Goals of Care as Guiding Stars: Working with Families in LTC

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Objectives

- Compare and contrast advance directives, advance care planning, goals of care
- Describe how family members’ “stance toward dying” can affect goals of care
- Discuss the four major factors that family members consider when deciding on a new medical procedure, care plan, or goals of care

Context

- Advanced chronic illness(es)
- Advanced old age
- Medical options
- Culture of “do something”
- Individualism

Compare and Contrast

- Advance Directives
- Advance Care Planning
- Goals of Care
- Surrogate’s role?

Goals of Care: 1967-2007 Medline

- Be cured
- Live longer
- Improve/maintain function/QoL/independence
- Be comfortable
- Achieve life goals
- Provide support for family and caregivers

*Understand diagnosis or prognosis

Later added:

135 hospitalized adults

- Goals of care
- "What are you expecting to be accomplished during this hospitalization?"
- Average of 5 goals

**Dying**

- When does it start?
- Is it normal?
- As a medical process
- As a social role
  "Role expectations"
  "obligations"
  "Appropriate care"

**Stance Toward Dying**

- Dying allowed
- Dying resisted
- Dying contested
- Mixed message dying


**Stance Toward Dying**

- Dying allowed - 13
- Dying resisted - 4
- Dying contested - 3
- Mixed message dying – 10
- **Not enough info to classify** - 15

**Guiding Star Model**

Source: Bern-Klug. (2009) JSWEoL&PC. Full citation on last page

**Half Way to Heaven**

- Completion of one’s life story matters
  - Excruciating
  - Meaning ful/less
  - Acceptable

  Can’t control everything.
  Can control more than we often do.
Practice Implications

- Language: normalize discussions
- Anticipate and act on triggers and teachable moments
- Recognize and address family emotional challenges related to decision-making and pressure to “do the right thing.”
  - Information
  - Support
  - Framing
  - Connections
- Recognize and work to improve constraints in the environment (social, political, financial)
- Build skills in engaging in ACP discussions
  - Respecting Choices®
  - Five Wishes
  - POLST Paradigm

AKA
Want valid directions from your GPS? Specify your destination.

Which star to follow?
Where do you want to go? (general direction—not a road map: a compass)

Guiding Star Model