

SESSION 2915 (PAPER)

CAREGIVING II (HS)

EMORY ROYBAL CENTER FOR DEMENTIA CAREGIVING MASTERY: DIVERSE RESPONSES TO LETTER OF INTENT CALL

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This new NIA-supported Roybal Center seeks to support Stage 1 pilot clinical trials of programs aimed at promoting caregiving competence and confidence in the great heterogeneity of dementia caregiving contexts. During our first cycle, we received 26 letters of intent (LOI) for full applications. Responses reaffirmed the Center's premise that dementia caregiving is remarkably varied in nature. While most proposed programs focused on generic caregiving, a number addressed caregiving issues facing specific ethnic/racial groups (African American; Korean American; Native Alaskan/American Indian; Latino), and several focused on specific dementing conditions (MCI, Lewy Body Dementia, TBI-based dementia). Most described programs centered on knowledge development and daily management skill issues (e.g., management of behaviors); others specified development of physical care skills. Decision-making and communication constituted the second most common topic. Over 40% proposed adaptation of existing programs; more than 25% proposed apps or technology interventions. Investigators represented a wide range of disciplines: 45% each from Health sciences (nursing, medicine, and social work) and Social/Behavioral sciences (principally psychology) and the rest from engineering and communications. LOIs varied most in their readiness to complete a clinical trial within a year. About 40% were in very preliminary stages; 25% were clearly poised for a Stage 1 trial; 15% did not sufficiently address the Center's aims. Key criteria for invitations to submit full applications (n=4) included: specificity of context; clinical trial readiness; reasonableness of proposed adaptation. These criteria should guide future LOIs addressing the diversity of important new research and intervention perspectives on the multifaceted work of caregiving.

IDENTIFYING THE ROLE OF SPATIAL TRANSITIONS IN THE PALLIATIVE CARE EXPERIENCES OF UNHOUSED OLDER ADULTS

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The national population of unhoused older adults is predicted to nearly triple by 2030. Unhoused older adults have a mortality rate four to nine times higher than housed populations, and face structural barriers during illness trajectory that likely influence both where care takes place and processes around attaining psychosocial later-life goals. This study aimed to (1) document patterns in the healthcare trajectories of unhoused older adults and (2) examine the

role of care transitions in psychosocial goal attainment. Retrospective chart review was completed in partnership with a mobile homeless palliative care team; additional data was gathered from provider focus group. Through a content analysis of this data, it was discovered that older unhoused palliative care patients experienced more transitions, and that numerous care transitions were associated with disruptions to goals. The type of care transitions patients experienced also did not reflect their later-life goals. Patients' movements impacted the role of formal and informal care networks in care and highlighted the implications of place in common psychosocial goals, such as family reconciliation. Unconventional neighborhood supports were found to help facilitate treatment adherence. These findings offer translational opportunities for further research, including "rapid respite" models and other innovations in mobile palliative care for unhoused and precariously-housed people with life-limiting illness.

PREDICTORS OF CAREGIVER BURDEN IN DELIRIUM: PATIENT AND CAREGIVER FACTORS

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Delirium — an acute disorder of attention and cognition — is a common, life-threatening and costly syndrome occurring frequently in older hospitalized persons. The unexpected, rapid, and volatile nature of delirium can be difficult for family caregivers to experience and may contribute to subjective feelings of distress (i.e. "delirium burden"). The aim of this study was to examine whether pre-admission patient characteristics or patient-caregiver relationship and living arrangements were associated with caregiver burden as measured by the delirium burden scale for caregivers (DEL-B-C; score 0-40, higher score is more burden). Our sample consisted of 208 older adults and their caregivers from the Better Assessment of Illness (BASIL) study, an ongoing prospective, observational study of surgical and medical patients ≥ 70 years old; 22% of patients experienced delirium by the Confusion Assessment Method (CAM) and the average DEL-B-C score was 7.9, 95% CI(6.95-8.88). Results indicated that neither patient-caregiver relationship and living arrangement or patient factors including pre-admission pain, sleep disturbance, or new onset incontinence were significantly correlated with delirium-related caregiver burden. However, DEL-B-C scores were significantly higher in caregivers of patients with any ADL impairment (mean 8.5 vs. 5.2, $p = .016$) during hospitalization although none of the individual functional deficits alone were statistically significant. This finding suggests that the association of ADL impairment and DEL-B-C scores is not driven by a single functional domain. Future studies are needed to further understand how

caregiver characteristics and patient factors occurring before and during hospitalization contribute to caregiver burden after the occurrence of delirium.

TRAVELING THE PATH TO STROKE CAREGIVER READINESS

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Family members are often poorly prepared to assume the caregiving role post-stroke leaving them feeling overwhelmed, frustrated, and abandoned by the healthcare system leading to physical, mental, and emotional strain. To address this, we developed and tested the Preparedness Assessment for the Transition Home after stroke (PATH-s) instrument based on a theoretical framework for improving stroke caregiver readiness. Consecutive studies were conducted over the past 10 years to 1) develop the caregiver readiness theoretical model identifying gaps in caregiver preparation in 80 interviews with caregivers and stroke survivors as they transitioned home from inpatient rehabilitation care; 2) develop and validate the PATH-s instrument with 183 caregiver-stroke survivor dyads, and 3) develop and implement a corresponding catalogue of interventions developed in consultation with 5 expert rehabilitation nurse case managers to improve stroke caregiver readiness. The Improving Caregiver Readiness Model has 2 preparedness domains; commitment and capacity and six sub-domains. In a factor analysis each domain/sub-domain subscale in the PATH-s demonstrated satisfactory internal consistency ($\alpha=0.69-0.86$). The overall mean score was 3.11 (range 1.68 to 4.00) with high internal consistency reliability ($\alpha=0.90$). The PATH-s is highly correlated with the Preparedness for Caregiving Scale. The stroke survivor's total FIM score at discharge had a small but significant correlation with the PATH-s. Case managers find the PATH-s results and corresponding interventions helpful in tailoring transitional care plans. Caregivers worldwide describe the negative impacts of providing stroke care post-discharge. The Path to Stroke Caregiver Readiness Program shows promise for improving stroke caregiver preparation for discharge home.

UNMET CAREGIVING NEEDS ARE ASSOCIATED WITH COGNITIVE FUNCTIONING AMONG OLDER SEPSIS SURVIVORS

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Sepsis survivorship is associated with cognitive decline and complex post-acute care needs. Family caregivers may be unprepared to manage these needs, resulting in decline or no improvement in patient outcomes. Using a national dataset of Medicare beneficiaries who were discharged from the hospital for sepsis and received post-acute HHC between 2013 and 2014 ($n=165,228$), we examined the relationship between unmet caregiving needs and improvement or decline

in cognitive functioning. Multivariate logistic regression was used to determine associations between unmet caregiving needs at the start of HHC and changes in cognitive functioning. Unmet caregiving needs included seven items from the start of care Outcome and Assessment Information Set (OASIS). Changes in cognitive functioning were measured using the start of care and discharge OASIS assessments. Twenty-four percent of patients either declined or did not improve in cognitive functioning from HHC admission to discharge, with variation seen by unmet need type. Sepsis survivors with unmet caregiving needs for activities of daily living assistance (OR 1.05, 95% CI 1.01, 1.09), medication assistance (OR 1.06, 95% CI 1.02, 1.10), and supervision and safety assistance (OR 1.110, 95% CI 1.06, 1.16) were more likely to decline or not improve in cognitive functioning, even after accounting for clinical and demographic characteristics. Older sepsis survivors with both cognitive impairment and unmet caregiving needs in the post-acute HHC setting are at high-risk for worsening cognition. Alerting the care team of cognitively impaired sepsis survivors with unmet caregiving needs may trigger evidence-based strategies to enhance caregiver training and reduce unmet caregiving needs.

SESSION 2916 (PAPER)

CHRONIC DISEASE AND MULTIMORBIDITY I

CHALLENGES TO COMORBIDITY MANAGEMENT FOR OLDER HIV-POSITIVE INDIVIDUALS

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70% of individuals with HIV in the United States are 50 years or older. These individuals' HIV is often well-managed, but they have acquired several comorbidities, including cardiovascular disease, non-AIDS defining cancers, renal disease, osteoporosis, liver disease, and neurocognitive disorders. Existing literature provides little guidance on structuring services to meet this burgeoning population's complex clinical and aging-related needs. To inform an approach, between April 2015 and June 2018, we conducted 13 exploratory qualitative group discussions with patients, providers and administrators receiving or providing HIV services in New York's Hudson Valley. We also conducted a retrospective electronic medical record chart review ($n=50$) of individuals >50 years receiving HIV care in 2017 at a Hudson Valley federally qualified health center (FQHC) to describe subspecialty referrals. Analysis of discussion groups highlighted challenges with initial access, the quality of encounters, and consistent follow-up. Patients thought 'ageism' contributed to poorer care quality, though extensive experience navigating the system was an advantage. The EMR review revealed patients receiving two referrals on average to (most commonly) ophthalmology/optometry (14%), gastroenterology (12%), dental (9%), cardiology (9%), and orthopedics (8%). Only half (54%) of scheduled referral appointments were attended. Documented barriers included insurance/costs, transportation, patient refusal, and fear