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Objectives

1. Examine relationships between sociodemographic factors and enrollment status in an early palliative care interventional clinical trial in the Deep South.
2. Describe baseline patient-reported outcome measures of quality of life, symptom burden, mood [anxiety/depression], activation, coping style, social support, self-reported health, health literacy, and spiritual/religious coping.

Original Research Background. Improving minority and underserved rural patient recruitment to palliative care (PC) clinical trials is a high clinical research priority area. We conducted a randomized trial of ENABLE CHF-PC (**E**ducate, **N**urture, **A**dvice, **B**efore **L**ife **E**nds **C**omprehensive **H**eartcare for **P**atients and **C**aregivers) early PC telehealth intervention for persons with heart failure.

Research Objectives. To explore racial (Black vs White) and rural (vs. urban/suburban dwellers) ENABLE CHF-PC participant enrollment rates and differences.

Methods. Using bivariate tests and measures of association, we compared consented and non-consented patients by race and residency status. Among randomized participants we examined baseline differences in sociodemographic/clinical characteristics and baseline patient-reported outcomes (PROs) (quality of life [QOL], symptom burden, mood, resource use, activation, coping style, social support, health literacy, and spiritual/religious coping).

Results. Of 564 eligible patients, 82% (n=461) consented and 90% (n=415) of those were randomized. Of 103 eligible participants who declined, 73.5% (n=75) were White compared to only 25% (n=26) who were Black (d-equivalent =0.57; p<0.01). Of those randomized, 26 % (n=108) resided in a rural area (by RUCA criteria). Among rural residents there was a higher portion of White 58.3% (n_w=63) compared to Black participants 40.7% (n_B=44) (d-equivalent=0.34; p=0.124). Baseline PROs were not statistically different based on rural/urban location.

Conclusion. Higher proportions of Black and rural patients were recruited, relative to the Alabama population (26% African American; 23% Rural). At baseline, patients reported a fair QOL, low anxiety/depression and average pain. Minority and rural patient recruitment is possible despite documented PC disparities.

Implications for research, policy or practice. High recruitment rates of Black patients may be attributable to racial congruence between

recruiters and patients. We found no PRO differences based on racial or rural status; lack of disparities may be due to similar access to care and socioeconomic status.

An Opportunity for Palliative Care: Symptom Burden in Patients with Amyloidosis (S872)



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Objectives

1. Evaluate symptom burden of patients undergoing treatment for amyloidosis.
2. Justify the need for palliative specialists to be a part of standard of care for patients with amyloid.
3. Propose a model for palliative care to be integrated with standard of care for patients with amyloidosis.

Original Research Background. Although significant symptom burden has been described in patients with amyloidosis, few studies have used a validated tool to assess symptom burden or severity. Amyloidosis has many similarities to cancer; prognosis is poor, multiple organs may be involved, and treatment toxicities are common.

Research Objectives. To evaluate baseline symptom severity using the Edmonton Symptom Assessment System (ESAS), and the change in total symptom burden between outpatient hematology-oncology clinic visits in patients with amyloidosis.

Methods. Retrospective chart review of 48 consecutive patients with amyloidosis presenting to a cancer center outpatient clinic. ESAS and Total Symptom Distress Scores (TSDS) representing the combined physical, emotional, and well-being intensities were reported at each visit. Individual ESAS scores ≥ 4 were considered moderate to severe intensity. The minimal clinically important difference (MCID) was calculated for TSDS between first and second visits. Based on past research cutoffs used were $\geq +3/90$ for improvement and $\leq -4/90$ for deterioration. Patients being co-managed with at least one appointment with palliative care (PC) during the study period, were noted.

Results. Baseline ESAS scores were collected on 48 patients with 31 also receiving a second. At baseline 34 (71%) had at least one or more moderate-severe symptoms. Fatigue in 23 (48 %) and insomnia 42% were most common. The MCID for TSDS showed 35% of patients improved while 35% showed deterioration. Only 6 (13%) of patients received palliative care.

Conclusion. Many patients with amyloidosis experience high symptom burden, and although the majority report moderate/ severe fatigue, and insomnia, few are co-managed by PC. About one third had improved symptom burden at their second visit.

Implications for Research, Policy, or Practice. Patients with amyloidosis have high symptom burden and may benefit from specialist palliative care. Further research is required to establish practice protocols and evaluate outcomes.

Testing Usability and Acceptance of the Electronic Patient Visit Assessment (ePVA) for Head and Neck Cancer: An Iterative Process (S873)



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Objectives

1. Describe usability testing of a web-based patient-report application for assessment of symptoms.
2. Evaluate the effectiveness of the usability testing and refinement of the electronic Patient Visit Assessment by the study population.

Original Research Background. Patients with head and neck cancer experience substantial symptom burden. A clinically useful tool is needed to evaluate symptoms for early detection of symptoms and functional limitations. Therefore, we developed a web-based electronic patient visit assessment (ePVA) for head and neck cancer. Using an iterative process to identify issues related to usability of the tool is imperative for the implementation of the ePVA in clinical settings.

Research Objectives. 1) Determine usability of the ePVA in head and neck cancer, and 2) refine the ePVA system over time based on patients' suggestions from the iterative process.

Methods. Study design consisted of usability testing using the Think Aloud technique to guide the iterative process to refine the ePVA based on participants' evaluations. After informed consent, 30 participants with head and neck cancer (Mean age = 61, 67% Male, 70% White, 83% stage IV cancer) completed the ePVA using iPads while thinking aloud about ease of use. Following ePVA completion, participants answered a valid and reliable survey about usability. All patient conversations were recorded, transcripts were analyzed using thematic analysis.

Results. Majority of participants reported symptoms (oral symptoms: 93%, fibrosis: 60%, fatigue: 60%); 90% strongly agreed/agreed that the system was easy

to use and 80% were very satisfied. Only minor usability problems were reported, decreasing in frequency over the study period. No usability problems were reported by the last 3 participants who completed the ePVA. Based on patients' suggestions from the iterative process, refinement of the ePVA included increased touch sensitivity and customized error messages to improve ease of use.

Conclusion. Study findings indicate that the ePVA is easy to use and has good acceptance by the study population.

Implications for Research, Policy, or Practice. Future research using the ePVA includes mapping of longitudinal trajectory of symptoms and clinical usefulness studies.

Bereavement Interventions for Grieving Family Members: A Systematic Review (S874)



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Objectives

1. Describe psychoeducational bereavement interventions that can be offered to family members during the first year of bereavement.
2. Identify family member outcomes that can be measured in an effort to determine if bereavement interventions are effective.

Background and Objectives. Bereavement care is part of palliative care that continues after patient deaths. It is important to determine what interventions are helpful and contribute to positive outcomes since supporting the bereaved may prevent long-term negative problems. The purpose of this systematic review was to review and evaluate the evidence regarding bereavement interventions for bereaved adults during the first year of bereavement.

Study Identification. Searches of MEDLINE, Embase, CINAHL, PsycINFO, and the Cochrane Central Register of Controlled Trials were conducted. Search terms used were grief, bereavement, mourning, intervention, program, support, therapy, outreach and counsel. A comprehensive review was conducted of bereavement intervention investigations published between 1979 and 2018.

Data Extraction and Synthesis. Twenty-five investigations were identified and analyzed. Of the 25 investigations 16 were randomized control trials and 9 were quasi experimental investigations. The interventions designed and tested included psychoeducational interventions (6), support group interventions (7), 1:1 support interventions provided by professionals, non-professionals or a combination of both (4), and