

Co-Chair: Nancy Hodgson, *University of Pennsylvania, Philadelphia, Pennsylvania, United States*

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Family caregivers, often “de facto” members of the care team for persons with dementia, play a central role in ensuring safety, support, quality of life, and continuity of care. Most often, they provide this care for loved ones at home and over a long period of time, as the illness progresses and care need intensifies. This session will provide a unique understanding of potential ways to optimize support for family caregivers in provision of day-to-day care in the home by examining often-overlooked factors influential in the health and wellbeing for both caregiver and persons with dementia. Presentations will draw from three large community-based trials testing interventions to support dementia caregivers. Drs. Samus and Sloan will present on common unmet needs identified by family caregivers and explore how needs differ by disease stage and race. Dr. Fortinsky will present baseline caregiver care-related challenges in a diverse cohort of caregivers and the effects of a caregiver intervention designed to mitigate these challenges. Dr. Hodgson will present the common symptoms clusters among home-dwelling persons with dementia patients and how these are associated with caregiver distress. Dr. Jutkowitz will discuss factors influencing dementia caregiver’s willingness to pay for help at home. Findings from this session will help elucidate care needs that matter most to family caregivers in diverse community-living cohorts and how we might optimize and tailor supportive home-based interventions to target these needs and challenges.

COMMON UNMET NEEDS OF DEMENTIA CAREGIVERS AND HOW THESE DIFFER BY DISEASE STAGE AND RACE

Quincy M. Samus,¹ Danetta Sloan,¹ Jeannie-Marie Leoutsakos,¹ Betty Black,¹ and Deirdre Johnston¹, 1. *The Johns Hopkins University, Baltimore, Maryland, United States*

This presentation (co-presentation Samus and Sloan) will use combined cross-sectional, baseline data from two intervention studies (n=642) conducted in Maryland evaluating the impact of dementia care coordination model (MIND at home) to provide a detailed description of common modifiable unmet care needs of family caregivers of community-living persons with dementia (PWD), explore how care needs may differ by the disease stage of the PWD, and presence of racial disparities in care needs. Unmet caregiver needs were identified based on comprehensive in-home assessments using a standardized tool (JHDCNA 2.0) with 6 care domains and 18 items covering caregiver needs. Family caregivers were 77% women; 63 years old (mean); 60% White; and 52% adult children. The most prevalent needs were for education/resources (98%), legal (74%), mental health (44%), and informal support (43%). Needs varied based on dementia severity. African American caregivers (vs. white) had significantly more unmet caregiver needs at baseline (p<.001).

FACTOR STRUCTURE OF NEUROPSYCHIATRIC SYMPTOM FREQUENCY IN HOME-RESIDING PERSONS WITH DEMENTIA

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This study evaluated neuropsychiatric symptom clusters in a sample of home residing persons with dementia, and the impact of distinct clusters on family caregiver outcomes. The expanded Neuropsychiatric Inventory (NPI-C), including measures of frequency, was collected at baseline from 250 caregivers enrolled in Reducing Agitation in People With Dementia: the Customized Activity Trial [NCT01892579]. Principle component analyses were conducted resulting in an eight behavioral clusters, accounting for 44% of total variance: 1=agitation/aggression; 2=anxiety; 3=apathy/withdrawal; 4=impulsivity; 5=psychosis; 6=restlessness; 7=circadian disturbance; 8=depression. In multiple linear regressions caregiver burden was significantly influenced by the anxiety cluster. Caregiver depression was significantly influenced by apathy/withdrawal cluster, and quality of life was significantly associated with anxiety and circadian disturbance clusters. Dimensional representation of neuropsychiatric symptom clusters can be useful in assessing the effect of multiple co-occurring symptoms (versus discrete individual symptoms) on caregiver outcomes and for planning personalized intervention strategies for persons with dementia.

INTERVENTION EFFECTS ON TARGET PROBLEMS EXPRESSED BY CAREGIVERS OF HOME-DWELLING PERSONS WITH DEMENTIA

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Care of Persons with Dementia in their Environments (COPE) is an evidence-based in-home intervention designed to optimize function and activity engagement in persons with dementia (PWD), and teach family caregivers (CG) how to manage dementia care-related problems. In this presentation, we report problems expressed by CGs, and intervention effects on these problems and CG outcomes, in the COPE CT translational study. CGs randomized to COPE who completed the assessment phase (N=134) expressed a total of 409 target problems, grouped as managing PWD behavioral problems (32%), caring for themselves (30%), managing PWD daily activities (24%) and engaging PWD in meaningful activities (14%). Most problems were reduced (75%) or eliminated (21%) among CG completing the intervention. In preliminary outcome analyses, compared to CG not receiving COPE, CG receiving COPE were more likely to report improved ability to manage dementia-related cognitive and behavioral symptoms (p<.001). Implications for scaling COPE will be discussed.