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Outcomes.

1. Describe the prevalence of unmet support service needs for rural caregivers in the U.S. and the distribution of specific unmet service need types

2. Explain the sociodemographic and caregiving-related variables associated with unmet support service needs among rural caregivers

Importance. Rural communities in the U.S. demonstrate growing racial and economic disparities and increasing barriers to healthcare access. Within this shifting landscape, understanding rural caregivers' unmet support service needs can help identify the most pressing gaps in supportive care.

Objective(s). We examined factors related to unmet support service needs among rural caregivers in a large, population-based study.

Method(s). We used data from the Behavioral Risk Factor Surveillance System for the 28 U.S. states (including DC and Puerto Rico) participating in the caregiving module across years 2015-2020. We identified rural caregivers by using metropolitan statistical area (rural) and the item, "During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?" Logistic regression models incorporating sampling weights provided adjusted odds ratios (aORs) of factors associated with unmet support service needs (classes about giving care, help with service access, support groups, individual counseling, respite). Factors included sociodemographic (gender, race, age, education, income, employment status, marital status) and caregiving-related (intensity [± 20 hours/week and ± 2 -year duration], caregiver-care recipient relationship and main care recipient health condition) variables.

Results. Of the 5,934 rural caregivers included, representing 1.7 million individuals, 17% endorsed unmet needs. Help accessing services was most frequently endorsed (47%), followed by support groups (17%) and respite care (16%). Factors associated with higher odds of any unmet need included Black vs. White race (aOR: 1.7; 95% CI: 1.1-2.5), college vs. high school graduate (aOR: 1.8; 95% CI: 1.3-2.5), and higher- vs. lower-intensity caregiving (aOR: 2.1; 95% CI: 1.4-3.1).

Conclusion(s). Many U.S. rural caregivers report unmet support service needs, particularly Black caregivers, those with higher educational attainment, and those with higher caregiving intensity.

Impact. Future interventions to benefit rural caregivers may benefit from focusing on the individuals with the highest unmet needs.

How Does Hospital Culture Influence the Intensity of End-of-Life Care? (CO201D)

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Outcomes.

1. Identify how hospital cultures influence intensity of end-of-life care

2. Propose hospital policies, practices, and resources that foster hospital cultures that mitigate burdensome end-of-life care

Importance. There is significant institutional variability in the intensity of end-of-life (EOL) care that is unexplained by patient preferences. Hospital culture and individual practice variations may contribute to burdensome or unwanted life-sustaining treatments near the EOL.

Objective. To understand how hospital cultures influence the intensity of EOL care.

Methods. A comparative ethnographic study was conducted at four academic hospitals in California and Washington. Hospitals were selected for differences in intensity of EOL care (e.g., high, medium, and low) based on the Dartmouth Atlas. Semistructured, in-depth interviews were conducted with 112 clinicians, hospital staff, and administrators between December 2018 and December 2020. Data were deductively and inductively analyzed using thematic analysis through a team-based, iterative coding process.

Results. There was a universal default of high-intensity care at all four sites; respondents recognized this as the norm in American healthcare. This default required respondents to use active and concerted efforts to de-escalate high-intensity EOL care, even when treatments were not consistent with patients' goals. Respondents at high-intensity hospitals described attempts to de-escalate high-intensity, goal-discordant care that were thwarted at multiple points during a patient's care trajectory. Conversely, hospital-specific resources, policies, and practices at hospitals whose culture favored low-intensity EOL care facilitated de-escalation. The aggregate tendency of a hospital's environment to either favor or thwart clinician attempts to de-escalate high-intensity EOL care is a foundational feature of different cultures of intensities of care.

Conclusion. Hospital cultures influence the intensity of EOL care through policies, practices, and resources that either facilitate or discourage resistance to a prevailing culture of high-intensity care in American medicine.

Impact. Interventions that target individual behaviors or interactions are insufficient to mitigate burdensome EOL care because extant hospital cultures will

undermine their impact. Consideration of systemic drivers of high-intensity care should be incorporated into palliative care interventions.

Effect of a Collaborative Palliative Care Intervention vs Usual Care on Quality of Life of Patients with Symptomatic Heart and Lung Diseases: A Randomized Clinical Trial (CO202A)

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Outcomes.

1. Propose a primary palliative care approach to improve quality of life in chronic obstructive pulmonary disease and chronic heart failure

2. Compare quality of life outcomes from a randomized clinical trial of a primary palliative care intervention

Importance. Patients with heart failure (HF), chronic obstructive pulmonary disease (COPD), and interstitial lung disease (ILD) endure poor quality of life (QOL) despite conventional therapy.

Objective(s). Determine whether a collaborative palliative care intervention improves QOL in outpatients with HF, COPD, or ILD compared to usual care.

Method(s). We conducted a single-blind, 2-arm, multi-site randomized clinical trial within 2 VA health care systems. We included outpatients with HF, COPD, and ILD at high risk of hospitalization or death who reported poor QOL. The intervention included symptom care provided by a nurse and psychosocial care provided by a social worker. The nurse and social worker met weekly with a study primary care and palliative care physician, pulmonologist, and cardiologist. The primary outcome was difference in change in QOL from baseline to 6 months between intervention and usual care (FACT-G score, range 0-100, higher score better, clinically meaningful change ~4-6 points). Analysis used the intent-to-treat approach and mixed models.

Results. A total of 306 patients were enrolled (154 intervention, 152 usual care). Participants were generally male (90.2%), White (80.1%), with a mean age of 68.9 (SD 7.7) years; 57.8% had COPD, 21.9% HF, 16% both COPD/HF, 4.2% ILD. Baseline FACT-G scores were similar (intervention, 52.9; usual care, 52.7).

FACT-G completion was 76% at 6 months for both intervention and usual care groups. In the intervention arm, 112/154 (73%) patients completed the planned intervention. At 6 months, mean FACT-G score improved by 6.0 points in the intervention arm and 1.4 points in the usual care arm (difference, 4.6; 95% CI 1.8, 7.4; $p = 0.001$; standardized effect size [ES], 0.41). This effect was observed at all time points (4-month ES 0.30, $p = 0.02$; 12-month ES 0.36, $p = 0.007$).

Conclusion(s). A collaborative palliative care intervention demonstrated early, persistent, clinically meaningful improvements in QOL for high-risk outpatients with heart and lung diseases.

Impact. A team primary palliative care approach increased the reach of palliative care for common, serious noncancer illnesses.

Racial Disparities in Advance Care Planning and Palliative Care Consultation in Kidney Transplant Candidates and Recipients (CO202B)

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Outcomes.

1. Discuss the state of the science on advance care planning and palliative care consultation in kidney transplant candidates and recipients

2. Describe the prevalence and racial and ethnic disparities of advance care planning and palliative care consultation in kidney transplant candidates and recipients

3. Propose solutions and interventions for the racial disparities and low prevalence of advance care planning and palliative care consultation among kidney transplant candidates and recipients

Importance. Among patients listed for kidney transplant (KT), 27% die or are removed from the waitlist. Many KT recipients will need another transplant in their lifetime; therefore, both candidates and recipients experience high mortality and symptom burden. These patients could benefit from palliative care (PC) and advance care planning (ACP), but it is unclear how many and which patients receive ACP and PC.

Objective. To estimate prevalence of ACP and PC by age and race among adult KT candidates and recipients.