

## **Healthcare Utilization and End of Life Care Outcomes for Patients with Decompensated Cirrhosis based on Transplant Candidacy (RP500)**

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### **Objectives**

1. Describe the current state of healthcare utilization and end-of-life care for patients with decompensated cirrhosis and present evidence regarding the influence of transplant candidacy on these outcomes
2. Explore strategies to promote collaboration between palliative care specialists and hepatologists to improve end-of-life care for patients with decompensated cirrhosis

### **Abstract**

**I. Importance:** Patients with decompensated cirrhosis have high rates of healthcare utilization at end-of-life (EOL). However, the impact of transplant candidacy on intensity of EOL care is currently unknown.

**II. Objective(s):** To assess the relationship between transplant candidacy and intensity of EOL care in the last year of life in an ambulatory cohort of patients with decompensated cirrhosis.

**III. Method(s):** We performed a retrospective analysis of 230 patients with decompensated cirrhosis who were evaluated for liver transplantation in a large healthcare system between 1/1/2010 and 12/31/2017 and died by 6/20/2018. We compared healthcare utilization in the last year of life and EOL care outcomes between transplant-listed (n=133) and non-listed (n=97) patients. We examined predictors of palliative and hospice care utilization using multivariate logistic regression.

**IV. Results:** During the last year of life, patients had a median of 3 [IQR 2-5] hospitalizations and spent a median of 31 days [IQR 16-49] in the hospital. In all, 80% of patients died in the hospital, with 70% dying in the intensive care unit. The majority (70.0%) received a life-sustaining procedure (mechanical ventilation, renal replacement therapy, or cardiopulmonary resuscitation) during their terminal hospitalization, which did not differ between transplant-listed and non-listed patients (74.4% vs. 63.9%, p=0.09). Transplant-listed patients had lower odds of receiving specialty palliative care (OR 0.43, p=0.005). Patients with hepatocellular carcinoma had higher odds of receiving hospice care (OR 2.03, p=0.049).

**V. Conclusion(s):** Patients with decompensated cirrhosis had intensive healthcare utilization during their last year of life regardless of transplant candidacy.

**VI. Impact:** Further work is needed to optimize EOL care for patients with decompensated cirrhosis, particularly for patients who are ineligible for transplantation.

## **Lack of Exposure to Hospice and Palliative Medicine Training for African American Students: the State of the U.S. Medical Education System (RP501)**

**Presenter:** Lindsay Bell, BA, Palliative Research Center, Univ. of Pit, Pittsburgh, PA  
Jessica Livingston, BS, MPH, Children's National Hospital, Washington, DC  
Yael Schenker, MD, University of Pittsburgh, Pittsburgh, PA  
Robert Arnold, MD,FACP,FAAHPM, University of Pittsburgh, Pittsburgh, PA  
Tessie October, MD, Children's National, Washington, DC

### **Objectives**

1. By the end of the presentation, participants will be able to compare HPM training opportunities at HBCUs, non-minority serving institutions with the highest and lowest percentage of AA students, and the top ten ranked medical schools in the U.S.
2. After attending this session, learners will be able to analyze factors in the U.S. medical education system that contribute to underrepresentation of African American doctors in the HPM workforce.

### **Abstract**

**I. Importance:** The hospice and palliative medicine (HPM) workforce lacks racial diversity; less than 5% of HPM fellows are African American (AA). Little is known about AA trainees' exposure to HPM during medical school and residency training.

**II. Objective(s):** To describe HPM training opportunities for AA students during medical school and residency training.

**III. Method(s):** Data were collected through publicly-accessible websites and communication with institutional representatives from 34 medical schools in 4 pre-determined categories: historically black colleges and universities (HBCUs) (N = 4), non-minority serving institutions with the highest (N = 10) and lowest (N = 10) percentage of AA medical students, and the top ten ranked medical schools nationally (N = 10). Questions focused on medical school curricula; internal, family, emergency, and pediatric residency training program curricula; and fellowship programs.

**IV. Results:** No HBCUs offer an HPM course, clerkship, fellowship program, or rotation during residency. Only 75% of HBCUs are affiliated with a hospital that has an HPM program or service. Institutions with a higher percentage of AA students are less likely to offer an HPM fellowship program than institutions with a lower percentage of AA students and top ranked medical schools (50% vs. 80%,  $p = 0.026$ ). Similarly, institutions with a higher percentage of AA students are less likely to offer HPM elective rotations during internal (62% vs. 100%,  $p = 0.027$ ) and family medicine (43% vs. 100%,  $p = 0.003$ ) residency training than institutions with a lower percentage of AA students.

**V. Conclusion(s):** Medical students and residents at schools with the highest percentage of AA medical students are less likely to have access to an HPM fellowship program and HPM elective rotation during their training.

**VI. Impact:** Lack of exposure to HPM training for African American medical students and residents may contribute to underrepresentation in the HPM workforce.

## **Keystones in Behavioral Intervention Research in Hospice and Palliative Care (RP502)**

**Presenter:** George Demiris, PHD, University of Pennsylvania, PA

Debra Parker Oliver, MS,MSW, University of Missouri, Columbia, MO

Karla Washington, PhD, University of Missouri, MO

### **Objectives**

1. Incorporate keystone considerations into the behavioral intervention research lifecycle
2. Integrate ethical and cultural considerations in the design and evaluation of behavioral research

### **Abstract**

**I. Importance:** The design of behavioral interventions in hospice and palliative care needs to acknowledge the unique challenges of these settings. Strategies to integrate ethical and cultural considerations, and to improve likelihood for translation into practice are needed.

**II. Objective(s):** This presentation demonstrates how ethical considerations, cultural congruence, interdisciplinary collaboration and engagement of stakeholders can serve as keystones, namely foundational threads that inform the design, implementation and evaluation of a behavioral intervention in hospice and palliative care.

**III. Method(s):** A model for behavioral intervention research was developed by our research team specifically for the hospice and palliative care settings. This model includes iterative steps that cover the spectrum of behavioral intervention research, starting from the definition and analysis of a problem, moving into the design of an intervention, pilot-testing, refining and formally evaluating the intervention as well as disseminate findings and translating the intervention.

**IV. Results:** Based on three federally funded clinical trials in various settings (including two clinical trials in home hospice and one in outpatient palliative care) we demonstrate how stakeholders can be engaged in all phases of the intervention development and testing. Similarly, strategies to address cultural congruence and methods to incorporate interdisciplinary perspectives are presented. Ethical considerations and challenges associated with the testing of behavioral interventions in these settings are discussed.

**V. Conclusion(s):** In order to ensure that behavioral interventions can be tailored and effective and easily translatable into practice, extensive planning is required. A structured approach that integrates ethical and cultural considerations as well as interdisciplinary perspectives in all phases of the intervention design and testing, rather than an afterthought, can maximize the chances of a successful implementation and translation into practice.

**VI. Impact:** The defined keystone considerations can inform and strengthen the design of behavioral interventions targeting patients, families, clinicians or other stakeholders in hospice and palliative care settings.

## **National Variation in Palliative Care and Associated Outcomes Among Decedents with Heart Failure in Veterans Affairs Medical Centers (RP503)**

**Presenter:** Shelli Feder, PHD, APRN, ACHPN, Yale University, New Haven, CT

Mary Ersek, RN, FPCN, Dept of Veterans Affairs, Philadelphia, PA

Ann Kutney-Lee, PHD, RN, FAAN, Corporal Michael J. Crescenz VA Medical Center, Philadelphia, PA

Nancy Redeker, PhD, Yale University, West Haven, CT

Lori Bastian, MD, Yale University and VA Connecticut, New Haven, CT

Kathleen Akgun, MD, MS, VA Connecticut Healthcare System, West Haven, CT

### **Objectives**

1. Understand system-level approaches to characterizing palliative care reach in a large, single-payer healthcare system.
2. Discuss study methodology for assessing variation in palliative care reach among multiple healthcare facilities.
3. Recognize the role of facility-level variation in palliative care reach and patient outcomes.

### **Abstract**

**I. Importance:** National policies require that all Veterans with serious life-limiting illness have access to palliative care at all Veterans Affairs Medical Centers (VAMCs).

**II. Objective(s):** To describe VAMC variation in rates of palliative care consultation (PCC) and associated outcomes among decedents with heart failure (HF).

**III. Method(s):** Retrospective analysis of Veterans Affairs (VA) medical records and Bereaved Family Survey data. Veterans with HF who received a PCC within 90 days of death were identified. Outcomes included 1) the Bereaved Family Survey-Performance Measure (BFS-PM), defined as an overall rating of “excellent” for care received during the last month of life, 2) death in inpatient hospice, 3) documented family contact with bereavement services and 3) death in the intensive care unit (ICU). Using multivariable logistic regression, we created VAMC-level quintiles of PCC rates, assigning Veterans to quintiles based on the VAMC where they died. We determined associations between quintiles and study outcomes adjusting for demographic and clinical covariates.

**IV. Results:** Of 8,655 decedents with HF in 122 VAMCs, 98% were male, 76% were white, 18% were black, and mean age at death was 78 years. VAMC rates of adjusted PCC ranged from 35-90% ( $p < .001$ ). Relative to Veterans who died in VAMCs with the lowest rates of PCC, family members of Veterans who died in VAMCs with the highest rates of PCC were more likely to report their loved one’s end-of-life care as “excellent” (odds ratio (OR) 1.32, 95% Confidence Interval (CI) 1.04–1.66) and Veterans were more likely to die in inpatient hospice (OR 4.29, 95% CI 2.30–8.03), receive bereavement services (OR 1.98, 95% CI 1.11–3.53) and were less likely to die in the ICU (OR 0.40, 95% CI 0.26–0.61).

**V. Conclusion(s):** Rates of PCC vary widely across the VA for decedents with HF, with high rates associated with higher-quality end-of-life care.

**VI. Impact:** Research is needed to evaluate palliative care delivery among high-performing VAMCs to identify and scale best practices across the VA system.

## **Compared to what? Comparing Counterfactuals in an Observational Study of Palliative Care (RP504)**

**Presenter:** Brystana Kaufman, PHD, Duke University, Durham, NC

Melissa Greiner, MS, Duke University, Durham, NC

Matthew Harker, MBA, MPH, Duke University / Social Science Research Institute, Durham, NC

Sarah Cross, MPH, LMSW, Duke University, Durham, NC

Sarah Petry, BS, Duke University Sanford School of Public Policy, Durham, NC

David Anderson, MS, Duke University, Durham, NC

Janet Bull, MD, HMDC, FAAHPM, Four Seasons, NC

Courtney Van Houtven, PHD, Duke School of Medicine, Durham, NC

### **Objectives**

1. Describe challenges encountered in identifying counterfactual cohorts for palliative care interventions.
2. Discuss the impact of counterfactual cohort selection methods on the evaluation of community based palliative care.

### **Abstract**

**I. Importance:** Palliative care improves patient and family outcomes, and evidence for cost-savings is needed to support scaling palliative care programs.

**II. Objective(s):** To evaluate the impact of the counterfactual cohort definition in the evaluation of Medicare costs in a palliative care (PC) program.

**III. Method(s):** Using 100% Medicare claims in North and South Carolina (the Carolinas) and 20% random samples from six other states. Medicare costs were compared in the 6 months before and after the index date for 2983 Medicare fee-for-service beneficiaries age 65+ participating in a PC program and for three matched usual care (UC) cohorts: 1) regional 2) two State and 3) eight State.

**IV. Results:** The PC cohort differed from the three UC cohorts on observable baseline characteristics including morbidity and utilization, as well as post-period costs. Monthly costs in the baseline period were significantly ( $p < .05$ ) higher in the PC cohort for two of three counterfactuals. The matching algorithm was most successful when the match pool was expanded to all eight states. When compared to the regional UC cohort using multivariable adjusted models, PC was associated with an [MG1] increase in costs of 64% (95% CI=51%-77%) post-entry relative to UC. This association was attenuated when PC cohort was compared to the two State (33%, 95% CI=22%-46%) and eight State (23%, 95% CI=10%-36%) UC cohorts.

**V. Conclusion(s):** While larger pools improved balance on observable characteristics between treatment groups, claims-based studies may underestimate the value of PC due to residual confounding

**VI. Impact:** Evaluation should be designed as an integral component of demonstrations, especially for interventions targeting populations with non-claims based inclusion criteria like the seriously ill. As more demonstration projects are proposed, PC demonstration designs may benefit from cluster randomization strategies by provider or county and clear eligibility criteria to facilitate evaluation and implementation.

## **Symptom Classes in End-Stage Liver Disease: A First Scientific Step (RP505)**

**Presenter:** Lissi Hansen, PHD, Oregon Health & Science University, Portland, OR

Arnab Mitra, MD, Oregon Health and Science University, Portland, OR

Michael Chang, MD, Portland VA Medical Center, Medicine, OR

Shirin Hiatt, MPH, MS, RN, Oregon Health and Science University, Portland, OR

Christopher Lee, PHD, Boston College, Chestnut Hill, MA

### **Objectives**

1. Describe the differences among the three distinct classes of symptoms in patients with end-stage liver disease
2. Describe the three distinct classes of symptoms in context of patient characteristics and disease severity

### **Abstract**

**I. Importance:** To date, patients with end-stage liver disease (ESLD) have been categorized by disease severity. This is the first step to identify symptom classes in patients with ESLD based on symptom grouping and not based on disease state.

**II. Objective:** To identify distinct classes of physical and psychological symptoms among patients with ESLD without liver cancer.

**III. Methods:** Adult patients with a MELD-Na score  $\geq 15$  were recruited from hepatology clinics of two healthcare organizations as part of a longitudinal study (1R01NR016017, NINR). At baseline patients completed the 14-item Condensed Memorial Symptom Assessment Scale (CMSAS) and 10-item Patient Health Questionnaire (PHQ-9). Using these data, latent class mixture modeling, ANOVA, and chi-square testing were used to address the objective.

**IV. Results:** The sample ( $n=154$ , age  $56.4 \pm 11.1$  years) was predominantly male (65.6%), Caucasian (88.4%), CTP class B (55.8%) and C (38.6%) with an average MELD-Na score of  $17.0 \pm 4.2$  and a mix of etiologies (34.4% ETOH, 24.7% NASH, 26.6% viral). Three distinct classes of symptoms were identified: 25.8% of patients had mild, 39.5% had moderate, and 34.7% had more severe symptoms. All 14 CMSAS symptoms were significantly different across 3 classes (all  $p$ -values  $< 0.05$ ) but the classes did not differ by PHQ-9 score ( $p=0.769$ ). The greatest differentiators among the 3 classes were lack of energy ( $\eta^2=0.48$ ), worrying ( $\eta^2=0.40$ ), and feeling sad ( $\eta^2=0.39$ ). There was no difference across the symptoms classes in gender, etiology, MELD-Na or CTP score. Patients in the mild class were slightly older compared with patients in the severe class ( $60.2 \pm 11.4$  years vs.  $54.7 \pm 11$  years,  $p=0.048$ ).

**V. Conclusion(s):** Symptom severity occurred independent of disease severity, contrary to common assumptions.

**VI. Impact:** Future research should examine interactions of symptoms within each class and the stability of symptoms over time to allow for more targeted and efficient symptom class management strategies in this population.

## **Inpatient Palliative Care Consultation is Associated with Lower Hazard of Readmission for Patients with Hepatocellular Carcinoma (RP506)**

**Presenter:** Christopher Woodrell, MD, Icahn School of Medicine at Mount Sinai, New York, NY

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Jaison Moreno, MA, Mount Sinai, New York, NY

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Melissa Garrido, PHD, Boston VA Healthcare System, Boston, MA

### **Objectives**

1. Identify one effect of inpatient palliative care consultation on healthcare utilization by people with hepatocellular carcinoma (HCC).
2. Understand the significance of developing programs that increase rates of palliative care receipt by people with HCC.

### **Abstract**

**I. Importance:** Hepatocellular carcinoma (HCC), the most common type of liver cancer, develops as a complication of chronic liver disease. While palliative care has been shown to reduce rates of healthcare utilization in other populations, little is known of the impact of inpatient palliative care consultation for people with HCC.

**II. Objective(s):** Quantify the association between inpatient palliative care consultation and time to readmission among people with HCC.

**III. Method(s):** We identified adult HCC patients hospitalized for any reason at a single hospital between July 2012 and April 2016, and collected data on demographics, illness severity, receipt of palliative care, and hospitalization. The outcome of interest was time to readmission after discharge, and our unit of analysis was a patient hospitalization. We used propensity score kernel weights to ensure our treatment and comparison group were as similar as possible other than receipt of palliative care. We used a Cox Proportional Hazards model to compare time to readmission in each group, and performed sensitivity analyses to account for competing risk of mortality, clustering at the level of the individual, and inclusion of only index hospitalization for each individual.

**IV. Results:** Overall, 1,837 hospitalizations were included for 814 individual patients; 139 of the hospitalizations had at least one palliative care visit. The hazard ratio for readmission for HCC patients who received palliative care during that hospitalization as compared with those who did not was 0.38 (95% confidence interval 0.26-0.56).

**V. Conclusion(s):** Inpatient palliative care consultation is associated with lower readmission hazard in a sample of hospitalizations of people with HCC. Qualitative research is needed to identify unmeasured factors that affect healthcare utilization, such as patient and caregiver preference.

**VI. Impact:** This is the first study to show that inpatient palliative care consultation is associated with lower readmission rates for HCC patients, and supports efforts to increase availability of palliative care to this population.

## **Factors associated with higher symptom burden and lower quality of life among older adults with advanced cancer (RP507)**

**Presenter:** Yael Schenker, MD, University of Pittsburgh, Pittsburgh, PA  
Andrew Althouse, PhD, University of Pittsburgh, Pittsburgh, PA  
Margaret Rosenzweig, PhD, FNP-BC, AOCNP, FAAN, University of Pittsburgh, PA  
Douglas White, MD, MAS, University of Pittsburgh School of Medicine, Pittsburgh, PA  
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Marie Bakitas, PhD, CRNP, FAAN, UAB School of Nursing, BIRMINGHAM, AL  
Thomas Smith, MD, FAAHPM, Johns Hopkins Medical Institutions, Baltimore, MD  
Kenneth Smith, MD, MS, University of Pittsburgh, Pittsburgh, PA  
Robert Arnold, MD, FACP, FAAHPM, University of Pittsburgh, Pittsburgh, PA

### **Objectives**

1. Discuss symptom burden and quality of life for older adults receiving ongoing oncology care for advanced cancer.
2. Recognize clinical and demographic factors associated with higher symptom burden and lower quality of life among older adults receiving ongoing oncology care for advanced cancer.

### **Abstract**

**I. Importance:** Identifying factors associated with higher symptom burden and lower quality of life among older adults with advanced cancer can help target palliative care services to patients' needs.

**II. Objective(s):** To identify demographic and clinical characteristics associated with higher symptom burden and lower quality of life among older adults with advanced cancer.

**III. Method(s):** We conducted a secondary analysis of baseline data from CONNECT, a multisite primary palliative care intervention trial that enrolled patients with advanced cancer receiving oncology treatment from 17 practices in Western Pennsylvania. Symptom burden was measured using the Edmonton Symptom Assessment Scale (ESAS; range 0-90, higher scores = higher symptom burden) and quality of life was measured using the FACIT-Pal (range 0-184, higher scores = better quality of life). Predictors included demographic (age, sex, race, education, marital status, ability to manage on income) and clinical variables (cancer type, treatment type, functional status assessed by ECOG performance status).

**IV. Results:** Among 449 older adults (mean age  $75 \pm 7$  years; 53% female), the mean ESAS score was 23.8 (SD 15.7) and the mean FACIT-Pal score was 132.5 (SD 24.9). In multivariable analyses, difficulty managing on one's income ( $p=0.01$ ), not being married ( $p=0.03$ ), and poor functional status ( $p=0.001$ ) were independently associated with higher symptom burden. Difficulty managing on one's income ( $p<0.001$ ) and poor functional status ( $p<0.001$ ) were also independently associated with lower quality of life.

**V. Conclusion(s):** Palliative care needs are highest amongst older patients with advanced cancer who have difficulty managing on their incomes, have worse functional status, and do not have a partner at home.

**VI. Impact:** Alleviating suffering in older adults with advanced cancer will require accessible geriatric palliative care services designed for patients with the highest needs. Addressing social as well as medical issues may be important.

## **A National Study of End-of-Life Care among Older Veterans with Hearing and Vision Loss (RP508)**

**Presenter:** Joan Carpenter, PhD, CRNP, ACHPN, FPCN, University of Pennsylvania School of Nursing, PA  
Mary Ersek, RN, FPCN, Dept of Veterans Affairs, Philadelphia, PA  
Francis Nelson, BA, Department of Veterans Affairs, Philadelphia, PA  
Daniel Kinder, MPH, Dept of Veteran Affairs, Philadelphia, PA  
Melissa Wachterman, MD, MPH, Veterans Affairs, Boston, MA  
Dawn Smith, MS, Philadelphia Veteran Affairs Medical Center, Philadelphia, PA  
Andrew Murray, BS, US Department of Veterans Affairs, Philadelphia, PA  
Melissa Garrido, PHD, Boston VA Healthcare System, Boston, MA

### **Objectives**

1. Discuss the associations among vision and hearing loss and health care quality, including end of life care, in older adults.
2. Identify areas for improvement and/or active monitoring in the end of life care experience for Veterans with sensory loss and their bereaved family members.

### **Abstract**

**I. Importance:** Individuals with vision and hearing loss are at risk for lower quality healthcare and inadequate communication with clinicians. The degree to which sensory loss is associated with end-of-life (EOL) care quality is unknown.

**II. Objective(s):** To describe associations between hearing and vision loss and EOL care quality among Veteran decedents.

**III. Method(s):** Retrospective medical record review of all Veterans who died in an inpatient Veterans Affairs (VA) Medical Center between 10/2012-9/2017 (n=96,424) and Bereaved Family Survey (BFS) of decedents' next-of-kin (N=42,428). Outcomes included EOL care quality indicators (palliative consultation, death in a non-acute setting, chaplain contact), and BFS responses (satisfaction with overall care, pain and post-traumatic stress disorder management, communication, and emotional/spiritual support). Relationships between sensory loss and outcomes were examined with logistic and linear regression models that adjusted for patient and facility characteristics.

**IV. Results:** Of the decedents, 43.2% were diagnosed with hearing loss. EOL care quality indicators and BFS outcomes for Veterans with and without hearing loss were similar; but hearing loss was associated with slightly lower BFS scores for pain management (OR=0.91;95%CI=0.85-0.97) and less satisfaction with communication ( $\beta$ =-0.40;95%CI=-0.76- -0.04). Decedents with vision loss (15.1%) were less likely to receive a palliative care consult (OR=0.90;95%CI=0.87-0.94) or chaplain contact (OR=0.95;95%CI=0.90-1.00), and their BFS respondents were less likely to be satisfied with emotional support ( $\beta$ =-0.84;95%CI=-1.60- -0.08) and report overall care as "excellent" (OR=0.94;95%CI=0.89-1.00) than those without vision loss.

**V. Conclusion(s):** We observed small, statistically significant associations between sensory loss and EOL care quality. The observed differences are unlikely to be clinically meaningful but should be monitored to ensure they do not grow.

**VI. Impact:** Our study offers the most comprehensive description of hearing and vision loss and EOL care quality to date. Our results suggest that the VA is meeting most needs of patients with sensory loss at the EOL through palliative care practices.

## **Electronically Triggered Hospital-Based Palliative Care: Patient and Clinician Perspectives (RP509)**

**Presenter:** Kate Courtright, MD,MS, University of Pennsylvania, Philadelphia, PA

Stephanie Szymanski, BA, University of Pennsylvania, Philadelphia, PA

Sydney Hyder, MD, Hospital of the University of Pennsylvania, Philadelphia, PA

Gary Weissman, MD,MS, University of Pennsylvania, Philadelphia, PA

Whitney Eriksen, PHD, University of Pennsylvania, Philadelphia, PA

Claire Bocage, BA, University of Pennsylvania, Philadelphia, PA

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Michael Draugelis, BS, Penn Medicine, Philadelphia, PA

Susan Regli, PHD, MA, University of Pennsylvania Hospital System, Philadelphia, PA

Nina O'Connor, MD,FAAHPM, University of Pennsylvania Health System, Philadelphia, PA

Scott Halpern, MD, PhD, University of Pennsylvania, Philadelphia, PA

### **Objectives**

1. Describe patient and clinician attitudes and preferences regarding triggered palliative care consultation.
2. Evaluate a conceptual framework of patient and clinician preferences for triggered palliative care delivery using the electronic health record.

### **Abstract**

**I. Importance:** Hospitals are increasingly using triggers for palliative care to identify patients most likely to benefit, yet perspectives of key stakeholders on this practice are unknown.

**II. Objective(s):** Describe patient and clinician attitudes and preferences regarding electronically triggered palliative care.

**III. Method(s):** A descriptive qualitative study across two urban hospitals from June 2018 to January 2019. We conducted semi-structured interviews with seriously ill hospitalized patients (predicted 6-mo mortality risk  $\geq 0.5$ ) who received a triggered consult, hospitalists, and palliative care clinicians. Transcripts were independently dual-coded among three trained coders and every third transcript from each group was double-coded to assess agreement. We used an inductive thematic approach to identify emergent themes.

**IV. Results:** We interviewed 12 patients (mean age 67 years, 50% female, 58% married); 14 hospitalists (mean age 39 years, 43% female, 72% in practice <10 years); and 15 palliative care clinicians, including 9 MDs, 5 CRNPs, and 1 MSW (mean age 40 years, 67% female, 60% in practice <10 years). Five emergent themes were grouped into two processes of care: (1) the trigger strategy: patient identification and consult delivery and (2) the patient and clinician experience of care: quality of care, resource use, and education. The majority of participants were receptive to electronically triggered palliative care for its potential to foster care coordination and collaboration, promote awareness and education, and increase consultation among appropriate patients. Some patients and hospitalists expressed concern with automated care decisions, while palliative care clinicians were concerned about the potential impact on consult volume.

**V. Conclusion(s):** Seriously ill patients and clinicians were generally amenable to electronically triggered palliative care to increase opportunity, education, and improve efficiency, favoring consult delivery approaches that retained clinicians' decision autonomy.

**VI. Impact:** Future trigger designs should strive to balance efficiency and equity of palliative care resource use, and to promote coordinated and collaborative care.

## **Informing Design of a Smart Phone Mobile Application to Improve Cancer Pain Management: A Survey of Cancer Care Institutions in Nepal (RP510)**

**Presenter:** Virginia LeBaron, PhD, APRN, University of Virginia School of Nursing, Charlottesville, VA  
Sandhya Chapagain Acharya, MD, NAMS, Bir Hospital, Kathmandu, Province 03  
Catherine Elmore, MSN,RN,CNL, University of Virginia School of Nursing, Charlottesville, VA  
Kara Fitzgibbon, PhD, Center For Survey Research, University o, Charlottesville, VA  
Martha Maurer, PhD, MPH, MSW, University of Wisconsin, Madison, WI  
Daniel Munday, PHD,MBBS,FFARCSI,FRCP, University of Edinburgh, Edinburgh,  
Ramila Shilpakar, MD, National Academy of Medical Sciences,Bir, Kathmandu, 3  
Arati Ghising Tamang, RN, University of Virginia, Charlottesville, VA  
Usha Thapa, Masters in Nursing, RN, BP Koirala Memorial Cancer Hospital, Bharatpur,  
Rebecca Dillingham, MD, University of Virginia, Charlottesville, VA  
Bishnu Paudel, MD, National Academy of Medical Sciences, Kathmandu,

### **Objectives**

- 1.Attendees will be able to describe why cancer control and effective pain management is a critical issue in low-and-middle-income countries.
- 2.Attendees will be able to describe the main findings of the multi-institution survey conducted at 4 diverse cancer care institutions within Nepal.

### **Abstract**

**I. Importance:** Cancer is an increasing concern in low-and-middle income countries, and mobile technology can help deliver effective pain management. The Nepalese Association of Palliative Care (NAPCare) developed Pain Management Guidelines (PMG) but they are paper-based which limits practical daily up-take.

**II. Objective(s):** Design a mobile health application ('app') to facilitate broader implementation and accessibility of the NAPCare PMG.

**III. Method(s):** A cross-sectional survey was conducted to inform design of the mobile app. Questions focused on: 1) demographics; 2) knowledge and attitudes in managing pain; 3) barriers to cancer pain management at individual, institutional and country levels; 4) awareness and use of the NAPCare PMG; and 5) barriers to smart phone use and desired features of a mobile app. Surveys were administered by pencil-and-paper and analyzed in SPSS (v. 26.1).

**IV. Results:** Surveys were completed by 97 healthcare providers from 4 institutions in Nepal: public general hospital (n=30); public cancer hospital (n=30); private cancer hospital (n=30); and hospice (n=7). 48 (49.5%) had training in palliative care/cancer pain management and the majority (n=62; 63.9%) reported high confidence levels (scores of 8 or higher/10) in managing cancer pain. Over half (n=52; 53.6%) 'strongly agreed' it is their role to manage cancer pain; 94.8% (n=92) believe cancer pain can be difficult, but usually controlled. Most respondents (n=78; 80.4%) use an Android smart phone and 95.9% (n=93) had heard of the NAPCare PMG. 70.1% (n=68) report high frequency app use for either personal or clinical reasons. Key barriers to smart phone use included cost of data access (n=60; 61.8%) and concern about using a mobile phone in front of patients (n=41; 42.2%).

**V. Conclusion(s):** Healthcare providers in Nepal view cancer pain as an important symptom management concern. They use smart phones and apps frequently and are receptive to a mobile app to provide PMG support.

**VI. Impact:** Tracking contextual barriers to pain management and PMG adherence can inform effective interventions and policies in low-resource settings.

## **Prevention and Treatment of Chronic and Opioid-induced Constipation in Patients with Cancer: A Systematic Review and Meta-analysis (RP511)**

**Presenter:** Pamela Ginex, EdD, RN, OCN, Oncology Nursing Society, PA

Brian Hanson, MD, University of Minnesota, Minneapolis, MN

Yufen Lin, MSN, RN, Duke University, Durham, NC

Kristine LeFebvre, MSN, RN, RN-BC, AOCN, Oncology Nursing Society, PA

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Rebecca Morgan, PhD, MPH, McMaster University, Hamilton, ON

### **Objectives**

1. List evidence-based recommendations for management of opioid-induced constipation in patients with cancer
2. Compare interventions for management of constipation in patients with cancer
3. Recognize components of rigorous systematic review methodology

### **Abstract**

**I. Importance:** Constipation occurs in over 60% of persons with cancer during treatment and in palliative care. Constipation leads to physical and psychological distress and impacts quality of life; however, the evidence on prevention and resolution of symptoms is limited.

**II. Objective(s):** A systematic review and meta-analysis was conducted to inform the development of national clinical practice guidelines on the symptom management of constipation among persons with cancer. This review presents the comparative efficacy of lifestyle, pharmacologic, and complementary therapy interventions for the prevention and treatment of chronic and opioid-induced constipation.

**III. Method(s):** We searched PubMed, Wiley Cochrane Library and CINAHL through May 2019. Two investigators independently reviewed titles, abstracts and full-text studies for inclusion, extracting data from eligible studies. Primary outcomes included spontaneous bowel movement, stool frequency, stool consistency, straining, quality of life, and adverse events leading to treatment discontinuation. We assessed risk of bias using the Cochrane risk of bias tool and assessed the certainty of the evidence using the GRADE approach.

**IV. Findings:** Eight studies informed low/very low certainty of evidence of moderate benefit for osmotic or stimulant laxatives, methylnaltrexone, naldemedine and small benefit for naloxegol, prucalopride, alvimopan, lubiprostone, and linaclotide in addition to lifestyle factors for OIC. For chronic constipation, 14 studies informed low certainty of evidence of moderate benefit of osmotic or stimulant laxatives, very low certainty of trivial benefit of acupuncture, and very low certainty of moderate benefit of electroacupuncture.

**V. Conclusion(s):** This review summarizes the evidence on lifestyle, pharmaceutical, and complementary medicine approaches to the management of chronic and opioid-induced constipation while identifying gaps in the evidence and synthesizing current evidence to guide clinical care.

**VI. Impact:** Constipation is a prevalent symptom in patients with advanced cancer receiving palliative care and evidence-based interventions are needed to improve patient outcomes.

## **Enhancing the Skills of Palliative Care Researchers in Designing and Conducting Clinical Trials: Lessons from the Palliative Care Research Cooperative Group (PCRC) (RP512)**

**Presenter:** Christine Ritchie, MD,FAAHPM, University of California San Francisco, San Francisco, CA

Jean Kutner, MD,MPH,FAAHPM, University of Colorado School of Medicine, Aurora, CO

Kathryn Pollak, PHD, Duke University, Durham, NC

Sarah Garrigues, BA, UCSF, San Francisco, CA

### **Objectives**

1. Understand the need for training of palliative care investigators in the design and conduct of rigorous multi-site clinical trials.
2. Appreciate the effectiveness of the team-based approach to clinical trials research training utilized in the PCRC Clinical Trials Intensives.

### **Abstract**

I. **Aims:** Research in palliative care has not kept pace with the growth of the field. One contributing factor is the paucity of investigators equipped to conduct rigorous palliative care studies, especially multisite intervention studies. A core mission of the Palliative Care Research Cooperative Group (PCRC) is to enhance investigator capacity. We describe a successful model for investigator training using a team science approach.

II. **Methods:** Based on the NIH Office of Behavioral and Social Sciences Research's clinical trials course, the PCRC developed a Clinical Trials Intensive to train palliative care investigators to design, implement, and manage clinical trials. The three-day Intensive uses an experiential small group format to design a mock clinical trial. Faculty give didactics on essential elements of trials then offer hands-on guidance on how to write and develop RCTs, provide ways to anticipate and respond to reviewers' critiques, and share their personal RCT experiences. At the end of the Intensive, trainees give a formal presentation about their group's proposed RCT and set personal future clinical trials research goals. Trainees evaluate each session and the overall training based on content, practical value, organization, and networking opportunity and complete a 6-month post-training survey.

III. **Results:** The PCRC conducted 4 Intensives between 2016 and 2019 with investigators from multiple disciplines (medicine, nursing, pharmacy, social work, chaplaincy). Content covered trial design, measurement, intervention development and fidelity, recruitment, retention, analytic approaches, and data safety monitoring. Session and overall course evaluations received mean ratings of "Excellent". Qualitative feedback described the value of interprofessional team-based learning, trial development, and access to experienced faculty mentors. Six months post-training, participants (n=71) reported receiving 44 new grant awards and preparing or submitting 89 grant proposals. In 2020, the PCRC will be adding an Intensive focused specifically on research in the Alzheimers Disease and Related Dementias (ADRD) population.

IV. **Conclusion:** With a focus on facilitating conduct of multi-site clinical trials, the PCRC Intensives foster rigorous multi-disciplinary research by supporting mentorship and hands-on research skills acquisition.

## **A Psychometric Examination of the PAINAD in Older Adults with Delirium (RP513) CANCELLED**

Joy Goebel, RN, PhD, FPCN, California State University Long Beach, CA

Michelle Ferolito, GNP-BC, DNP, University of California Los Angeles, Santa Monica, CA

Nicholas Gorman, EdD, Keck Graduate Institute, Claremont, CA

### **Objectives**

1. Describe the psychometric properties of the PAINAD in a sample of older adults with delirium in a medical-surgical setting.
2. Discuss the need for holistic assessments of pain for older adults with delirium.

### **Abstract**

**I. Importance:** In patients with cognitive impairments who are unable to self-report pain, providers must rely on behavioral observation tools to assess and manage pain. Although frequently employed in medical-surgical units, evidence supporting the psychometric efficacy of the Pain in Advanced Dementia (PAINAD) for pain screening in older adults with delirium is lacking.

**II. Objective(s):** To examine the psychometrics of the PAINAD for older adults with delirium in medical-surgical settings.

**III. Method(s):** A descriptive repeated measures design was used to address the aim of the study. Sixty-eight older adults on two medical-surgical units with delirium (Confusion Assessment Method [CAM] +) unable to self-report pain were screened by two data collectors with the PAINAD and the Critical Care Pain Observation Tool (CPOT) between 2015-2016. Patients with a PAINAD score  $\geq 3$  or a CPOT score  $\geq 2$  received a pain intervention. Pain assessments were repeated 30 minutes post baseline or pain intervention.

**IV. Results:** Patients were predominately female (58.8%), with dementia (71%), and had a mean age of 85.4 years. Thirty-nine patients screened positive for pain and received a pain intervention. PAINAD reliability was strong (Cronbach's  $\alpha = 0.81-0.87$ ; interrater intraclass coefficients [ICC] = 0.91-0.94; test-retest ICC = 0.76-0.77). Construct validity was supported by a statistically significant interaction effect between time (baseline versus follow-up) and condition (pain intervention versus no pain group; Rater 1:  $F(1, 66)=8.31$ ,  $p=0.005$ ,  $\eta_p^2=0.11$ ; Rater 2:  $(F(1,66) = 8.22$ ,  $p=0.006$ ,  $\eta_p^2=0.11$ ).

**V. Conclusion(s):** The PAINAD is a reliable and valid pain screening tool for older adults with delirium in medical-surgical settings. This research found that delirium screening may be sub-optimal in practice.

**VI. Impact:** Pain and delirium frequently co-occur in the older adult population. Best practices require a holistic assessment for contributing pain and non-pain factors in older patients exhibiting distress.

## **Identifying trends in published palliative care research: A 5-year review (RP514)**

**Presenter:** Rishi Patel, DO, CBCC, CA

Ambereen Mehta, MD, MPH, UCLA, CA

Dheer Patel, Completing Undergraduate Degree, University of Michigan, CA

### **Objectives**

1. Identify the breakdown between qualitative and quantitative research in the peer-reviewed publications of hospice and palliative medicine. Discuss the call for more quantitative publications in the field of HPM.
2. Recognize trends in gender disparities within HPM hospice and palliative medicine authorship.

### **Abstract**

**I. Importance:** As research in the field of Hospice and Palliative Medicine (HPM) has grown, there has been a call for an increase in both quantitative research and representation of women in research.

**II. Objective(s):** To understand the landscape of published research in HPM, we evaluate the study type and author gender over the last 5 years.

**III. Method(s):** The authors reviewed every issue of the three US HPM journals with the highest impact factors (Journal of Pain and Symptom Management, Journal of Palliative Medicine, and American Journal of Hospice and Palliative Medicine) from 2013 to 2018 and the year 2004. Brief reports and original articles were included, all other publication types were excluded. The authors evaluated each publication for study type (qualitative, quantitative, mixed) and author (first and last) gender.

**IV. Results:** Of 2,639 studies reviewed, 101 were excluded because gender was indeterminable. There was no difference in the percent of quantitative papers published in 2013 compared to 2018 (68% vs 69%, respectively,  $p=0.8$ ). There was no significant difference in the percentage of first authors who were women in 2013 (56%) compared to 2018 (60%) ( $p=0.25$ ); however, there were significantly more female first authors in 2018 (60%) compared to 2004 (40%) ( $p=0.003$ ). There was no significant difference in the percentage of last authors who were women in 2018 (48%) compared to 2013 (51%) or 2004 (35%) ( $p=0.26$ ,  $p=0.07$ , respectively).

**V. Conclusion(s):** The majority of published papers in HPM peer-reviewed journals are quantitative, which remains unchanged over the past 5 years. Although there is a trend towards increasing female first authorship, the overall percentage is not proportional to the percentage of women in the HPM workforce. Senior female authors remain underrepresented. Future work will include more years of publications with expanded characteristics.

## **Trends in Non-Invasive and Invasive Mechanical Ventilation and at the End of Life (RP515)**

**Presenter:** Donald Sullivan, MD,MA, MCR, Oregon Health and Science University, Portland, OR  
Jennifer Bunker, MPH, Oregon Health & Science University, Portland, OR  
Hyosin Kim, PhD, Oregon Health & Science University, OR  
Joan Teno, MD,MS, OHSU, Portland, OR

### **Objectives**

1. Understand trends in non-invasive and invasive mechanical ventilation use at the end of life.
2. Explain potential reasons for differences in non-invasive and invasive mechanical ventilation at the end of life by patient subgroup, with an emphasis on use intended for palliation at the end of life.

### **Abstract**

**I. Importance:** Non-Invasive ventilation (NIV) has been suggested as a palliative approach to avoid invasive mechanical ventilation (IMV) use in dying persons.

**II. Objective(s):** Characterize the use of NIV and IMV among decedents between 2000 and 2015 with hospitalization in the last 30 days of life.

**III. Method(s):** Based on validated procedure codes that identify use of NIV and IMV, we examined trends in the use of NIV and IMV between 2000 and 2015 among 20% sample FFS Medicare Beneficiaries decedents. Multivariable regression models examined increase in NIV and IMV adjusting for age, gender, race, admitting diagnosis, comorbidities and Charlson comorbidity index. Exclusions: primary admitting diagnosis of cardiac arrest or pre-existing tracheostomy.

**IV. Results:** Between 2000 and 2015, 2.1 million hospitalizations (44.6% male, mean age 82.4, admitting diagnosis was pneumonia/sepsis 24.4%, cancer 10.5%, CHF 6.5%) occurred within 30 days of death. Overall, use of NIV increased from 0.8% to 7.4% while IMV use was stable from 13.6% to 13.1% from 2000 to 2015. The adjusted odds ratio (AOR) NIV increase compared to 2000 for 2005 was 2.5 (95% CI: 2.18-2.97), 2010 was 6.9 (95% CI: 5.84-8.09), and 2015 was 12.2 (95% CI: 10.41-14.36). A similar analysis of IMV found no striking increase in the use of IMV. In sub-analyses, a trend in increased NIV use was found among those with CHF (AOR 13.7, 95% CI: 11.17-16.78) and COPD (AOR 8.34, 95% CI: 6.42-10.83) from 2000-2015. NIV use also increased among persons with advanced dementia (AOR 12.8, 95% CI: 9.91-16.42) from 2000-2015.

**V. Conclusion(s):** Overall, there is a striking increase in the use of NIV in Medicare decedents without a reciprocal decrease in the use of IMV at the end of life. Among patients with CHF or COPD NIV may be intended to extend life, while use among persons with advanced dementia may be for palliation.

**VI. Impact:** Rapid growth in the use of NIV at the end of life necessitates trials to evaluate the effects.

## **Disparities in Supportive Care Needs Over Time among Minority and Non-Minority Patients with Advanced Lung Cancer (RP516)**

**Presenter:** Cardinale Smith, MD,PHD, Icahn School of Medicine at Mount Sinai, Bronxville, NY

Lihua Li, PHD, Mount Sinai Hospital, New York, NY

Jose Morillo, BS, Icahn School of Medicine At Mount Sinai, New York, NY

Juan Wisnivesky, MD, DrPH, Icahn School of Medicine at Mount Sinai, New York, NY

### **Objectives**

1. Describe the differences in supportive care needs among racial/ethnic minorities with advanced lung cancer patients at diagnosis.

2. Describe the differences in supportive care needs among racial/ethnic minorities with advanced lung cancer patients throughout the trajectory of illness.

### **Abstract**

**I. Importance:** Minority patients with lung cancer often have higher rates of morbidity and mortality. This leads to increased suffering among minority patients with lung cancer. Little is known, however, about disparities in supportive care needs among patients with advanced lung cancer and how these needs evolve over time.

**II. Objective(s):** To identify the differences in supportive care needs among minority and non-minority patients with lung cancer and identify how these needs change throughout the trajectory of illness.

**III. Method(s):** We performed a prospective cohort study of newly diagnosed patients with advanced lung cancer (stage III and IV). Patients completed a validated survey at baseline, 4-, 8- and 12-months assessing supportive care needs among seven domains: medical communication and information, psychological and emotional support, daily living, financial concerns, physical symptoms, spiritual needs, and social needs. Univariate and multivariate regression analyses compared differences in supportive care needs among minority (Black and Hispanic) and non-minority patients with advanced lung cancer. A mixed effect model with minority status, follow-up time and the interaction between minority status and time assessed the association between each need and minority status with changes over time.

**IV. Results:** We enrolled 99 patients; 55 (56%) were minorities and 44 (44%) were non-minorities. At baseline, minorities reported having significantly higher needs across each domain except medical communication and information ( $p=0.09$ ). Over time, the needs of both minority and non-minority patients increased with significant trend in the psychological/emotional ( $p=0.0002$ ), daily living ( $p=0.02$ ) and physical symptom ( $p<0.0001$ ) domains. After adjustment, the disparities in all domains between minority and non-minority remains the same over time.

**V. Conclusion(s):** Minority patients with advanced lung cancer are more likely to have increased supportive care needs than non-minority patients.

**VI. Impact:** Clinicians caring for minority patients with cancer need to provide targeted supportive care evaluation and treatment to ensure health equity among patients with lung cancer.

## **Engaging Palliative Care Patients to Improve Quality Measurement: Preliminary Findings from a Series of Cognitive Interviews (RP517)**

**Presenter:** Julia Rollison, PHD, MPH, RAND Corporation, Arlington, VA  
Sangeeta Ahluwalia, PHD, RAND Health Care, Santa Monica, CA  
Mary Lou Gilbert, JD, RAND Corporation, CA

### **Objectives**

1. Summarize challenging constructs for patients and caregivers related to feeling heard and understood and symptom management
2. Identify circumstances or constructs that may be challenging for patients to reflect on within a specified time period
3. Describe the complexity of item wording to assess critical care components in the context of palliative care.

### **Abstract**

**I. Importance:** There are significant gaps in symptom management and meaningful communication measures, despite the noted importance of these domains to seriously ill patients and their families. In partnership with AAHPM and the National Coalition for Hospice and Palliative Care, RAND Health is testing measurement items for a short survey about the care patients receive from their palliative care doctors, nurses, and other team members. Survey questions focus on concepts related to communication (e.g., feeling heard and understood) and symptom management (e.g., receiving help wanted for pain).

**II. Objective(s):** The interviews were designed to assess comprehensibility, ambiguity, and adaptability to context-specific circumstances for patients and caregivers as well as gather suggestions for language refinement for both symptom and communication measure concepts.

**III. Method(s):** The team conducted 22 one-hour telephone cognitive interviews using a convenience sample of patients and caregivers drawn from partner networks. Participants were mailed interview materials in advance of each call. Across four different interview rounds, the team adjusted item wording and question ordering to assess the items under different conditions.

**IV. Results:** Participants generally understood the intended meaning of the question content although there was ambiguity for some terms, like “whole person.” For some constructs, such as trust, participants struggled with restricting their responses to the stated three-month reference period. While there were expressed preferences for format and question wording, no clear patterns emerged across participants although some responses varied slightly depending on item wording.

**V. Conclusion(s):** In general, question wording and response options did not present challenges to understanding content, but certain constructs had different interpretations depending on the respondent. Further, the context setting, such as the lookback period and referenced provider team, were more difficult to answer for some questions than others.

**VI. Impact:** The items being tested will be part of a national study to understand the quality of care patients receive and may be used in the future by Medicare to help programs improve their care.

## **Unequal Access to Hospital Palliative Care in the US: A State-by-State Report Card (RP518)**

**Presenter:** Maggie Rogers, MPH, Center To Advance Palliative Care, New York, NY  
Diane Meier, MD,FACP,FAAHPM, Mount Sinai School of Medicine, New York, NY  
R Sean Morrison, MD,FAAHPM, Icahn School of Medicine Mount Sinai, New York, NY  
Jaison Moreno, MA, Mount Sinai, New York, NY  
Rachael Heitner, MA,CHPCA, Center to Advance Palliative Care, New York, NY  
Melissa Aldridge, PhD,MBA, Mount Sinai School of Medicine, New York, NY

### **Objectives**

1. Assess the growth and changes in the prevalence of hospital palliative care in the United States
2. Examine the relationship between hospital and geographic characteristics and the presence of palliative care

### **Abstract**

**I. Importance:** Given the continued growth of palliative care and the evolving healthcare market, understanding differences in availability of and access to palliative care programs in hospitals across the United States is key to improving the care of those with serious illness and their families.

**II. Objective(s):** To identify the regional, structural, and market correlates that are associated with the presence of palliative care programs in US hospitals.

**III. Method(s):** Using data from the 2017 American Hospital Association Annual Survey, we identified palliative care status in 2,409 hospitals with more than 50 beds. Multivariable logistic regression was used to examine the relationship of hospital and regional characteristics to the presence of palliative care programs.

**IV. Results:** 72% of hospitals were found to have palliative care programs. The percentage of states with at least 60% of hospitals with palliative care grew from 6% in 2008 to 41% in 2019. Seventeen percent of rural hospitals reported palliative care programs compared to 79% of urban hospitals. The Northeast had the highest prevalence of programs, while the lowest was found in the South. Hospital characteristics were significantly associated with palliative care, with the highest prevalence in mid-large size hospitals - 300 or more beds (94% vs. 62%), children's (86% vs. 71%), Catholic Church-operated (91% vs. 68%), teaching (98% vs. 67%), and nonprofit (82% vs. 46%) hospitals. Sole community (40%), for-profit (35%), and small hospitals with 50-150 beds (51%) were least likely to have palliative care.

**V. Conclusion(s):** Although 72% of hospitals with 50 or more beds have palliative care programs, there is marked variability in program prevalence by hospital type. Possible explanations for variation in availability include inadequate palliative care workforce, insufficient financing and incentives, lack of accountability for access to palliative care, and continued lack of knowledge about palliative care.

**VI. Impact:** Strategies to close gaps in access to hospital palliative care are required to meet the needs of millions living with serious illness.

## **Distress at End of Life: A Concept Analysis (RP519)**

**Presenter:** Kathryn Robinson, PhD(c), MSN, RN, CHPN, University of San Diego, San Diego, CA

### **Objectives**

1. Recognize the attributes, antecedents, consequences of, and empirical referents for distress at end of life.
2. Describe how this operational definition will aid the multidisciplinary team's approach to end of life care.

### **Abstract**

**I. Importance:** Distress is a common phenomenon at end of life (EOL). While the concept of distress has been researched and documented in multiple patient populations, contexts, and from specific dimensions (e.g. physical or psychological distress), a complete conceptualization of distress at EOL is limited in the current literature.

**II. Objective(s):** The purpose of this concept analysis was to synthesize the interdisciplinary literature related to distress to define attributes, antecedents, and consequences of distress at EOL. Additionally, empirical referents for validated measures of distress were also explored.

**III. Method(s):** The Walker and Avant method for concept analysis was utilized to choose a relevant concept of interest; determine the purpose/importance of analysis; identify all uses of the concept in the current literature; define attributes, antecedents, and consequences; identify a model, borderline, related, and contrary cases; identifying empirical referents; and synthesize an operational definition.

**IV. Findings:** Based on the attributes, antecedents, and consequences defined through the literature review, the following operational definition of distress within the context of EOL was formulated: Distress at end of life is a multidimensional (physical, psychosocial, existential, or spiritual) phenomenon involving moderate to severe discomfort, anguish or suffering due to mental and/or physical upset caused by severely unpleasant symptoms or stressors that are reported or observed and quantified by the patient, family, or provider. This distress threatens or causes harm and burden to the person or their family/caregiver and ultimately decreases quality of life.

**V. Conclusion(s):** A new operational definition of distress at EOL can aid the multidisciplinary team providing holistic care through timely assessment of and intervention for distress in its many dimensions. It will support the development and validation of appropriate measures and foster a unified interdisciplinary approach to distress management, EOL research, and ultimately increase comfort and quality of life for patients at EOL.

## **How Does Quality of Care at the End of Life in Medicare Advantage Compare to Traditional Medicare? (RP520)**

**Presenter:** Claire Ankuda, MD, MPH, Icahn School of Medicine at Mount Sinai, New York, NY  
Amy Kelley, MD,MSHS,FAAHPM, Mt Sinai School of Medicine, New York, NY  
Joan Teno, MD,MS, OHSU, Portland, OR

### **Objectives**

1. To appraise what is known about the benefits and disadvantages of enrollment in Medicare Advantage plans for a population with serious illness and the implications for the impending hospice carve-in
2. To compare the proxy-reported quality of care at the end of life in MA vs. TM.

### **Abstract**

**I. Importance:** Medicare Advantage (MA) programs now insure 34% of Medicare beneficiaries, but little is known about how they shape end-of-life care.

**II. Objective(s):** We aim to compare the quality of end-of-life care in MA vs. traditional Medicare (TM).

**III. Method(s):** We conducted a cross-sectional study of decedents ages  $\geq 65$  using the 2011-2017 Medicare-linked National Health and Aging Study. Next-of-kin or close friends reported their perception of end-of-life care quality measured with 8 items, including overall care rating, unmet needs, and concerns with communication. A multivariate model using survey weights examined the association of each item with MA vs. TM enrollment, adjusting for socio-demographics, function, respondent relationship, and regional MA penetration.

**IV. Results:** Of 2,168 decedents (weighted N 9,015,622), 31.6% were enrolled in MA. Decedents in MA were younger and more likely to be non-white race, low-income, and residing in a metropolitan region. They were less likely to have functional disability. In the first model, which accounted for survey design and sampling approach, respondents for decedents in MA were more likely to report: care that was not excellent (OR 1.31, 95% CI 1.07-1.60); that the decedent had unmet psychological needs (1.46, 1.00-2.14) or was not always treated with respect (1.39, 1.03-1.85); and that the family was not always kept informed about patient's condition (1.48, 1.15-1.92). In fully adjusted models, MA enrollment remained significantly associated with care not rated as excellent and family not always kept informed. Gaps in quality between MA and TM were most pronounced among individuals who died in nursing homes or resided in regions with a high penetration of MA plans.

### **V. Conclusion(s):**

Bereaved family and close friends of MA decedents report lower quality of care at the end of life compared to those in TM.

**VI. Impact:** These findings are concerning given the rapid growth in MA and plans to carve-in hospice to MA.

## **The Epidemiology of Loneliness and Social Isolation among Older Adults during the Last Years of Life (RP521)**

**Presenter:** Ashwin Kotwal, MD, University of California, San Francisco, San Francisco, CA

Irena Stijacic-Cenzer, MA, University of California, San Francisco, CA

Linda Waite, PhD, University of Chicago, IL

Carla Perissinotto, MD,MHS, UCSF, CA

Kenneth Covinsky, MD, UCSF, CA

Louise Hawkey, PhD, NORC at the University of Chicago, IL

Alexander Smith, MD,MPH,MS, UCSF Division of Geriatrics, San Francisco, CA

### **Objectives**

1. To describe the prevalence of loneliness and social isolation among older adults in the last years of life.
2. Identify independent risk factors for loneliness and social isolation in the last years of life.

### **Abstract**

**I. Importance:** While the last years of life have an intense focus on medical care, the same emphasis has not been placed on social well-being. Consequently, the epidemiology of key indicators of social health is unknown.

**II. Objective(s):** To determine the prevalence and correlates of loneliness and social isolation among older adults during the last four years of life.

**III. Method(s):** We used nationally-representative Health and Retirement Study data to examine adults age >50 who died while enrolled (N=3,540). Subjects were interviewed once in the last four years of life and classified into one of eight 6-month cohorts based on the number of months between the interview and death. We used validated measures of loneliness (3-item UCLA Loneliness Scale) and social isolation (13-item scale describing whether an individual lived alone, was unmarried/unpartnered, had minimal interaction with children, family, or friends, and had minimal community engagement). We modeled the relationship between loneliness or social isolation and time before death adjusting for sociodemographic and key health covariates.

**IV. Results:** The mean age at death was 76 (SD=11.4) and 50% were female. The prevalence of loneliness and social isolation in the last 4 years of life was 51% and 9%, respectively, and these rates were constant for four years prior to death. After adjustment, there were distinct risk factors for loneliness and social isolation ( $p<0.01$ ); cognitive impairment (Normal: 44%, CIND: 52%, Dementia: 56%), vision impairment (54% vs 46%), and incontinence (54% vs 46%) were risk factors for loneliness, whereas race (White: 11% vs Non-White: 5%), low income (20% vs 8%), and inability to walk a block (12% vs 8%) were risk factors for social isolation.

**V. Conclusion(s):** Loneliness occurs in half of older adults and social isolation occurs in nearly 10% of older adults, with a consistent prevalence for the four years prior to death.

**VI. Impact:** Study results provide insight into the burden of and populations at highest risk for end-of-life loneliness and social isolation.

## **Examining Population-Level Differences in Serious Medical Illness Between Veterans With and Without Post-Traumatic Stress Disorder (RP522)**

**Presenter:** Kathleen Bickel, MD,MPHIL,MS, University of Michigan, Aurora, CO  
Paula Langner, MS, Rocky Mountain Regional VA Medical Center, CO  
Anna Baron, PhD, Colorado School of Public Health, CO  
Cari Levy, MD PhD, University of Colorado, CO  
Gary Grunwald, PhD, University of Colorado, CO

### **Objectives**

1. Upon completion of this activity, the participant will recall at least 3 psychosocial issues commonly associated with post-traumatic stress disorder.
2. Upon completion of this activity, the participant will be able to describe at least 3 medical conditions commonly associated with post-traumatic stress disorder and describe how this population level study may or may not support an association with those medical conditions.

### **Abstract**

**I. Importance:** Post-traumatic stress disorder (PTSD) has been linked to specific medical conditions, such as cardiovascular disease and dementia. However, little is known about the intersection of PTSD and serious medical illness.

**II. Objectives:** To examine differences in demographics and in medical and psychiatric comorbidities between veterans with and without PTSD, among a cohort of veterans dying with serious medical illness.

**III. Methods:** Descriptive data of 564,262 users of Veterans Affairs, dying between 2012 and 2015 with serious medical illnesses, based on ICD-9 codes and stratified by PTSD, were compared using Student's t-test (continuous data) and chi-square (categorical data). Relative risks were calculated for psychiatric and medical diagnoses, comparing veterans with PTSD to those without PTSD, stratified by age (<60, 60-69, 70-79, ≥80).

**IV. Results:** Of the cohort, 55,804 (9.9%) had a PTSD diagnosis. Veterans with PTSD were more likely to be younger at death (age 71.9 vs 78.7,  $p<0.001$ ), non-white (17.6% vs 11.7%,  $p<0.001$ ), of lower socioeconomic status (4.0 vs 4.4,  $p<0.001$ ) and have a history of homelessness (13.7% vs 5.4%,  $p<0.001$ ). The relative risks (RRs) for alcohol and drug use disorders in veterans with PTSD were 3.07 (95% CI 3.00-3.15) and 2.35 (95% CI 2.30-2.40), respectively. For medical conditions, the highest RR for veterans with PTSD was for chronic liver disease (2.04, 95% CI 1.99-2.10). The RR for dementia in veterans with PTSD was 0.85 (95% CI 0.84-0.86). However, when stratified by age, dementia RR was highest for those < age 60 (1.42, 95% CI 1.26-1.61) and was >1 across all age subgroups (range 1.22-1.42). Only chronic pulmonary disease had RRs > 1 overall (1.14, 95% CI 1.13-1.15) and across all age subgroups. Cardiac disease risk was more modest, even with age stratification.

**V. Conclusion:** A combination of social, psychological, and medical challenges may contribute to the experiences of veterans with PTSD and serious medical illness.

**VI. Impact:** The impact of lung and liver disease in veterans with PTSD may be greater than previously identified.

## **Outcomes of Inpatient Hospice and Palliative Care Unit, and Role of Physician Assistants as Emerging Work Force in Upstream Inpatient Palliative Care (RP523)**

**Presenter:** Serife Eti, MD,FAAHPM, Montefiore Medical Center, NY

Felicia Slade, PAC, Montefiore Medical Center, NY

### **Objectives**

1. The learners will be able to understand the structural and operational needs of palliative care unit admits patients independent of code status and disease modifying treatments as well as home hospice patients for improved symptom management, and/or treatment of serious infections.
2. The learners will be able to understand the role of physician assistants in the Hospice and Palliative Care Inpatient Unit, and importance of inter professional education and training for the PAs

### **Abstract**

**I. Importance:** The models for inpatient palliative care units tend to evolve based on institutional settings, funding mechanisms or professional backgrounds of clinician champions. The palliative care unit at the Montefiore Medical Center as few other units distinguishes itself from the traditional inpatient hospice and palliative care units by employing physician assistants since 2007, with the same administrative regulation and standard of clinical competence.

**II. Objective(s):** 1. Outcomes and impact of the hospice and palliative care unit in an academic medical center, 2. Associated cost savings related to utilization of the palliative care unit for the care of seriously ill patients, 3. The role of physician assistants as an important work force in the management of the palliative care units

**III. Method(s):** Retrospective chart review for patient demographics and operational metrics such as admission resources, length of stay, disposition.

Palliative Care Impact Calculator, Center to Advance Palliative Care (CAPC) which is customized by the Special Projects team at the Department of Finance, Montefiore Medical Center, Bronx, NY.

**IV. Results:** In summary, there were total 454 discharges from the unit in 2017. 53% of the patients admitted to unit died during hospitalization. 30 % of the admissions converted to hospice general inpatient level care, average length of stay (LOS) was 10 days for hospice and non-hospice admissions. The average palliative care patient census was 8 per day. Median LOS in the unit for non-hospice patients was 3 days.

21% of patients admitted from ED, 63% admitted from Med-Surg units and step-down units. Approximately 10% of transfers was from ICUs. 38% of the patients discharged with hospice care to home and hospice residences. 25% of the patients died.

We estimated direct cost saving per case after palliative care consultation as \$11,185. Patient transfers to palliative care unit produced net cost avoidance of \$2,074,393 in 2017.

**V. Conclusion(s):** Palliative Care Units can be effectively run by employing physician assistants to provide upstream palliative care.

## **Outpatient Cardiac Palliative Care Reduces Healthcare Utilization (RP524)**

Todd Barrett, MD, MBA, FAAHPM, The Ohio State University, Columbus, OH

### **Objectives**

1. Outline hospitalization and healthcare utilization savings from an outpatient palliative care clinic.
2. Analyze the impact of a high value cardiac palliative care clinic from for a healthcare institution.

### **Abstract**

**I. Importance:** The American Heart Association and American Stroke Association have put forth policy statements recommending early and continuous access to palliative care for patients with advanced heart disease. Early integration of palliative care has been proven to improve the quality of life of patients with advanced heart failure. Other studies have suggested that palliative care in general has cost savings to hospital systems.

**II. Objective(s):** Determine if outpatient cardiac palliative care impacts hospitalization rates and cost of care in a quaternary care center.

**III. Method(s):** A cardiac specific outpatient palliative care clinic was opened at a major academic medical center in the United States. In the first 6 months (N=104) patients were referred to the clinic for goals of care and symptom management. Patients were tracked 90 days prior to their initial outpatient palliative care clinic visit and 90 days post visit to assess hospital utilization and total cost of care in the university hospital system.

**IV. Results:** Total hospitalizations reduced 30% (91 prior to palliative care compared to 64 post). 30-day readmission dropped by 11%. 36% (N=33) of pre-intervention hospitalizations were 30-day readmissions compared to 25% (N=16) in the post intervention time period. Total per-patient hospital system health expenditures were \$121,549 pre-palliative intervention and reduced to \$60,857 post-palliative intervention. This represents a total reduction in health spending of \$5,886,599.51 in the post palliative care time period. Average per hospital stay cost dropped by 27% from \$133,571 to \$97,943. A paired T-test shows this is a statistically significant reduction in per hospital stay charges (p=0.03).

**V. Conclusion(s):** Outpatient palliative care is known to improve quality of life in patients with advanced heart disease. Integration of outpatient cardiac palliative care reduces hospitalizations, 30-day readmission, total healthcare expenditures, and reduces cost of hospitalizations.

**VI. Impact:** Cardiac palliative care clinics are high value entities for patients and healthcare systems and teams should consider subsidizing the cost of palliative care clinic development.

## **African American Faith Leaders' Experience, Knowledge, and Perceptions of Hospice and Palliative Care (RP525)**

**Presenter:** Clare Stacey, PHD, Kent State University, OH

Nicholas Kreatsoulas, DO, FACEP, Mercy Health Youngstown, OH

Debra Pohlman, MD, PeaceHealth, St. John Medical Center, WA

Brittany Watts, MA, MDiv, Kent State University, OH

Steven Radwany, MD, FACP, FAAHPM, The Ohio State University Wexner Medical Center, Columbus, OH

### **Objectives**

1. Recognize key barriers to African American use of HPC services, as articulated by a African American clergy.
2. Identify key strategies for increasing African-American use of HPC services, based on recommendations of African American clergy in the sample.

### **Abstract**

African-American patients with life threatening illnesses are far less likely to use hospice and palliative care (HPC) services and are more likely to receive intensive treatments at end of life, relative to their white counterparts. Existing research points to numerous factors responsible for these disparities and to the important role spirituality and religion play in the lives of African-Americans, who may view HPC at odds with their faith.

To further explore religious and spiritual barriers to enrollment in hospice and palliative care, we conducted focus groups (N=6) with African-American clergy (n=22) living in the greater Akron-Canton-Youngstown area of Ohio. Sixteen of the clergy identify as Historical Black Protestants, five are Mainline Protestants, and one is an Evangelical Protestant. Seven clergy are women. Clergy were asked to discuss their understandings of and experiences with hospice and palliative care; how they minister to seriously ill congregants; how religious doctrine and beliefs impact understanding of end of life; and how they perceive the relationship between their congregants and the medical community. Respondents also completed a short demographic survey that measured perceptions of and experiences with HPC.

Across the focus groups, clergy report both positive and negative associations when it comes to HPC (their own perceptions and those of their congregants). For clergy who have encounters with HPC, positive experiences were more frequent than negative. Clergy identify several barriers to African-American utilization of HPC: History of racial discrimination; misinformation about HPC; and lack of education and outreach regarding the benefits of HPC. Clergy view themselves as playing a role in outreach regarding HPC and offer several strategies for change, including employing hospital chaplains as liaisons, increasing outreach and education about HPC, and developing carefully crafted public health and social marketing campaigns about HPC to the African-American faith community.

## **Palliative Care and Infection Management in Nursing Homes: A Nationwide Survey (RP526)**

**Presenter:** Aluem Tark, PhD, FNP-BC, RN, CHPN, University of Iowa, Iowa City, IA  
Leah Estrada, MA,BSN,RN, Columbia University School of Nurisng, New York, NY  
Mary Tresgallo, ACHPN, Columbia Universtiy, NY  
Denise Quigley, PHD, RAND, Santa Monica, CA  
Pat Stone, PhD, Columbia University, New York, NY  
Mansi Agarwal, PhD, Columbia University, New York, NY

### **Objectives**

1. Evaluate the current integration status of infection management and palliative care in nursing homes across the United States.
2. Interpret areas of infection management at EoL that could benefit from educational interventions for NH staff to improve practice.

### **Abstract**

**I. Importance:** Infections are common in nursing home (NH) residents at end-of-life (EoL) and often lead to antibiotic misuse and burdensome treatments. Palliative care (PC) is a proposed strategy to improve infection management at EoL in NHs.

**II. Objective(s):** To describe the current infection management policies, PC policies, and integration status of PC and infection management at EoL in NHs nationwide.

**III. Method(s):** In 2017/18 we conducted a cross-sectional survey of a representative random sample of NHs nationwide. Directors of Nursing completed the survey, which included validated items on the NH's infection management policies, palliative care policies, and integration of the two. Eligible NHs were non-specialized, free-standing, with at least 30 beds. Weighted descriptive statistics were computed from responses, including standardized means and standard errors.

**IV. Results:** We received 892 surveys (49% response rate), representing a weighted national sample of 15,381 NHs. 90% of NHs document what is important to residents and discuss spiritual needs at EoL. Patient preferences for infection management were mostly elicited in response to suspected infections (85%) and least upon NH admission (73%). In terminally ill residents, while 59% of NHs reported treating with only comfort measures and no antibiotics, 53% reported giving antibiotics near EoL, and 67% reported treating with antibiotics in suspected urinary tract infections. Notably, 59% of NHs reported transferring a terminally ill resident to the hospital for suspected aspiration pneumonia.

**V. Conclusion(s):** Wide variations in NH PC practices exist among timing of EoL care discussions and antibiotic usage for suspected infections, inconsistent with clinical guidelines. Despite this, most NHs reported considering all aspects of PC beyond relief of physical symptoms, including spirituality.

**VI. Impact:** This is the first national study to describe the integration of infection management and PC in NHs, illuminating the need for future research to understand if suboptimal practices are related to certain populations and/or settings (e.g., racial/ethnic minorities or rural).

## **The Namaste Care Intervention for People with Advanced Dementia Living in Care Homes: Results from a Feasibility Cluster Randomised Controlled Trial (RP527)**

**Presenter:** Catherine Walshe, PhD, Lancaster University, Lancaster,  
Anne Davidson Lund, Ed D, Lancaster University, Lancaster,  
Claire Goodman, PhD, University of Hertfordshire, Hatfield,  
Frances Bunn, PhD, University of Hertfordshire, Hatfield,  
Joanna Coast, PhD, University of Bristol, Bristol,  
Julie Kinley, PhD, N/A, London,  
Guillermo Algorta, PhD, Lancaster University, Lancaster,  
Nancy Preston, PhD BSc RGN, Lancaster University, Lancaster,  
Lesley Dunleavy, RN, Lancaster University, Lancaster,  
Katherine Froggatt, PhD, Lancaster University, Lancaster,

### **Objectives**

1. Understand the importance of feasibility studies in palliative care research.
2. Evaluate Namaste Care as a potential palliative care intervention for people with advanced dementia.
3. Understand the feasible components of a future study of Namaste Care in people with advanced dementia, and how these may be important in other studies in similar populations or settings.

### **Abstract**

**I. Importance:** Quality of life, care and dying can be variable for people with advanced dementia cared for in nursing homes. It is important that interventions are tested that may enable high quality care at the end of life; Namaste Care is one such intervention.

**II. Objective(s):** To establish the feasibility and acceptability, to staff and informal carers, of carrying out a cluster randomised controlled trial of the Namaste Care intervention for people with advanced dementia in nursing homes.

**III. Method(s):** Feasibility cluster trial with process evaluation and economic analysis. Nursing homes were randomised to intervention or usual care. The complex group intervention provided personalised care in a dedicated space, focused on sensory engagement, comfort management and physical environment enhancements. Participants were residents with advanced dementia (FAST score 6-7), their informal carers and nursing home staff. Primary outcomes: quality of dying (CAD-EOLD) and quality of life (QUALID). Secondary outcomes included: sleep/activity (actigraphy), neuropsychiatric symptoms, agitation, pain and satisfaction with care at the end of life.

**IV. Results:** Recruitment was feasible; 8 homes were recruited (2 withdrew before intervention commencement, 4 intervention and 2 control sites completed the study). 32 residents (intervention n=18; control n=14), 12 informal carers (intervention n=5; control n=7) and 97 staff (intervention n= 75; control n=22) were recruited. Primary outcome completion was high (100% at baseline; 96.8% at 4 weeks) with QUALID being more responsive to change over 24 weeks. The intervention was acceptable; the frequency of delivery varied reflecting the staffing, and physical environment of each home. Staff and informal carers reported changes for residents of increased social engagement and greater calmness. No adverse events due to the intervention were reported.

**V. Conclusion(s):** A future definitive trial is feasible with some adaptations to recruitment process, outcome measure choice and intervention specification.

**VI. Impact:** If effective, Namaste Care may improve quality of life and death for a traditionally hard to care for population.