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Objectives

1. Discuss sampling strategies for measuring palliative care quality among Veterans with end stage liver disease (ESLD).
2. Describe approaches for measuring the quality of care for Veterans with (ESLD).

Original Research Background. Nineteen palliative care quality indicators (QIs) for patients with End Stage Liver Disease (PC-ESLD) were recently developed using the RAND/UCLA appropriateness method (RAM).

Research Objectives. These indicators were developed to measure the quality of care for patients with decompensated cirrhosis and a MELD > 19 or a CTP Score of 12 or greater.

Methods. We identified patients newly diagnosed with decompensated cirrhosis in 2012 who lived at least 30 days after diagnosis at a single Veteran health center using any of three ICD-9 based sampling strategies and followed them for one year or until death. A chart abstraction tool established a gold standard for clinical documentation of ESLD to compare the sensitivity and specificity of sampling strategies. We also pilot tested the PC-ESLD QIs in all patients confirmed to have ESLD.

Results. Out of 167 patients identified using at least one sampling strategy, 62 were confirmed to meet eligibility criteria after chart abstraction. The best performing sampling strategy had a sensitivity of 62% and specificity of 60%. The addition of laboratory values can improve specificity while limiting sensitivity. 98% of Veterans in the cohort were male, mean age at diagnosis was 61, 74.2% were white, 14.5% African American, 1.6% Asian, 6.5% other, and 3.2% did not have data on race. 38% were married or living with significant other, 36% homeless, and 66% had a history of drug or alcohol use. The overall QI pass rate for our cohort was 65% (59% for information care planning QIs and 76% for supportive care QIs). Patients receiving palliative care consultation were more likely to meet criteria for information care planning QIs (68% vs. 36%, $p=0.02$).

Conclusion. PC-ESLD Quality Indicators are valid and feasible.

Implications for Research, Policy, or Practice. Measuring the quality of palliative care for patients with ESLD is feasible and can identify opportunities for quality improvement in a vulnerable population.

Palliative Care Needs of Individuals with Cystic Fibrosis: A National Survey of Patients, Caregivers, and Cystic Fibrosis Care Team Members (S862)

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Objectives

1. Describe patient, caregiver, and providers perceptions of how palliative care in cystic fibrosis differs from palliative care in other conditions.
2. Identify the top palliative care needs of individuals with cystic fibrosis.

Original Research Background. Although palliative care (PC) has been demonstrated to alleviate suffering for patients with serious illness, no evidence exists for its role in cystic fibrosis (CF).

Research Objectives. To ensure the relevance of future CF-specific PC education and interventions, we 1) identified top PC needs of individuals with CF; and 2) examined perceptions of if/how PC may need to be different in CF.

Methods. Adults with CF (“patients”), family caregivers (“caregivers”), and CF care providers (“providers”) recruited from online listservs maintained by the Cystic Fibrosis Foundation completed an online survey. We used descriptive statistics to analyze responses.

Results. All participant groups, including 85% of 70 patients, 87% of 100 caregivers, and 84% of 350 providers felt PC in CF differs from PC in other conditions. All groups ranked the unpredictable disease course as the top difference (44% of patients, 42% of caregivers, 39% of providers). Other key differences included shortened life expectancy and CF being a lifelong disease. Emotional support was identified as the top PC need of individuals with CF (ranked first by 38% of patients, 45% of caregivers, 49% of providers), with emotional symptom management also being a top need per patients and caregivers. Patients and providers felt advance care planning is a top PC need. Adult providers ranked physical symptom management as a top need more often than pediatric providers (47% vs 29%, $P=0.001$). Pediatric providers identified caregiver support as a top need more often than adult providers (28% vs 16%, $P=0.011$).

Conclusion. Most patients, caregivers, and providers feel that PC is different in CF than in other serious illnesses and identify a variety of PC needs.

Implications for Research, Policy, or Practice. PC education and interventions targeting key differences and needs could enhance the impact of PC in CF.

