

caregivers. Caregivers who feel supported by relationships with the patient they care for, family or friends may be buffered from the stress from patient heart failure.

Research Objectives. Test the moderating role of social support and caregiver-patient relationship quality on the longitudinal association between baseline heart failure patient illness severity and subsequent caregiver outcomes.

Methods. Longitudinal data were analyzed for 100 heart failure patient-primary caregiver dyads, a subset of participants in a randomized clinical trial of a symptom management and psychosocial care intervention. Key patient-reported predictors were symptom severity and level of disability. Moderating variables, measured at baseline, included caregiver-perceived social support and relationship quality. Caregiver outcomes included depression and caregiver burden at 12 months. Separate multiple regression analyses were used to examine the moderating role of social support and relationship quality. Regression models were adjusted for baseline demographics and baseline caregiver burden.

Results. Significant moderation effects were found on the caregiver burden outcome only. The association between baseline patient symptom severity and subsequent caregiver burden was mitigated by caregiver reports of higher relationship quality with the patient ($\beta=-0.30$, $p<0.05$ for interaction, model $r^2=0.50$). Similarly, social support moderated the association between patients' reports of disability and caregivers' later burden. Lower levels of perceived social support magnified the longitudinal association between baseline patient disability and caregiver burden 12 months later ($\beta=-0.24$, $p<0.05$ for interaction, model $r^2=0.54$).

Conclusion. Caregivers' relationships with their care recipient and perceptions of their social network can shape how they respond to and interpret the demands of caregiving from patient illness severity.

Implications for Research, Policy, or Practice. Promoting and cultivating positive social relationships within and outside the caregiver-patient dyad is a promising avenue for interventions aimed at reducing the burden experienced by caregivers for patients with heart failure.

Palliative Care Needs and Perspectives on Early Palliative Care from Individuals with COPD and their Family Caregivers: A Mixed Methods Study (FR441D)



Anand Iyer, MD, University of Alabama, Birmingham, AL. James Dionne-Odom, PhD RN ACHPN, University of Alabama at Birmingham, Birmingham, AL. Lanier O'Hare, MSN, University of Alabama at Birmingham,

Birmingham, AL. Sandhya Mudumbi, MD, University of Alabama at Birmingham, Birmingham, AL. deNay Kirkpatrick, DNP, University of Alabama at Birmingham, Birmingham, AL. Nataliya Ivankova, PhD MPH, University of Alabama at Birmingham, Birmingham, AL. Rodney Tucker, MD MMM FAAHPM, University of Alabama at Birmingham Center for Palliative and Supportive Care, Birmingham, AL. Mark Dransfield, MD, University of Alabama at Birmingham, Birmingham, AL. Cynthia Brown, MD MSPH, University of Alabama at Birmingham, Birmingham, AL. Marie Bakitas, DNSc NP-C FAAN, UAB School of Nursing, Birmingham, AL.

Objectives

- Identify chronic obstructive pulmonary disease (COPD) patient and caregiver palliative care needs.
- Describe COPD patient and caregiver perspectives on early palliative care.
- Synthesize qualitative perspectives and quantitative measures of palliative care needs.

Original Research Background. Little direction exists on how to integrate early palliative care (EPC) in COPD.

Research Objectives. To identify patient and family caregiver palliative care needs and to explore their perspectives on EPC in COPD.

Methods. We conducted a concurrent (quantitative + qualitative) mixed methods study of purposively sampled patients with moderate-to-very-severe COPD ($FEV_1/FVC<0.70$ and $FEV_1<0.80$) and their family caregivers. We measured patient quality of life using the COPD Assessment Test (CAT), with scores >20 defining poor quality of life. We conducted semi-structured in-depth interviews of patients and their family caregivers on palliative care needs and EPC, which were transcribed, coded, and examined for recurring themes. Results from quantitative and qualitative analyses were integrated to compare themes on palliative care needs by CAT ≤ 20 and >20 .

Results. Ten patients were on average 60 years old, 50% were African American, 30% female, and 40% had very severe COPD ($FEV_1<0.35$); 10 family caregivers were on average 58 years old, 40% were African-American, and 90% female. The 70% of dyads with a patient who had poor quality of life (CAT >20) reported greater palliative care needs including challenging respiratory and emotional symptoms, difficulty coping with COPD and defining caregiver roles, and concerns about outlook planning. Only 35% of participants had awareness of palliative care, and only 5% had an advanced directive. After we described EPC, patients and their family caregivers unanimously wanted EPC for: 1) Comprehensive supportive care; 2) Outlook planning; and 3) Illness education.

Conclusions. Patients with moderate-to-very severe COPD and their family caregivers had several unmet palliative care needs and limited awareness of palliative care; however, dyads unanimously found EPC acceptable after being given a description.

Implications for Research, Policy, and Practice. These data will guide development of interventions to integrate EPC in COPD.

3–4 pm

Concurrent Sessions

AAHPM Collaborations in the Field: Mapping Community Palliative Care and Modernizing the EDRS System (FR450)



Cordt T. Kassner, PhD, CEO, Hospice Analytics, Colorado Springs, CO. Maggie Rogers, MPH, Center to Advance Palliative Care, New York, NY. Rachael Heitner, MA, Center to Advance Palliative Care, New York, NY.

Objectives

- Describe the current status of the Mapping Community Palliative Care project goals.
- Understand how to register a new program on the Mapping Community Palliative Care website.
- Summarize key goals and progress of the Next Generation Electronic Death Registration System (EDRS).

AAHPM collaborates with multiple partners across the country, and this session will review two such collaborations. First, the Academy works with the Center to Advance Palliative Care (CAPC) and the Mapping Community Palliative Care project. Currently over 2,000 community palliative care providers are included – is yours one of them? Presenters will review current status of this project, how information being collected is being used, and answer your questions. Second, the Academy works with the Centers for Disease Control and Prevention to update the Next Gen Electronic Death Registry System (EDRS). Presenters will review goals and current status of this project, and answer any questions.

Making Meaning of Metrics: Utilizing Data in Home- and Community-Based Palliative Care in Large Healthcare Systems (FR451)



Sarina Isenberg, PhD MA, Sinai Health System, Toronto, ON, Canada. Bonnie Chen, MD, Kaiser Permanente, Oakland, CA. Laura Cantino, MD, Kaiser Permanente East Bay and Oakland Medical Center, Oakland, CA. Steve Lai, MD FAAHPM, Palo Alto Medical Foundation, Palo Alto, CA. Amy Hsu, PhD, Ottawa Hospital Research Institute, Ottawa, ON, Canada.

Peter Tanuseputro, MD MHS CCFP FRCPC, University of Ottawa, Ottawa, ON, Canada. Dana Benton, MS RN CNS, Kaiser Permanente Northern California, Sonoma, CA. Kuljeet Multani, MD HMDC, Palo Alto Medical Foundation, Fremont, CA.

Objectives

- State common potential benefits and challenges of collecting data about home and community-based palliative care (HCPC) in a variety of health systems.
- Compare approaches about how to best leverage this data to assess the impact of HCPC and to inform program growth.

Our international, multi-disciplinary panel will discuss both opportunities and lessons learned in leveraging data collection to support the growth of home and community-based palliative care (HCPC) programs within large health care systems.

Our presentation showcases three case studies:

- The single payer healthcare system in Ontario, Canada has allowed for large health administrative datasets. We will provide an overview of the data, and present two studies demonstrating the datasets use for research, policy and practice. Our 2011-2015 study (n=277,128) examined the relationship between receipt of HCPC in the last 90 days of life and subsequent health utilization/outcomes. This research has informed the Ontario government's investments into HCPC.
- Palo Alto Medical Foundation/Sutter Health is a large, multispecialty group serving about 1 million patients in Northern California at 4 clinical sites, with each providing a community-based palliative care program. We will discuss our efforts to leverage data to plan for sustainable growth for the program, including measurement to capture the work of each discipline, processes to utilize resources on interdisciplinary team effectively, and standardization of clinical assessments.
- Kaiser Permanente Northern California is an integrated health care system serving 4.2 million members at 15 clinical sites and 21 hospitals, with ambulatory palliative care available at all sites. We will present on efforts to standardize care across our system, including provision of process measures to allow sites to standardize clinical assessments, unifying documentation, and proactive patient identification using a regional registry.

By the end of this presentation, participants will be familiar with approaches to collecting data in HCPC, including challenges of doing so in diverse practice settings. Lessons learned in this session will assist participants in thinking through how to use this data for research and clinical applications.