

The Last Days: What Patients and Families Want

Cedarville University
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Objectives

- To review what patients and families have reported concerning end-of-life desires to clinical researchers
- To encourage each of us to reflect upon our own goals and desires for approaching the end of life

What do patients want at the end-of-life (EOL)?

Fears:

- Die on machine
- Die uncomfortable
- Die alone
- Be a burden
- Long dying process
- Die in an institution

Desires:

- Die unattached to a machine
- Die in comfort
- Be with loved ones
- Maintain control
- Die at home

C. Hook, MD
Singer, et al. *JAMA* 1999;281:163

IMPORTANT FACTORS AT THE END OF LIFE

Steinhauser, et al *JAMA* 284:2476-2482, 2000

- Survey of 340 seriously ill patients
332 recently bereaved family members
361 physicians
429 nurses, social workers, chaplains & hospice workers
- 26 items were consistently rated as being important (>70% so responding) across all four groups

IMPORTANT FACTORS AT THE END OF LIFE

Steinhauser, et al *JAMA* 284:2476-2482, 2000

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|---------------------------------------------------|---------------------------------------------------|
| • Be kept clean (99%) | • Be free of shortness of breath |
| • Name a decision maker (98%) | • Be free of anxiety (90%) |
| • Have a nurse with whom one is comfortable (97%) | • Have MD with whom can discuss fears (90%) |
| • Know what to expect about one's condition (96%) | • Have MD who knows one as a whole person (88%) |
| • Have someone who will listen | • Resolve unfinished business |
| • Maintain one's dignity (95%) | • Have physical touch (86%) |
| • Trust one's physician (94%) | • Know MD comfortable talking about death & dying |
| • Have financial affairs in order | • Share time with close friends |
| • Be free of pain (93%) | • Believe family prepared (85%) |
| • Maintain sense of humor (93%) | • Presence of family |
| • Say goodbye to important people | |

Dignity Therapy

Thompson & Chocinov *Current Opinions in Supportive & Palliative Care* 2008; 2:49-53

- Dignity conserving perspectives
 - Continuity of Self
 - Role Preservation
 - Generativity/Legacy
 - Maintenance of Pride
 - Hopefulness
 - Autonomy/Control
 - Acceptance
 - Resilience/Fighting Spirit
- Dignity conserving practices
 - Living in the Moment
 - Maintaining normalcy
 - Seeking Spiritual Comfort

Factors Producing Distress

Chochinov, et al. *J of Symptom & Pain Management* 2008; 36: 559-571

- Symptom Distress
 - Physical symptoms
 - Feeling depressed
 - Feeling anxious
 - Feeling uncertain
 - Can't think clearly
- Existential Distress
 - Changed appearance
 - Feel dispossessed of self
 - Feeling worthless
 - Feeling a burden
 - Can't carry out roles
- Dependency Distress
 - Can't perform tasks of daily living
 - Can't attend to bodily functions
 - Reduced privacy
- Loss of Peace of Mind
 - Spiritual concerns
 - Unfinished business
 - Sense of lack of contribution
- Social Distress
 - Not feeling supported by friends, family, health care providers
 - Not treated with respect

Dignity Psychotherapy Questions - 1

Chochinov, et al. *JCO* 2005; 24: 5520-5525

- Tell me a little about your life history; particularly the parts you think are most important? When did you feel the most alive?
- Are there specific things you would want your family to know about you?
- What are the most important roles you have played in life? Why were they important to you?
- What are your most important accomplishments, and what do you feel most proud of?
- Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?

Dignity Psychotherapy Questions - 2

Chochinov, et al. *JCO* 2005; 24: 5520-5525

- What are your hopes and dreams for you loved ones?
- What have you learned about life that you would want to pass along to others? What advice or guidance would you wish to pass along to your...?
- Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
- In creating this permanent record, are there other things that you would like included?
