

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 patient/caregiver: 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.

How I know death

- My family history
- Personal losses
- Hospice volunteer
- Hospice internship
- Hospice social worker
- Death Cafe



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

-Socrates

**"You think you know
 everything.
 let me tell you,
 you don't know JACK!"**

-student supervisor to presenter

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.¹
- Certain diagnoses are more likely to have sudden death
- "Consciousness" is a clinical term

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.

1 Doyle, D., Banks, G.W., & MacDonall, N. (1999). Oxford textbook of palliative medicine, 2nd edition. Chicago, p. 983.

Assumption #3:

Family will want to be with their loved one when they are dying.

- A person can love someone and not want to 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 TOD.
 - Be cautious about how you notify a family member of impending death.

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 #4:**

People don't want to be alone when they die.

- "How" 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
...or a patient may die with a room full of people
- Interventions:
- Assess and re-assess 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, SET OUT OF IT.

**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.



If we do not know
about life, how can we
know about death?

-Confucius

Z en student: "What happens after death?"
Z en Master: "I do not know."
Z en student: "How can that be? You are a Z en Master!"
Z en Master: "But I am not a dead Z en 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)

