Serious Illness Learning Community: Summary of Key Themes

June 10, 2020
Responding to Themes from the Interviews

- Finding participants at the beginning of decline
- Timing of advance care planning and goals-of-care conversations
- Understanding burdens and needs
- Varying staff comfort levels in “end of life conversations”
- Creative use of hospice providers
EARLY IDENTIFICATION OF THOSE IN DECLINE/TIMING /ADDRESSING NEEDS
Identifying Those on the Decline

Hoefer, Daniel, M.D.
Evidence-based Predictors

➔ LACE Index – risk of hospital re-admission and death based on hospital experience
➔ Charlson Co-Morbidity Index – risk of death based on conditions and severity
➔ Walter Index – risk of death based on ADLs and specific DX and labs

Clinical opinion has not been shown in the literature to be a reliable means to predict decline
Looking for Frailty

➔ Loss of Strength
➔ Weight Loss (unintended)
➔ Low Activity Level/Increased Sleeping
➔ Poor Endurance/Easily Fatigued
➔ Slowed or Unsteady Gait
  – Timed Get Up and Go Test (>15s)
Increased Illness Burden and Lack of Clarity – Predictors of NEED

- Pain and other symptom distress
- Caregiver stress and burn-out
- Misunderstanding of prognosis
- Unarticulated values and goals
- Existential worry
- Disagreement within family
Key Assessments of Need

➔ Symptom Burden
  – Edmonton Symptom Assessment System (ESAS-r)

➔ Functional Decline
  – Karnofsky Performance Status Scale (or PPS)

➔ Caregiver Burden
  – Zarit Burden Interview

➔ Spiritual Distress
  – Beck Hopelessness Scale
Ideas From the Interviews

➔ Assess and hold initial conversations during intake
  – Part of comprehensive question-and-answer process

➔ Incorporate symptom distress assessment into formal 6-month re-assessment process

➔ Remember to use physical therapy as a means to manage pain
  – CDC Guidelines for Prescribing Opioids for Chronic Pain, 2016
CLARIFYING GOALS-OF-CARE AND ADVANCE CARE PLANNING
What conversations are needed? When?

- Goals of Care
- Advance Care Planning
- Prognosis
- Five Wishes
- Respecting Choices
Try a Different Frame

→ Prognosis
→ Understanding
→ Fears
→ Goals
→ Trade-Offs

Many professionals find this conversation easier to start, and can more naturally lead to questions around medical interventions
Speaking with Participants: Some Best Practices

➔ Make sure that they know their condition(s) and what to expect from it. Do not proceed unless they do.

➔ Start by finding out what is important to them at this time in their life, and if time were to run short

➔ Allow for silence
Advance Directives – Health Care Decisions

➔ Start with identification of a surrogate decision-maker/health care proxy
  – Upon admission is best

➔ POLST/MOLST – advance medical decisions
  – See VitalTalk and Compassionate Coalition of California Scripts and Videos
Communication Skills Training – CAPC Courses

- Delivering serious news
- Discussing prognosis – ALL STAFF
- Clarifying goals-of-care – ALL STAFF
- Conducting a family meeting
- Advance care planning conversations
- ACP courses from Respecting Choices
Ideas from the Interviews

➔ Social Work taking more responsibility for goals-of-care and advance care planning

➔ MOLST/POLST conversation part of formal 6-month re-assessments

➔ Special palliative care team for those nearing the end-of-life
  – Completely revisit the care plan
  – Enables continuing planning conversations
  – (expert symptom management as well)
CREATIVE USE OF HOSPICE
Most Programs Prefer to Manage End-of-Life Care

➔ Keep a familiar care team/minimize hand-offs
➔ Hospice not as able to provide extensive home health aide services
➔ Hospice expense
➔ Disenrollment required
However, Hospices bring certain advantages

➔ Inpatient facility
  – Caregiver respite

➔ Expertise with opioids

➔ Family bereavement support
Ideas from the Interviews

→ Contract with Hospice(s) for inpatient care only
→ Professional training arrangement with hospice
  – Medication management
  – Communication skills
→ Contract with Hospices(s) for bereavement support
  – For participant family members
  – For PACE staff