SESSION 7110 (SYMPOSIUM)

ENGAGING UNDERREPRESENTED CAREGIVING COMMUNITIES IN DEMENTIA RESEARCH

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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

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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