

SESSION 7110 (SYMPOSIUM)

ENGAGING UNDERREPRESENTED CAREGIVING COMMUNITIES IN DEMENTIA RESEARCH

Chair: Andrea Gilmore-Bykovskiy

Discussant: Ishan Williams

Family and friend caregivers of persons with dementia from underrepresented and traditionally underserved backgrounds are significantly underrepresented in dementia and caregiving research despite heightened disease risk, poorer outcomes, and disproportionate use of services within these populations. Efforts to develop and disseminate methods that foster greater inclusion of underrepresented caregiving populations in research are essential to ensuring that culturally specific understandings, priorities, and needs of these groups are systematically understood and addressed. In this symposium, we present a variety of studies that illustrate successful efforts to include dementia caregivers from underrepresented backgrounds in research. Two presentations focus on African American caregivers, one on caregivers residing in highly under-resourced areas, one on Latino caregivers, and one on sexual and gender minority (SGM) caregivers. The first presentation describes a capacity building approach through African American faith communities to develop a research registry and address informational needs regarding dementia. The second presentation focuses on eliciting African American caregivers experiences of crisis events. Presentation three describes a coalitional, community-informed approach to engaging caregivers in highly under-resourced areas to investigate experiences with post-acute care. The fourth presentation describes a community-network approach to implementing a text-message based support intervention among Latino caregivers; and the fifth presentation illustrates the utility of digital methods for engaging SGM dementia caregivers. Collectively, these presentations demonstrate a variety of approaches to engaging dementia caregivers from underrepresented and traditionally underserved backgrounds in research that are specific to individual communities and local contexts – as well as the findings that result from these efforts.

ENGAGING DEMENTIA CAREGIVERS IN UNDER-RESOURCED AREAS TO EXAMINE DISPARITIES IN POST-ACUTE CARE QUALITY AND ACCESS

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Dementia disproportionately impacts racial/ethnic minorities and individuals from under-resourced environments, yet these groups are under-represented in research. For caregivers, managing dementia often involves navigating frequent post-acute care (PAC) transitions. Despite evidence of segregation-associated disparities in PAC access and quality, the perspectives of caregivers from under-resourced areas regarding these disparities and how they are experienced, are poorly understood. We engaged a coalitional, community-informed approach to engaging caregivers in highly under-resourced areas to elicit experiences surrounding PAC through semi-structured interviews (N=25; 65% African

American; 25% White; 88% female). Data were analyzed using thematic analysis. Caregivers spontaneously connected issues in PAC quality to racial/ethnic disparities and discrimination citing differences in geographic availability, financial barriers, eligibility, access to information, and transportation. To mitigate these challenges caregivers remained highly involved in the care recipient's PAC, describing the need to continue to "advocate" and "supervise." Collectively, these perspectives can help inform future, targeted policy interventions.

LEVERAGING DIGITAL METHODS TO ENGAGE SEXUAL AND GENDER MINORITY CAREGIVERS OF PEOPLE WITH DEMENTIA

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Digital methods are a way to engage marginalized populations, such as sexual and gender minority (SGM) adults. No study to date has leveraged these methods to engage SGM caregivers of people with dementia. We used digital methods to access SGM caregivers of people with dementia in our study of psychosocial measures of caregiving for recruitment and data collection. Posts on social media and online registries targeted SGM caregivers. The study landing page received 2201 views; 285 caregivers completed the survey. Participants learned of the study most frequently from Facebook (45%). The sample was 84% white, with gay (52%), lesbian (32%), bisexual (11%), and other sexual orientations (5%) and transgender (17%) caregivers represented. While we exceeded goals for inclusion of Latinx (26%) and Native American (4%) caregivers, the number of African American SGM caregivers was lower than projected (7%). Digital methods are effective for engaging SGM caregivers of people with dementia.

PARTNERING WITH AFRICAN AMERICAN CHURCHES TO SUPPORT FAMILIES AFFECTED BY DEMENTIA THROUGH RESEARCH

Fayron Epps, *Emory University, Atlanta, Georgia, United States*

African Americans (AA) are disproportionately impacted by dementia when compared to the non-Hispanic white population, yet are significantly underrepresented in research. Often times, families in the AA community turn to their church for help when in distress. Recognizing that churches are frequently the cornerstone of AA communities, they are an ideal setting for health promotion, research, and education. However, many AA churches do not have the resources to support their congregants affected by dementia. To build capacity within churches to address brain health promotion and facilitate research access/participation, we partnered with 6 predominantly AA churches in the metropolitan Atlanta area to facilitate research and develop dementia-related programs. While stakeholders were

initially reluctant, continual engagement with senior faith leaders helped to facilitate the successful development of a research registry of congregants interested in participating in faith-based and clinical research and establishment of new programs to congregants around brain health and dementia.

CUIDATXT: A TEXT MESSAGE DEMENTIA-CAREGIVER INTERVENTION FOR LATINOS

Jaime Perales Puchalt, *University of Kansas, Fairway, Kansas, United States*

Latino family caregivers of people with dementia have low access to caregiver support. Text messaging holds potential to dramatically enhance the reach of caregiver support interventions among Latinos. This presentation will describe the CuidaTXT Project, with a special emphasis on approach to recruitment and community engagement to achieve the objectives of designing and testing the first dementia caregiver-support text message intervention for Latinos. Based on the Stress Process Framework, CuidaTXT incorporates social support and coping components including AD education, problem-solving skills training, social network support, care management and referral to community resources via tailored two-way messaging. Engagement in CuidaTXT benefited from multi-source recruitment efforts in the Latino community-network built over a three-year period. The network is comprised of senior, religious and community centers, the local media, clinics, a Latino registry and a dementia health navigation service. This presentation will describe processes for assembling and engaging the network for CuidaTXT.

EXAMINING HOW AFRICAN AMERICAN FAMILY DEMENTIA CAREGIVERS CONCEPTUALIZE AND MANAGE CRISIS EVENTS

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African American (AA) family dementia caregivers report high unmet needs, which often culminate in crisis – an unplanned stressful situation requiring immediate decision. However, perspectives from AA caregivers regarding crisis are lacking. To gain insight into caregivers' conceptualization and experiences of crisis, we used community/coalitional-based recruitment of AA caregivers to conduct semi-structured interviews with 34 AA caregivers which were analyzed using thematic analysis (N=34, 94% female, 56% ages 65 to 74). AA caregivers largely perceived crisis as stressful events, a normal part of caregiving and viewed management of these events as routine. Crisis was characterized as ongoing, lengthy or emergent, sometimes necessitating external support (e.g. hospitalization). Caregivers managed crisis by increasing caregiving work, de-prioritizing their own health and needs, involving family and friends, and accessing emotional support through neighborhood connections. These perspectives can inform future culturally-tailored interventions that are responsive to AA strengths, values, and help seeking preferences.

SESSION 7115 (SYMPOSIUM)

FIGS STUDY OUTCOMES: DISENTANGLING RELATIONSHIPS BETWEEN VISION LOSS, THE ENVIRONMENT, PHYSICAL ACTIVITY, AND FALLS

Chair: Pradeep Ramulu

Co-Chair: Laura Gitlin

Discussant: Jennifer Schrack

The longitudinal relationships between various aspects of mobility (with each other and with vision loss) are important to understand for healthy aging. The Falls in Glaucoma Study (FIGS) was a three-year longitudinal study conducted in persons with a range of visual field damage from glaucoma (from normal visual fields to severe visual field damage) and evaluated several aspects of mobility: physical function (gait and balance), physical activity (annual accelerometer trials), fall rates (prospectively-collected falls calendars), environmental features (an in-home assessment), and fear of falling. In this symposium, we present data demonstrating that: (1) physical activity is altered by visual field damage - lowering the overall amount of physical activity, and also resulting in more fragmented activity (i.e. shorter activity bouts); (2) specific home environmental features, such as better lighting, are associated with lower rates of falls within the home; (3) specific gait and balance features increase the risk of falling, but do not explain the association between visual field damage and a higher rate of falls; (4) injurious falls, but not non-injurious falls, lead to future reductions in physical activity; and (5) worsening of fear of falling (FoF) leads to either a higher rate of falls (at low FoF levels) or decreases in physical activity (at higher FoF levels). Study findings will educate the audience about the types of mobility problems found in persons with visual field damage, potential methods to prevent falls in older adults, and factors likely to predict future mobility deficits in older adults.

IMPACT OF FEAR OF FALLING ON FUTURE FALLS AND CHANGES IN PHYSICAL ACTIVITY IN OLDER ADULTS WITH GLAUCOMA

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To understand how Fear of falling (FoF) alters mobility, FoF was evaluated annually in 243 older adults (median age=70) with varying degrees of visual field loss from glaucoma, and Rasch-analyzed FoF scores associated with the likelihood of falling in the following year (judged by prospective calendar data) and changes in physical activity (Judged by annual accelerometer trials). At lower FoF levels, each one-unit worsening in FoF was associated with a 2.73-fold higher odds of reporting a fall in the next year (95% CI:1.55,4.81) but not with average daily steps taken