(Dis)comfort with Death and Dying & Priorities in End-of-Life Care

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Background & My Agenda

1. What are providers’/residents’/family members’ priorities in end-of-life (EOL) care? What informs these?

- Hanson et al. 2015
  - Family members - communication, access to providers, better pain management

- Heyland et al. 1998 & Signer et al. 1999
  - Patients - honest communication, completion (resolving conflicts, saying goodbye), trust and confidence in providers, adequate pain management, avoidance of inappropriate prolongation of death

- Steinhauser et al. 2000
  - Providers - preparation for death, symptom management, clear-decision making
Background & My Agenda

1. What are providers’/residents’/family members’ priorities in end-of-life (EOL) care? What informs these?

2. How does (dis)comfort with death/dying functions in a space where death/dying is prevalent?
   - Manifestation in practices and discussions
     - Euphemistic or humorous language
       - Coping mechanism for discomfort/fear (Denis)
     - Practices at facility
Population and Method

● Local nursing home/rehabilitation center
● Few residents, no family members
● Diversity of staff roles, but otherwise homogeneous
  ○ Administrators, nurses, social workers, hospice workers, unit manager, administrative assistant
    ■ Majority = 50+, female, white, <5 yrs at facility but >10 years in EOL care
● Limitations
  ○ Response rate
  ○ Access/lack of control
  ○ Recruiting through the facility’s top administrator
Defining End-of-Life (EOL) Care

“Care given to people who are near the end of life and have stopped treatment to cure or control their disease. End-of-life care includes physical, emotional, social, and spiritual support for patients and their families. The goal of end-of-life care is to control pain and other symptoms so that the patient can be as comfortable as possible. End-of-life care may include palliative care, supportive care, and hospice care.”

- National Cancer Institute
Defining EOL Care

From interviews:
- Some expanded my definition (ex. post-death care)
- Others had narrower definitions (ex. only the moments/hours before death)

From survey:
- Lack of consensus on definition/what is included
Major Findings

1. EOL priorities depend on past personal experiences
2. Witnessing, individuality, and human connection in EOL care matter
3. Debate over transport of bodies from the facility: honoring the deceased and/or (dis)comfort with death
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Priorities of EOL Care & the Role of Personal Experiences

My personal experiences with death (eg. in my family) impact my priorities in providing EOL care.

- Relief of emotional and physical suffering
  - Comfort/pain
  - Having people (loved ones, staff) present at time of death

- Personal experiences (ie. in family) forefronted in staff responses

- Why: emotional impact
Major Findings

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3. Debate over transport of bodies from the facility: honoring the deceased and/or (dis)comfort with death
Witnessing, Individuality, and Human Connection

Witnessing = the acknowledgement of and listening to a patient and their family's individual experiences, beliefs, and humanity

- End-of-life conversations and decisions
  - “What is at the top of your worries list?”
  - “What do you need me to know about you?”
  - Goals, needs, and wishes

- Daily life
  - Recognition and praise for individuality
  - Human connection = what makes a good day
Major Findings

1. EOL priorities depend on past personal experiences with death
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3. Debate over transport of bodies from the facility: honoring the deceased and/or (dis)comfort with death
Debate over the Transport of Bodies

According to focus group (all front exit proponents):

- Current practice: bodies transported out the front or side door currently
- The debate: esp auxiliary staff and those involved in admissions want back door exit
- Two camps
  - Front door → respect the recently deceased
  - Back door → not everyone is comfortable with seeing a dead body
Viewpoints of Staff on the Transport of Bodies

What exit do you think bodies should be taken through?

- Use of “other” category and “prefer not to say”
- **Not** just 2 camps at the facility
  - Back door
  - Front door
- Many unrepresented perspectives
Ritualizing the Transport of Bodies from the Facility

The transport of bodies out of the facility should be a more ritualized salute-like practice.

- Respondents can both be in favor of back door transport and of ritualizing body exit to honor deceased
- Not mutually exclusive

![Graph showing survey responses]
My Major Takeaways & Steps Forward

**#1:** Greater emotional/personal connection to deceased → greater impact on professional priorities moving forward

**#2:** Human connection & recognition of individuality = essential to EOL care
   → incorporate more moments of human connection/recognition into residents’ daily lives

**#3:** Body transport = highly controversial with multiple interests at play
   → have conversations about body transport with residents, family members, and all staff

**#4:** Honoring the deceased and respecting some people’s discomfort with seeing a dead body are not necessarily mutually exclusive
References


- Heyland, Daren K.; Dodek, Peter; Rocker, Graeme; Groll, Diane; Pichora, Amiram; Shortt, Sam; Tranmer, Joan; Lazar, Neil; Kutsogiannis, Jim; and Miu Lam. 2006. “What matters most in end-of-life care: perceptions of seriously ill patients and their family members.” Canadian Medical Association Journal 174(5): 627-633.


