



THE HEART AND SCIENCE OF HOSPICE

Midwest Regional Conference
Kansas City, MO 2023



OBJECTIVES_

- Identify communication techniques to foster trust and create relationships with patients and caregivers
- Implement practices to facilitate effective family conferences
- Demonstrate effective skills to guide patients and caregivers through the dying process and death.
- Describe the impact of communication and connection on CAHPS satisfaction surveys.

How do we describe Death?

- Medical event
- Biological event
- Spiritual event
- Psychosocial event
- Relational event
- Community event
- A shared human experience

Who are we inside Death work?

PROFESSIONALS

- Clinicians
- Collaborators
- Last resort of the healthcare system
- Saints
- “Angels of death”

Who are we inside Death work?

PEOPLE

- Witnesses
- Grievers
- Givers of self
- Boundary setters
- Empathizers
- Companions
- Partners

What influences our work?

- Industry administrative burden
- Public perception of what we do
- Feeling insignificant
- Questioning our value
- Remembering our “why”
- Creating meaning
- Coping with grief

ADVANCE CARE PLANNING_

**It's the conversations that give us confidence
to make decisions
on a loved one's behalf.
The conversations are what we remember.**

- Lisa Pahl, hospice social worker,
co-creator of the EOL Deck

STATS_

- While 92% of Americans say it's important to discuss their wishes for end-of-life care, only 32% have had such a conversation.
- 95% of Americans say they would be willing to talk about their wishes
- 53% even say they'd be relieved to discuss it

(The Conversation Project National Survey, 2018)

THINGS TO CONSIDER__

- Consumer – culture, education, fear, money
- Service provider – training, time, documentation
- System – legal and EMR/EHR standardization



That's just
the tip of
the
iceberg...

QUESTIONS TO ASK_

- What barriers to ACP discussions have you encountered?
- What tools have made you most successful?
- Have you completed your own ACP?

FAMILY CONFERENCES_

**A dysfunctional family
is any family
with more than one person in it.**

- Mary Karr, author and poet

STATS

BENEFITS OF FAMILY CONFERENCES

- Reduce caregiver distress
- Mitigate the perception of unmet needs
- Prepare family for caregiving
- Improvement bereavement outcomes
- Reinforce alliance with families
- Promote consensus
- Provide opportunity to show empathy and see the family's perspective

(Current Treatments in Oncology, 2022)

THINGS TO CONSIDER_

- Culture
- Religion(s)
- Education levels
- Healthcare literacy
- Healthcare trauma
- Relational histories
- Current family dynamics
- Time

QUESTIONS TO ASK_

- What disciplines on the team are needed to support this patient/family?
- What are they communicating without words?
- What are we communicating without words?

COMMUNICATION_

**connection is the result
of authenticity.**

- Brene Brown,
author, researcher, storyteller

STATS_

18 of 47 questions on the CAHPS surveys are related to COMMUNICATION

38%

STATS_

CAHPS surveys are related to **COMMUNICATION**

- Informing
- Explaining
- Listening
- Discussing
- Coordinating
- Reporting
- Training
- Supporting

THINGS TO CONSIDER_

- How we talk **with** patients
- How we talk **with** caregivers
- How we talk **about** patients/caregivers

THINGS TO CONSIDER_

Communication should be:

- Timely
- Detailed
- Respectful
- Accurate
- Repeated
- Accessible
- Appropriate
- Documented!!

QUESTIONS TO ASK_

- What do our IDT discussions reflect?
- Are we listening to reflect or respond?

*Listening is the most respectful part
of communication.*

THE GOOD DEATH_

**A good death does honour
to a whole life.**

- Petrarch,
Italian scholar, Renaissance poet

STATS__

Research shows that:

- **80% of Americans wish to die at home**
- **Less than 25% do**
- **75% of hospice patients die at home**

(National Hospice Foundation)

THINGS TO CONSIDER_

Definition of a “good death”

- Provider version
- Patient version
- Caregiver version

QUESTIONS TO ASK_

- How can we respond?
- How can we show respect?
- What can we say?
 - You're in charge.
 - The decision is up to you.
 - I'm here to support you.
 - It's your choice.

FINDING BALANCE IN HOSPICE WORK

- Companionship vs compliance
- Patients vs policy
- Touch vs technology
- Mission vs monetizing
- People vs profits
- Presence vs productivity

RESOURCES_____

- CAHPS Hospice Survey - hospicecahpsurvey.org
- National Hospice Foundation - nationalhospicefoundation.org
- The Conversation Project National Survey Findings 2018 - <https://theconversationproject.org/wp-content/uploads/2018/07/Final-2018-Kelton-Findings-Press-Release.pdf>
- The EOL Deck - thedeathdeck.com
- The Heart of Hospice podcast - theheartofhospice.com

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Hospice workers are a beautiful human
blend of the heart and science
of end of life care.

