CARE TRAIN: THE PILOT STUDY OF A LAY-LED SUPPORT GROUP FOR AFRICAN AMERICAN CAREGIVERS

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Background: The study aim was to address the health disparity regarding the prevalence of dementia in African Americans, yet the lack of connection to dementia support services. To that end, a feasibility study of a lay led support group for African American caregivers called the CARE TRAIN project was conducted.

Methods: In partnership with local churches attended by predominantly African American congregants, 11 participants were recruited for an 8-week counselor led caregiver support group. Interested completers of this group attended a one day training to prepare them to facilitate an 8-week lay led support group for 8 African American caregivers. Data on attendance was collected and within and between group outcomes were compared. Results: Paired t-tests revealed no pretest-posttest changes on burden, well-being, or depression for both the counselor led and lay led groups. However, self-reported knowledge of dementia (n = 13, p = .001) and coping skills (n = 13, p = .0004) did improve with participants in both groups. ANOVA models comparing pre-post changes between groups revealed no differences. Average attendance for the counselor led group was 7 members per group (out of 11 total participants). Average attendance for the lay led group was 5.37 members per group (out of 8 total participants). Conclusions: Conducting a lay led support group for African American caregivers in partnership with local churches is feasible. Further CARE TRAIN program development is needed as well as additional research with higher numbers of participants.

DIFFERENCES IN THE EXPERIENCE OF CAREGIVING BETWEEN SPOUSE AND ADULT CHILD CAREGIVERS IN DEMENTIA WITH LEWY BODIES

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Background: Caregiving for dementia has been associated with increased burden, depression, grief, a decreased sense of well-being, and a lessening of social support. Dementia with Lewy bodies (DLB) is the second most common form of dementia. The purpose of the present study was to examine differences in the caregiving experience of spouse versus adult child caregivers caring for individuals with DLB. Methods: Spouse (n = 255) or adult children (n = 160) caregivers of individuals with DLB completed a series of online self-report surveys. Results: Adult children perceived more symptoms of depression and total behavioral problems in the care recipient than spouse caregivers. Adult children further reported more overall burden and experiencing more distress in reaction to depression symptoms perceived in their loved one than spouse caregivers. Adult children also reported experiencing more depression symptoms themselves, and indicated that these symptoms had a greater impact on their life than spouse caregivers. Spouse caregivers reported more grief and less social support than adult children, but indicated a greater improvement in their wellbeing. Conclusions: Adult child caregivers were more likely to interpret dementia symptoms as disruptive and depressive, and more likely to report experiencing and being impacted by depression symptoms. Spouse caregivers report more improvements in wellbeing and appear less emotionally reactive to dementia symptoms, while simultaneously reporting more grief. These findings support the hypothesis that there are differences in the experience of caregiving between spouses and adult children when caring for those with DLB.

DO INFORMAL CAREGIVERS’ BURDENS PREDICT Recipients’ DEMENTIA ONSET?

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Background: Caregiver health may be impacted by the demands of providing care for older adults, including those who will have dementia. It may also be valuable to understand the ways in which caregiver burdens are related to the changing health of the care recipient. This study examines associations between several types of caregiver burden and the risk for dementia onset in care recipients. Methods: Five domains of caregiver burden were analyzed in relation to care recipients’ change in cognitive status over four years using National Health and Aging Trends Study, a nationally representative sample aged 65 and up, along with its associated National Study on Caregiving data. The study sample of consisted of 703 care recipients, excluding those with dementia at baseline, and their primary informal caregivers. Discrete time survival analysis was employed using weighted data to test caregiver role overload, social limitation, financial strain, positive mood, and psychological distress as predictors of incident dementia in the care recipients over a four year period. Results: In the baseline sample of non-demented care recipients, dementia occurred in 187 during the subsequent study years. Caregiver burdens including social limitation, role overload, and psychological distress were associated with dementia onset, while positive mood and financial burden were not, in separate survival models with controls for care recipients’ sex, age, race/ethnicity, marital status, education, self-rated health, and “possible dementia” status. Determinants of caregiver burden were examined as well. Simultaneous regression of all five burden measures on care recipient and caregiver characteristics reveals several factors. Notable predictors of specific caregiver burdens are recipients’ relationship to the caregiver, their health, and caregivers’ employment status, marital status, and gender. Caregiving on a set schedule is associated with social limitation, role overload, and psychological distress. Distress is greater among sons who are primary caregivers, compared with those who are the care recipients’ spouse, while being married (but not the recipients’ spouse), is protective. Conclusions: This study provides new evidence in support of caregiver burdens as a risk factor for dementia using longitudinal data. That only baseline caregiver information is used is a limitation that should be addressed in future studies.