WE DON'T KNOW DEATH
7 Assumptions We Make about Dying
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Assumption #1:
If you have experienced a death, you know how death happens.
Patients, staff, and families can have pre-conceived notions about:
- Pain and other symptoms
- Length of time it takes to die
- Environment preferences
- Family dynamics

Interventions:
- Ask patients/caregivers: What has been your experience with being around someone who is dying?
- Consider using the words, “typically” and “may” when you talk about what “might” happen.
- Be cautious about how you tell a family that you’re seeing something new.
- Self-reflect on assumptions that you’re making.

Assumption #2:
You’re supposed to be unconscious when you’re about to die.
- People seem to always die the same way in the media.
- Excluding sudden and unexpected deaths, 6-30% of patients are conscious 15 minutes before death.
- Certain diagnoses are more likely to have sudden death.

Interventions:
- Always address patient when you walk in the room.
- Always assume patient can hear you.
- Inform families of patient’s ability to hear.
- Do not let consciousness or responsiveness alone be your barometer for determining “actively dying” status.

"The only true wisdom is in knowing you know nothing."
-Socrates

"You think you know every thing. let me tell you, you don’t know JACK!"
-student supervisor to presenter

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Assumption #3:
Family will want to be with their loved one when they are dying.

- A person can love someone and not want be there when they die (Although a person can be mad at someone and still want to be present)
- Family members of patients with dementia may say they’ve “already lost” their loved one
- Family members may change their minds

Interventions:
- Ask at admission, “Is it your hope or expectation to be present at time of death?”
- Normalize patient “no” response to question about being present at TID.
- Be cautious about how you notify a family member of impending death.

Assumption #4:
People don’t want to be alone when they die.

- “Here” a patient chooses to go may reflect on their personality
-Patients may die when family has temporarily left the room
- Patients may die in the middle of the night
- At a patient may die with a room full of people

Interventions:
- Assess and reassess patient’s desire for companionship.
- Honor patient wishes for privacy.
- Educate family on purposeful possibility that they may not be present when patient dies.
- If patient doesn’t want family there and family doesn’t want to leave, STAY OUT OF IT.

Assumption #5:
Family matters will get resolved.

- We do not know family history
- Family may refuse to visit even when patient is dying
- We have to table our own ideals of the dying process

Interventions:
- Provide support to family members who are distressed by non-involvement of other family members.
- Allow family to stay un-involved.
- Self-reflect on our own feelings about non-reconciliation.

Assumption #6:
The secrets to the universe will be revealed.

- We can sometimes get caught up in believing every word is meaningful.
- Sometimes a door is just a door
- Some patients process internally rather than through dialogue

Interventions:
- Ensure you are not setting false expectations for yourself or family.
- Recognize that not every bedside experience will be meaningful.
- Educate families that sometimes people turn inward and away.

Zen student: “What happens after death?”
Zen Master: “I do not know.”

Zen student: “How can that be? You are a Zen Master!”
Zen Master: “But I am not a dead Zen Master.”

-Quoted by Ram Dass
Assumption # 7:
You should tell your loved one, “It’s okay to let go.”

- Actions speak louder than words
- Sometimes it’s not about them, it’s about you letting go (or families)
- Repeatedly telling someone they can “let go” may be distressing for them to hear

Intervention
- Consider saying, “This is your schedule. Go when you feel comfortable.”
- Educate families on what “letting go” means for themselves.
- Recognize that each person’s dying process has its own pace.

Reflection:
The source of your “knowledge” about death?

- Family history and passed on stories
- Personal experience
- Friend’s stories
- Professional experience
- Media (Movies, television, magazines, books)