one on life support forever"
- "...I don't need therapy because I'm waiting for a miracle"

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continued

Spirituality:

Why we are uncomfortable...

- Science versus religion
- Not my job (division of labor)
- Don't wish to impose my beliefs on others
- Don't want others to impose their beliefs on me



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Spirituality: what do I do?

- Affirm
 - "This is very important for you."
 - "This is a real source of strength for you, isn't it?"
 - "It takes courage to grapple with these things."
- Share your beliefs as appropriate (do not impose)
- Facilitate environmental support for ritual
- Refer as appropriate



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Spirituality: what do I do?

- The health-care team may help provide for a patient's spiritual needs by the following (National Cancer Institute, 2013).
- Suggest goals and options for care that honor the patient's spiritual and/or religious views.
- Encourage the patient to speak with a religious or spiritual leader.
- Provide information regarding other adjunct therapies that have been shown to increase spiritual well-being, such as mindfulness meditation, art and music therapy, and journaling.



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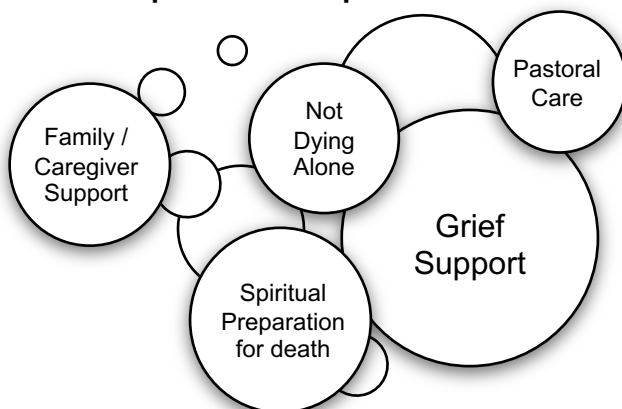
Hospice Chaplain

- Chaplains are part of a larger hospice health care team.
 - Medicare requires hospice providers to offer the option of spiritual care from a trained hospice chaplain. (72% opt in for this)
- Hospice chaplains need to hold a master's degree and have completed Clinical Pastoral Education.
- Chaplains are required to be ordained ministers and usually need certification.
- Hospice chaplains work in hospitals, nursing homes, health care facilities and patients' homes.



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Hospice Chaplain



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Emotional Coping

- The end-of-life process takes a spiritual and emotional toll on a patient's family, who may find themselves:
 - Confused;
 - Angered;
 - Anxious;
 - Guilt-ridden;
 - or questioning the meaning of life itself.



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Grief is Normal

Preparatory or anticipatory grief

- Bereavement (after the patient dies; the experience of death)
- Grief of Loss (Response to a loss)



*Grief is subjective and can occur as a physical, emotional, and social response to loss.

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Psychological Responses

sadness, guilt, anxiety, anger, depression, helplessness, and loneliness. Shock and disbelief, and may include feelings of relief

Social Changes

Dependent on the relationship between the deceased and the bereaved. Roles may change.

Physical Symptoms

crying, loss of appetite, decreased energy, fatigue, apathy, lethargy, and sleep difficulties, weight loss or gain, sighing, heart palpitations, restlessness, shortness of breath, dry mouth and others

Spiritual Issues

may cause the bereaved to question the meaning of life

Grief Symptoms

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Healing From Grief

- The healing of cells and tissues
- A shift from resentment to forgiveness, a release of old hurts, and new energy for growth and an expanded consciousness
- A feeling of being loved unconditionally and for all time so there is no separation between a feeling of oneness with a higher power and a oneness with all creation



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Complicated Grief

Complicated Symptoms:

- Clinical Depression
- Psychosis
- Lack of progress over time

Risk factors:

- Traumatic, violent, unexpected deaths
- Death involving children
- Multiple losses
- Overt mental illness



**unable to address acceptance and adaptation to the loss

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“No one ever told me grief
felt so much like fear”
-CS Lewis

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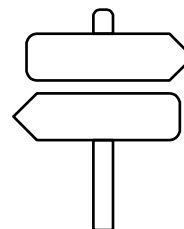
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Institutional
Change

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Driving Questions

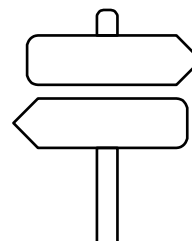
- If there were no obstacles or barriers, what is the best end-of-life care we could have here?
- What kinds of changes would you like to see happen in end-of-life care here?



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Obtaining Buy-in

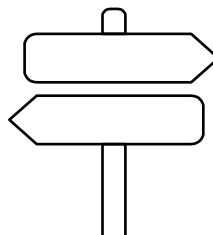
- What do we need to know to institute these changes?
- What do we need to do to institute these changes?



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How Can You Make This Happen?

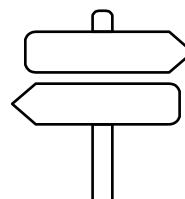
- Who are the allies?
- How can we build on strengths?
- What are the barriers?
- What Training is Necessary?



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Mission Accomplished?

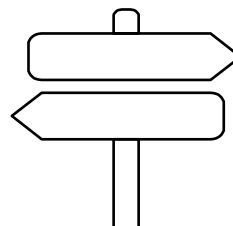
- How Will We Know the Goals Have Been Accomplished?
 - What Data are you taking
 - Participation
 - Outcomes
 - Pre-/Post-
 - Patient/Family Survey
 - What are you comparing it against?



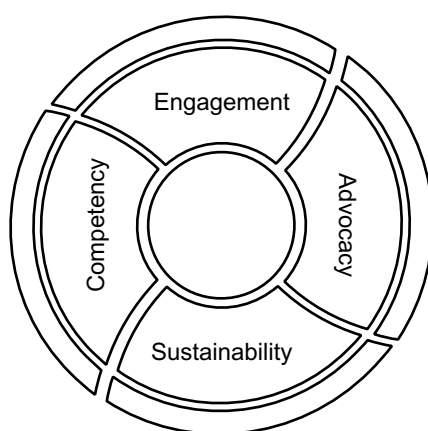
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Sustaining the Work

- In-house newsletter announcement
- Special achievement awards
- Newspaper article
- Report research in a journal article



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Moving
the
Needle

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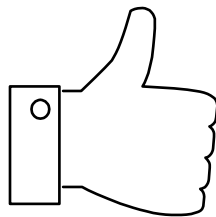
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“We listen to the stories that people believe have shaped their lives. We listen to the stories people choose to tell, and the meaning they make of those stories.”

— Kerry Egan, *On Living*

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continued



Thanks!

Any questions?

You can find me at

amanda.stead@pacificu.edu

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continued

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