SESSION B2

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SESSION B2 OBJECTIVES

• Discuss variations and myths in the concept of what a “perfect death” is in our society.
• Discuss how different facets of the health care system can impact not only how a person’s death occurs but also how it is perceived.
• Discuss strategies health care providers can implement to facilitate mitigation of the impacts of bias on the acceptance of patients’ choices regarding death.

SESSION B2 SPEAKER

Barb Hansen, M.A., R.N.
Barb received her BS in Nursing from OHSU and a Master of Arts in Interdisciplinary Studies at Oregon State University. Barb has an extensive background in end-of-life care. She has served in many roles, some of which include; Home Care Surveyor for the Joint Commission, Wound, Ostomy, Continence RN for Samaritan Health Services; Manager of Samaritan Evergreen Hospice and Director of Hospice and Home Health. Currently, Barb serves as the Executive Director of Washington State Hospice & Palliative Care Organization and as CEO of the Oregon Hospice and Palliative Care Association.
You Only Die Once: How Health Care Providers May Contribute to a Less-Than-Perfect Death—by Creating Pressure to Have One!

Barb Hansen, MA, RN, CEO
Oregon Hospice & Palliative Care Association

To begin: let’s get to know each other!
Objectives and Needs Assessment

- What would be a good use of your time today?
- What are you hoping to get out of this session?
- Objectives:
  - Discuss variations and myths in the concept of what a “perfect death” is in our society.
  - Discuss how different facets of the health care system can impact not only how a person’s death occurs but also how it is perceived.
  - Discuss strategies health care providers can implement to facilitate mitigation of the impacts of bias on the acceptance of patients’ choices regarding death.

First, let’s consider what society considers a “perfect death”?

- In old age, w/ all legal documents in place & “arrangements” made
- At home (wherever “home” is)
- In bed, perhaps with a cat or dog curled up alongside
- Surrounded by loved ones
- Painless—no needless diagnostic tests, lab draws, etc.
- Soft lighting, perhaps a beautiful sunset in the background
- Soft music playing in the background
Now: how do you want to die?

Do you have an “ACP” (Advanced Care Plan)? Do you have a more personal version—and have you shared it with your family or friends?

What location would you choose?

- If you want to die at home, in which room would you like to be?
- What view do you want out your window?
- What “views” do you want in the room?
- What surface do you choose: bed, sofa, chair?
- If you do not want to die at home, where would you prefer to be?
Who would you like to be present? (Who would you like to NOT be present?!) 

Do you want music playing? What kind?
Do you want prayers being spoken? Visits from a Spiritual Care Provider? (Do we often assume “Yes” is the answer? What if it’s “No”?)

Do you want the TV on? What channel? (Who gets the remote?)
What do you want for your last meal?

If you have pets, do you want them on the bed with you --assuming you’re in bed? Or on your lap? Or just nearby?

Bonnie  
Riley  
Sally  
Millay
What is the **reality**: how does death usually occur in our country? Let’s consider: age at death

**How old is “in old age”, when it comes to dying?**

**In Oregon: the median age of death in 2017 was 78*.**

But if you died from
- Alzheimer’s Disease it was 88.
- heart disease it was 82.
- diabetes it was 73.
- unintended injury, it was 63.
- alcohol-induced causes, it was 55.
- suicide, it was 48.

*We should all move to Wheeler County!

**Next: location**

14,285/36,640 deaths in Oregon in 2017 occurred at “home” (~39%).

24% of deaths were in a hospital & ~2% in a Hospice House.

~15.4% took place in an ALF, Foster Home or other residential facility.

9.5% of deaths took place in a nursing home.

~4% of deaths took place in an Emergency Room.
Consider Ambiance: How’s the lighting & sound in an ICU?

Nationally, the # of deaths in hospitals has been decreasing.

- The number of inpatient hospital deaths decreased 8% from 776,000 in 2000 to 715,000 in 2010 (Figure 1).
- At the same time, total hospitalizations increased 11%, from 31.7 million in 2000 to 35.1 million in 2010 (data not shown).
- Female inpatient hospital deaths decreased from 411,000 in 2000 to 364,000 in 2010.
- Male inpatient deaths did not change significantly during this time.

Figure 1. Inpatient hospital deaths: United States, 2000–2010

How can we change the system within our own work settings or at least in our personal lives?

This day is coming right up—let’s take advantage. What if we all had both a “macro” ACP and a “micro ACP”?

How can Healthcare Providers assist patients to have the kind of death they would like to have?

Is this a time for

Don’t Ask, Don’t Tell
You’ve got to **ask specific questions**—and then communicate the responses/requests with others on the team.

How often is this communication left to the last minute?

- The average length of stay in a hospital was 4.5 days in Oregon in 2016. (Nationally it ranged from 4.6 to 10.5 days for all hospitals in 2015.)
- Nationally, inpatients who died in the hospital stayed an average of 7.9 days in 2010, compared with an average of 4.8 days for all inpatients.
- Although 45% of those who died in the hospital stayed from 1–3 days, 57% of all inpatients had stays that were this short.
- Over one-quarter of the patients who died in the hospital stayed 10 days or more, compared with 10% of all inpatients.
- >25% of Hospice patients are on hospice for less than 7 days.
Capturing the information must be intentional and integral to the admission process. Then it must be easily located by others.

- Could a “Death Plan” become part of a patient’s “Care Plan”?
- How would this kind of information be captured within your system?
- Would everyone know where to document this information?
- Where would it be kept within your EMR?
- If not IN the EMR, then where?
- Would everyone know how to find this information?

What if what the patient prefers is not easily achievable?

- What if the caregiver is not capable of providing 24/7 care?
- What if the caregiver IS capable but does not want to provide the care?
- What if there are not resources to provide additional care?
- What is the patient lives alone?
What about Patients w/o Available Caregivers?

Patients with relatives or friends but there are “limits”:
• Is what we--as healthcare providers--ask them to do always reasonable?
• Do we pass judgment on them if or when they try to set limits?

Patients who live alone & have no relatives or other caregivers
• Do we discriminate against them if we choose not to “serve” them?
• Does it make an unsafe home situation more safe if we choose not to admit them for care?

Healthcare Providers can sometimes be barriers to a “good” death. Why is that?

Some “last request” stories...
Are we always thoughtful about applying the “rules”? 

Can I visit my grandpa?

Visiting Hours:
11:00 a.m.-8:00 p.m.

When do we bend or change the rules?
E.g.: why would we not allow pets to visit?
Is an EMR for the pet really needed before a visit?
We know we should not impose our notions about what a family is—and should do—at the end of life. (But we do.)

Does everyone’s family look like this? (Did yours?) Did everyone have a happy childhood?

Sometimes patients won’t die while someone is “hovering”. This information should be shared with families or friends who are “vigiling”.
What do survivors often focus on later?

- What happened before their loved one's death?
- What didn’t happen but should have happened?
- And why it didn’t happen: the “coulda/shoulda”.

How can we incorporate acceptance of individual choices into orientation and ongoing training programs for staff?

- How well is the topic of respecting individual choices covered at your place of work?
- How much depends on the opinions of the leadership? (Program director, Medical director, Supervisors, peer pressure?)
- How much training is left up to the individual trainers/mentors? (And who trained them, anyway?)
How do we change the culture within our organizations?

- Can we begin “in our own backyards” to examine our policies, procedures and processes?
- Can we eliminate policies that are needlessly restrictive?
- Can we include as part of our regular process a way to call ourselves out when value judgments are getting in the way of providing care?
- Can we find a way to say “Yes” to honoring requests and choices as much as we possibly can?

Does anyone have a story to share?

How was a “good death” facilitated?

Or what barriers existed which prevented a “good death”?
Are there other comments or questions? Is anyone willing to share their “micro ACP” or “Death Plan”?

Thank you for your time!

• Please contact me if you have questions or comments:
• Hansen@oregonhospice.org
• 541-231-2440
• (Any of my grandchildren are welcome to be with me at the end of my life—if my pets will make room!)