



Patient-Centered Palliative Care Delivery for Adult Patients with Advanced Illnesses and Their Caregivers: Refined Questions for Breakout Groups

Communication, Education, and Decision-Making Questions (N=14)

Clinician training and education

1. What is the comparative effectiveness of different approaches to facilitate goal-directed decision making for older adults with multimorbidities in the primary care setting (provider education vs. provider education plus decision support tools incorporated in the EMR)?

Patient and caregiver support and education

2. What is the comparative effectiveness of supportive care interventions (such as education by health professionals, peer dialogue) when offered together to patient and caregiver dyads versus offered separately to patient or caregiver on important patient and caregiver behaviors and outcomes?
3. What is the comparative effectiveness of different approaches for facilitating patient and caregiver preparedness and self-care ability across the trajectory of advanced illnesses on patient and caregiver functioning and quality of life and how does it differ in multicultural communities?
4. What is the comparative effectiveness of different approaches to motivating seriously ill outpatients to prospectively document their desired approaches to care on patients' satisfaction with their care plans, patients' long-term outcomes, and caregivers' bereavement outcomes?
5. What is the comparative effectiveness of different communication and education approaches that engage patients with Parkinson's disease (PD) and their caregivers in discussions about palliative care options and advance directives earlier in the disease course versus later (mild PD vs. moderate PD vs. advanced PD) on patient and caregiver quality of life, functioning, completion of advance directives, and referrals to and utilization of palliative care services?
6. What is the comparative effectiveness of multicomponent advance care planning interventions, including decision aids that utilize technology, on increasing competence and capacity for

caregivers of individuals with cognitive impairment to make advance care decisions?

Shared decision making

7. What is the comparative effectiveness of different approaches for communicating palliative care decisions to patients with conditions that severely limit their participation (e.g., those with cognitive impairment) on ensuring input from patients and respect for the patient's preferences as opposed to those of a surrogate decision maker alone?
8. What is the comparative effectiveness of different approaches to shared decision making on discontinuing medications for patients with advanced illnesses in a way that is consistent with patient and family goals of care as well as the patient and family's culture, ethnicity, or religion?

Approaches to advanced care planning

9. What is the comparative effectiveness of traditional advanced care planning outcomes such as goals of care discussion in advance directives/power of attorney in advanced illness vs. implementation of the POLST paradigm on presence of needed documentation at point of care at necessary time, congruence of preferences stated and system response in the face of change in condition, healthcare utilization, and patient/family satisfaction?
10. What is the comparative effectiveness of models that include a standardized communication protocol (e.g., advanced care planning documents, POLST) versus tailored patient/family education on improving patient and family outcomes?
11. For persons living with serious and progressive disabilities associated with aging (frailty and advanced organ system illnesses), what is the comparative effectiveness on patient and caregiver health outcomes and care experience of comprehensive care planning approaches that make the care plan available in all settings over time versus the fragmentary, hit-or-miss, and short-term planning that is not generally transferred across settings that is commonplace now?
12. What is the comparative effectiveness of efficacious and widely used interventions designed to facilitate advance care planning conversations between culturally diverse patients, caregivers, clinicians, and healthcare agents on patient- and family-centered outcomes including understanding of prognosis, congruence between patient preferences and care choices made, healthcare utilization, production of advance directives, patient and caregiver activation, and decision satisfaction?

13. What is the comparative effectiveness of web- and video-based interventions versus enhanced clinical communication on advanced care planning in patients with advanced cancer?

Family communication

14. What is the comparative effectiveness of different formats of family meetings (face-to-face, technology-supported, synchronous, asynchronous, physician-led, non-physician-led) on goals of care and end-of-life wishes for adult patients with advanced malignancies who develop renal failure and are considering implementation of hemodialysis?

Models of Palliative Care Delivery Questions (N=17)

Timing of palliative care delivery

1. What is the comparative effectiveness of different models of palliative care (fully integrated versus consultative approaches) when initiated early in the course of advanced cancers such as lung and pancreatic cancers versus when disease is progressing rapidly versus when all medical treatments have failed to control the disease on patients' symptom burden, physical and mental functioning, healthcare utilization, and caregiver outcomes including burden, quality of life, hours of care, and satisfaction?

Integrated versus consultative models

2. What is the comparative effectiveness of integrated palliative care models (including training of existing providers, improved multidisciplinary support for palliative care interventions, and quality measurement) compared to specialty palliative care consultation models, for improving patient- and family-centered outcomes for patients with advanced illness and minimizing patient and family burden?
3. What is the comparative effectiveness of different coordinated patient-centered palliative care delivery models (i.e., dialysis centers vs. home-based programs vs. hospice vs. hospital inpatient consultations) on patient-centered outcomes for patients on dialysis with multiple comorbidities such as uncontrolled diabetes and congestive heart failure?
4. What is the comparative effectiveness of different approaches to integrating palliative care specialists into the primary care setting (integrated care vs. co-location vs. offsite consultation) for patients with advanced illnesses on patient-centered and caregiver outcomes?

Nurse-led models of palliative care

5. What is the comparative effectiveness of different nurse-led (APRN) outpatient palliative care programs on various patient-centered outcomes for home-based patients with advanced heart or lung failure (includes: CHF, COPD, ILD, lung cancer resulting in symptoms of chest pain or dyspnea requiring advanced medical interventions such as: VADs, continuous parenteral infusion therapy, or BiPAP)?

Setting of palliative care delivery

6. What is the comparative effectiveness of external palliative care consultation versus systematic training in palliative care knowledge and skills for regular care staff on patient outcomes (symptoms, burdensome transitions, feeding tube placement, development of resistant organisms, family satisfaction) in nursing homes?
7. What is the comparative effectiveness of patient access to community-based palliative care versus usual care (hospital-based palliative care only or no palliative care) on improvement in health outcomes of adult patients with advanced illnesses, identification of patient priorities/goals, attainment of patient priorities/goals (examples: maintain independence, maintain or improve function, reduce pain and symptoms, maximize length of life) and completion of an advance directive?
8. What is the comparative effectiveness of palliative care delivered in wraparound systems such as Sutter Care at Home vs. standard care on patients receiving care that is consistent with their end-of-life wishes and preferences?
9. What is the comparative effectiveness on patient and caregiver outcomes of new developed models of care and payment for hospice that would involve co-management with time-limited escalation of involvement of the interdisciplinary team based on the needs of the patient with advanced illness and multimorbidity and family?

Integration of different professionals as part of the care team

10. What is the comparative effectiveness of palliative care models that integrate a pharmacist into the interdisciplinary patient care team vs. models without a pharmacist on improved healthcare utilization, quality of life, and patient safety for patients with life-limiting illness?
11. What is the comparative effectiveness of care teams that integrate peer specialists as part of the care team vs. care teams without a peer specialist on outcomes for patients with advanced illnesses and their caregivers?
12. What is the comparative effectiveness of models involving social workers to facilitate palliative care discussions with patients who are approaching end-stage renal failure (CKD stages 3-4) vs.

models that don't involve social workers on patient functioning, quality of life, reducing avoidable hospital and emergency department visits, and reducing caregiver's burden?

13. What is the comparative effectiveness of palliative care models that include a dedicated care coordinator/case manager to liaise between palliative care specialists and the primary neurological specialist vs. those that don't include a care coordinator on symptom experience, medication complications, quality of life, ADLs, and other patient outcomes for patients with advanced Parkinson's disease or neurodegenerative dementia as well as on caregiver outcomes?

Models of care focused on caregivers

14. What is the comparative effectiveness of different palliative care delivery models (physician consult-based, nurse education, or social work supportive services) for reducing caregiver burden and distress in the outpatient setting?
15. What is the comparative effectiveness on patient-centered outcomes and caregiver burden of different approaches by which healthcare professionals can facilitate caregivers in coordinating the care for patients with advanced illnesses?

Leveraging technology to deliver palliative care

16. What is the comparative effectiveness of delivering palliative care to patients with neurodegenerative illnesses with mobility or transportation issues using telemedicine versus usual outpatient care on improved patient quality of life?
17. What is the comparative effectiveness on patient and caregiver health outcomes of electronic reporting systems that enable patients and caregivers to provide clinicians with real-time reports from home of their symptoms, functioning, and quality of life?