

**Results.** The final sample (n=30 articles) had publication dates from 2000 to 2017 and represented international family caregivers aged 18–89 caring for patients with cancer (20%), heart disease (20%), progressive neurological disease (10%), diabetes (7%), chronic obstructive pulmonary disease (3%), and other serious, chronic conditions (40%). Self-management practices grouped into the areas of focusing on the patient's illness needs (e.g., managing symptoms), activating resources to support oneself as the family caregiver (e.g., using technology for information and support), and living with a patient with a serious, chronic illness (e.g., managing caregiver emotions). We categorized facilitators and barriers into the areas of Personal/Lifestyle Characteristics (e.g., patient empowerment), Health Status (e.g., caregiver stress), Resources (e.g., assistive devices), Environmental Characteristics (e.g., stigma), and the Health Care System (e.g., access to care).

**Conclusion.** Across health conditions, the family caregiver role is complex and makes considerable demands that challenge support of patient self-management.

**Implications for Research, Policy, or Practice.** Data indicate areas for assessment and potential intervention to support and sustain family caregivers' role in managing serious, chronic illness.

### *The Power of Human Connection (FR441B)*

Amy An, MD, University of Rochester Medical Center, Rochester, NY. Susan Ladwig, MPH, University of Rochester, Rochester, NY. Ronald Epstein, MD FAAHPM, University of Rochester, Rochester, NY. Holly Prigerson, PhD, Weill Cornell Medicine, New York, NY. Paul Duberstein, PhD, University of Rochester, Rochester, NY.



#### *Objectives*

- Recognize the importance of therapeutic alliance between caregivers and oncologists in the care of cancer patients.
- Describe the relationship between caregiver-oncologist therapeutic alliance and the caregiver bereavement experience.

**Original Research Background.** The therapeutic alliance (TA) between oncologists and patients with cancer has been associated with an array of end-of-life (EOL) outcomes, but we are aware of no studies on TA between oncologists and cancer caregivers.

**Research Objectives.** To examine the associations between caregiver-oncologist TA and cancer caregiver bereavement outcomes.

**Methods.** We conducted secondary analyses of data collected in the Values and Options in Cancer Care

(VOICE) study, a randomized clinical trial aimed at improving quality of communications between oncologists and patients with advanced cancer and their caregivers. Having previously reported the intervention's effects on patient outcomes, we now report secondary analyses, focusing on the effects of caregiver-oncologist TA on bereavement outcomes in 102 caregivers. Shortly after study entry, we assessed TA using the Human Connection Scale. Two months after death of the patient, we assessed caregiver-reported experiences of EoL care using the Quality of Death scale (QOD), Caregiver Evaluation of the Quality of End-Of-Life Care (CEQUEL) and the Modified Decision Regret Scale. Seven months after death of the patient, we assessed for Prolonged Grief symptoms (PG-13) and Purpose in Life (PIL). We conducted multivariable regressions examining associations between TA and outcomes after adjusting for study design variables (e.g., intervention arm, study site) as well as caregiver age, patient gender, patient education, and whether patients lived with their caregivers.

**Results.** TA was significantly associated with higher QOD ( $p=0.01$ ), CEQUEL ( $p<0.005$ ), and less decisional regret ( $p<0.01$ ). The relationships between TA and PG-13 ( $p=0.60$ ) and PIL ( $p<0.1$ ) were not statistically significant.

**Conclusion.** A stronger TA between caregivers and oncologists was associated with better caregiver perceptions of the quality of the patient's EOL care, and serves an important role in helping caregivers navigate the complicated environment of cancer treatment.

**Implications for Research, Policy, or Practice.** Improving TA between physicians and caregivers in the care of cancer patients may have widespread effects on caregivers' bereavement experiences.

### *Social Support and Relationship Quality as Moderators in the Association Between Heart Failure Patient Illness Severity and Caregiver Outcomes (FR441C)*



Teresa Cooney, PhD, University of Colorado Denver, Denver, CO. Christine Proulx, PhD, University of Missouri, Columbia, MO. David Bekelman, MD MPH, University of Colorado, Denver, CO.

#### *Objectives*

- List two ways that caregiver burden from heart failure patient illness severity can be moderated.
- Describe the stress process model as a theory that explains the connection between heart failure patient illness severity and caregiver well-being, and the potential for social support to moderate that association.

**Original Research Background.** Heart failure, a leading cause of hospitalization and death, can present severe challenges for patients and their

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 ( $FEV1/FVC<0.70$  and  $FEV1<0.80$ ) 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  $\leq 20$  and  $>20$ .

**Results.** Ten patients were on average 60 years old, 50% were African American, 30% female, and 40% had very severe COPD ( $FEV1<0.35$ ); 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.