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# FAMILIES: an effective healthcare intervention for caregivers of community dwelling people living with dementia

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## ABSTRACT

**Objectives:** Caregiving for a person with dementia (PWD) carries increased risk of poorer health and quality of life. Non-pharmacological interventions improve outcomes for caregivers of PWDs. We evaluated the efficacy of a modified New York University Caregiver Intervention (NYUCI), named FAMILIES, delivered to spousal and non-spousal caregivers of PWDs from diverse etiologies in a reduced number of sessions.

**Methods:** Participants were 122 primary caregivers for community dwelling PWDs in Virginia. The intervention included two individual and four family/group counseling sessions that integrated dementia education, coping skills and behavioral management training, emotional support, and identification of family and community resources. Assessment of depression, caregiver well-being and burden, and caregiver reactions to the behavioral symptoms of dementia (BSD) were completed at baseline, the sixth session, and 6-month follow-up.

**Results:** Symptoms of depression ($p < .001$) and caregiver burden ($p = .001$) and caregivers' capacity to effectively manage their reactions to BSD ($p = .003$), significantly improved at the sixth session. Benefits were maintained at 6-month follow-up. Being married and female predicted improvement in caregiver burden; being male and living in a rural area predicted reduced risk of depression. Caregivers reported that the intervention was helpful and had a positive impact on the PWD.

**Conclusions:** Modifications to the NYUCI did not diminish its efficacy. Caregivers in FAMILIES experienced improvements in depressive symptoms, caregiver burden, and their ability to effectively manage their reactions to BSD. Systemic support for implementing FAMILIES could have a broad impact on caregivers, PWDs, and the healthcare system.

## Introduction

In the United States, of the 6.6 million older community dwelling adults who receive caregiving assistance, 66% rely exclusively on help from informal caregivers (Freedman & Spillman, 2014). Persons with dementia (PWD) comprise a significant proportion of this population. As the prevalence of Alzheimer's disease (AD) and related dementias increases (Mayeux & Stern, 2012), so will its associated impact on caregivers.

Caregiving can be a rewarding experience (Picot, 1995) that contributes to reductions in anxiety and depression (Beach, Schulz, Yee, & Jackson, 2000) and improvements in well-being (Lundh, 1999). However, many find caregiving demanding on their health and quality of life (QoL; Pinquart, Sörensen, Vitaliano, Zhang, & Scanlan, 2003). Caring for a PWD increases the risk of health (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995; King, Oka, & Young, 1994) and psychological problems (Pinquart & Sörensen, 2003b; Kiecolt-Glaser et al., 1995), as well as mortality (Schulz & Beach, 1999). Older caregivers and caregivers of PWDs are particularly vulnerable to poor outcomes (Pinquart & Sörensen, 2003a; Pinquart et al., 2003).

Behavioral symptoms of dementia (BSD) often affect caregiver burden more than cognitive decline (Fauth & Gibbons,

2014; Mioshi, Bristow, Cook, & Hodges, 2009). A systematic review showed depression to be the most distressing symptom for caregivers (Feast, Moniz-Cook, Stoner, Charlesworth, & Orrell, 2016), whereas others have shown disruptive behaviors, irritability, and delusions to be most problematic (Fauth & Gibbons, 2014; Huang, Lee, Liao, Wang, & Lai, 2012). Fortunately, non-pharmacological interventions are effective in reducing neuropsychiatric symptoms (Brodaty & Arasaratnam, 2012; Olazarán et al., 2010), mitigating caregiver distress (Mittelman, Roth, Haley, & Zarit, 2004; Brodaty & Arasaratnam, 2012), improving caregiver health (Shelton, Schraeder, Dworak, Fraser, & Sager, 2001; King et al., 2002; Hosaka & Sugiyama, 2003), and delaying the PWD's time to institutionalization (Mittelman, Haley, Clay, & Roth, 2006; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Mittelman et al., 1993).

Randomized controlled trials (Roth, Mittelman, Clay, Madan, & Haley, 2005; Mittelman et al., 1995; Mittelman, Roth, Coon, & Haley, 2004; Mittelman, Roth, Haley, et al., 2004; Mittelman et al., 2006; Gaugler, Reese, & Mittelman, 2013) and a recent meta-analysis (Olazarán et al., 2010) have demonstrated the particular efficacy of multi-component caregiver interventions on caregiver and PWD outcomes. One such intervention is the New York University

Caregiver Intervention (NYUCI; Mittelman et al., 1993). The NYUCI is a psychosocial intervention initially developed for spousal caregivers of persons with AD. One goal of the NYUCI is to improve caregiver well-being by increasing caregiver support and modifying caregivers' appraisal of BSD. Positive outcomes of the intervention include improvements in caregivers' support networks (Roth et al., 2005), mental health (Mittelman et al., 1995; Mittelman, Roth, Coon, et al., 2004), and ability to effectively manage their reactions to BSD (Mittelman, Roth, Haley, et al., 2004), as well as delayed time to nursing home placement for PWDs (Mittelman et al., 2006; Gaugler et al., 2013; Mittelman et al., 1993, 1996). These benefits are likely realized for different, but overlapping reasons. For example, as caregivers learn positive coping strategies to manage BSD, and how to differentiate behaviors that pose significant health and safety risk from those that do not, they may begin to experience BSD as less distressing (Mittelman, Roth, Haley, et al., 2004) and in turn see improvements in mental health and QoL. Similarly, improvements in caregivers' support networks can have a positive impact on caregiver depression (Roth et al., 2005).

The NYUCI has been effectively modified in its delivery to adult child caregivers (Gaugler, Reese, & Mittelman, 2015). It has also been implemented in multiple states, although results from cross-state application have been mixed, with minimal benefit in caregiver burden, QoL, and depression being reported (Fauth et al., 2017). In the present study, we sought to evaluate the efficacy of a newly modified NYUCI protocol, named FAMILIES (Families Access to Memory Impairment and Loss Information, Engagement, and Supports), implemented in a Southeast region of the country. The intervention's name was changed based on local socio-historical knowledge in an attempt to improve enrollment of people from rural communities and with less access to healthcare resources. The modifications to the original NYUCI include 1) delivery of the intervention to include non-spousal caregivers, 2) delivery of the protocol to caregivers of PWDs with non-AD related dementia, 3) a 25% reduction in the total number of intervention sessions, and 4) extension of the time to complete the intervention. The first two modifications were made in order to provide services to a broader number of caregivers, by making it available to all informal primary caregivers of community dwelling PWDs, regardless of their relationship to the PWD (e.g. spouse, child, sibling, etc.) or the etiology of dementia. The third modification was made by integrating the assessment and individual counseling sessions in order to direct financial resources towards the provision of services to more caregivers, reduce the burden of participating for those with limited resources, and assess the efficacy of the NYUCI delivered in fewer sessions. The fourth modification was also made in order to reduce burden for those participating. We hypothesized that via the development of a strengthened support network and new coping skills, caregivers participating in FAMILIES would experience greater self-efficacy and more benign reactions to PWDs' BSD (Zarit, Todd, & Zarit, 1986), and subsequently improvements in depression and caregiver burden.

## Design and methods

### Participants

Caregivers lived in the Charlottesville or Williamsburg areas of Virginia, each of which contain urban and rural communities. Potential participants were identified by clinicians as having a high level of caregiver-related distress and were primarily recruited via the University of Virginia's Memory and Aging Care Clinic (MACC), Riverside Center for Excellence in Aging and Lifelong Health, Alzheimer's Association, and Jefferson Area Board on Aging. Concerted effort was made to recruit non-White caregivers and people from rural and traditionally marginalized communities with less access to healthcare resources. Caregivers were eligible if they 1) identified as the primary caregiver for a community dwelling PWD, 2) provided any form of care to the PWD at least three times per week, 3) lived in one of the two service areas and, 4) were emotionally and physically capable of participating.

### Intervention

In the original NYUCI, caregivers first completed a detailed assessment with a counselor before entering a 4-month intensive counseling phase that included an individual counseling session, followed by four family counseling sessions, another individual counseling session, and then a follow-up assessment. After the last session, caregivers entered the second phase of the intervention, characterized by ongoing support via ad hoc counseling and support groups.

In contrast to the original NYUCI, FAMILIES integrated the assessments into the first and last individual counseling sessions to minimize the total number of sessions and demand placed on participating caregivers. FAMILIES therefore consisted of two individual and four family/group counseling sessions, ad hoc counseling, and access to support groups. The time in which caregivers had to complete the intervention was also extended to 6 months in order to reduce burden. All counselors received formal training in the NYUCI. In the Charlottesville area, the intervention was delivered by clinical neuropsychologists at the University of Virginia's MACC and a licensed clinical social worker at the Alzheimer's Association. In the Williamsburg area, FAMILIES was delivered by social workers strategically located in diverse regions across the catchment area, in order to increase access to caregivers living in rural and traditionally underserved communities. All sessions were held in-person, in a counselor's office. When family/group members lived too far to participate in-person, or they were unable to attend sessions for other logistical reasons, phone tele-conferencing was utilized.

Interested caregivers first completed telephone screening to determine eligibility and discuss the intervention and importance of family/group involvement. They were also provided referrals for alternative care services, if necessary. Caregivers were then assigned to a counselor.

The first individual session consisted of counseling and a semi-structured, person-centered assessment of caregivers' physical, emotional, social, and basic needs. The assessment also paid focus to the make-up of caregivers' current support network, caregiving environment, and the

cognitive and behavioral symptoms of the PWD with whom they were providing care. Information about caregivers' coping skills, level of distress, mood, and goals for participation were identified. Potential family/group participants were identified and goals for their involvement were collaboratively constructed. Caregivers were also made aware that their counselor was available for ad-hoc support.

The four family/group counseling sessions were solution focused and addressed the practical and emotional needs of the caregiver. Importantly, because the counseling sessions were designed to be person-centered and attentive to the individualized needs of each caregiver, a manualized treatment protocol was not utilized. The focus of each session was therefore intentionally driven by the needs of each caregivers' unique circumstances. That said, there were commonalities in themes discussed across caregivers and counseling sessions. These include the need for assistance in identifying areas of caregiving need; development of positive coping skills and strategies to effectively manage BSD, including use of distraction and redirection, rather than trying to rationalize with the PWD or directly change their behavior; development and utilization of positive communication strategies amongst those in the caregiver's support network; methods of identifying and asking for caregiving help; provision of education about dementia and disease processes; and identification of community resources. Emotional support was provided across all sessions. Counselors utilized time within each session to model positive communication and interactions between caregivers and the people within their support network attending the sessions.

The sixth session consisted of individual counseling and a semi-structured, person-centered assessment with the caregiver to identify changes, specifically those related to their coping skills, emotional health, support network, and basic needs. Counselors also worked to help the caregiver consolidate the accomplishments of the family/group meetings, identify ongoing needs, connect the caregiver to community groups and resources, and discuss ways in which the counselor could lend continued support through ad-hoc contact over the following 6 months.

Six months after the last counseling session, the counselor met with the caregiver for an individual follow-up session, to provide further support, examine areas where progress was made or where barriers to progress were encountered, and assess long-term outcomes. When necessary, long-term goals were modified and new resources were provided.

### Measures

Caregivers completed a comprehensive evaluation comprised of well-validated measures. PWDs' independence with basic (ADLs) and complex (iADLs) activities of daily living was assessed with the Katz Index of Independence in Activities of Daily Living (Katz; Katz, Downs, Cash, & Grotz, 1970) and Lawton Instrumental Activities of Daily Living Scale (Lawton; Lawton & Brody, 1969), respectively. Caregivers rated PWDs as being either fully independent or dependent in six ADLs and eight iADLs. Depression was assessed with the Center for Epidemiologic Studies

Depression Scale-Revised (CESD-R; Eaton, Smith, Ybarra, Muntaner, & Tien, 2004). The CESD-R assesses twenty symptoms of depression in nine different symptom groups on a scale of '0–4'. A CESD style score was calculated by assigning equal value to the most severe responses (i.e. '5–7 days a week' and 'nearly every day for two 2 weeks') and summing responses to all questions (Lewinsohn, Seeley, Roberts, & Allen, 1997). The frequency with which 24 common BSD and the severity of caregivers' reactions to these symptoms were assessed with the Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al., 1992). Frequency was rated on a scale of 0 ('never occurred') to 4 ('occurred daily or more often'), as was the severity of caregiver reactions 0 ('not at all') to 4 ('extremely'). Total frequency (RMBPC-F) and reaction (RMBPC-R) scores were derived by summing item responses. Caregiver well-being and caregiver burden were assessed with the Caregiver Well-Being Scale-Short Form (CWBS-SF; Tebb, Berg-Weger, & Rubio, 2013) and Zarit Burden Interview 4-Item Version (ZBI; Bédard et al., 2001), respectively. The CWBS-SF is a 16-item measure that assesses the extent to which caregivers' activities (CWBS-SF Activities) and needs (CWBS-SF Needs) were met over the prior 3 months, with each item rated on a scale of 1 ('rarely') to 5 ('usually'). The ZBI consists of four questions rated on a scale of 0 ('never') to 4 ('nearly always'). Lastly, caregivers responded to two open-ended questions and rated their satisfaction with the intervention using a 26-item Caregiver Satisfaction Survey (CSS). Items were rated on a five-point scale, ranging from 'strongly disagree' to 'strongly agree'.

### Primary and secondary outcomes

The primary outcomes were differences in mean total scores on the ZBI, RMBPC-R, CESD-R, and CWBS-SF between baseline and the sixth session. Secondary outcomes were differences in mean total scores on each of these measures between baseline and 6-month follow-up. We also examined differences in the number of caregivers classified as having a higher risk of clinical depression (CESD style score $\geq$16; Lewinsohn et al., 1997), mean symptom group scores on the CESD-R, and mean subscale scores on the RMBPC-R between baseline and the sixth session. Lastly, we examined the demographic and clinical predictors of change scores for each primary outcome measure that showed evidence of significant improvement at the sixth session.

### Statistical analysis

We conducted descriptive analyses of caregiver and PWD demographic information. We used paired t-tests to compare differences in scores on all measures between baseline and the study's primary end point, with exception of the CESD-R scores, for which we used a Wilcoxon signed rank test to account for normative violations. Similar methods were used to examine secondary outcomes at 6-month follow-up. A chi-square test was used to examine differences in the number of caregivers classified as having a higher risk of clinical depression at baseline and the sixth session.

In addition, we used paired t-tests and Wilcoxon signed-rank tests to assess mean differences in CESD-R symptom group scores at baseline and the sixth session. We then

examined the predictors of change for all primary outcome measures that showed a significant improvement in mean total score from baseline to the sixth session. Demographic variables (i.e. PWD age and the age, education, marital status, gender, race, and household income of the caregiver) and level of independence in ADLs and iADLs were entered into stepwise forward linear regression models to assess predictors of change in total ZBI, RMBPC-R, and CESD-R scores. These same variables were entered into a stepwise Wald logistic regression model to examine the predictors of converting from a classification of having a higher to a lower risk of clinical depression at the sixth session.

Lastly, we used descriptive statistics and a thematic analysis approach (Boyatzis, 1998) that employed first and second cycle coding methods to analyze caregivers' responses on the CSS.

## Results

### Demographics

Of the 167 caregivers who enrolled, 122 (73%) completed the intervention. Attrition occurred due to diverse factors, including PWD transition to a higher level of care or death and unknown causes. There were no significant demographic or clinical (i.e. Katz ADL, Lawton IADL, RMBPC-R, RMBPC-F, CWBS-SF Needs, ZBI, and CESD-R) differences between those who completed the intervention and those who terminated early, with the exception that caregivers who completed the intervention were able to complete activities more frequently at baseline than caregivers who terminated early (CWBS-SF Activities, $p = .01$). Descriptive information for caregivers who completed the intervention and the PWD they care for is presented in Table 1. There were no significant demographic or clinical differences between caregivers who completed the intervention and returned for 6-month follow-up and caregivers who completed the intervention, but did not return for follow-up. At baseline, caregivers had a mean age of 67.48 (9.92) and were generally college-educated. The majority were female (74.6%) and married (86.2%). In terms of financial resources, 33.6% and 59.3% of caregivers had a household income below $50,000 and the state median (i.e. $71,535), respectively. The majority of PWDs were male (53.3%), living in an urban area (62.2%), and White (85.7%).

### Primary outcomes: sixth session

Mean comparison analyses for all primary outcome variables between baseline and the sixth session are presented in Table 2. ADLs ($p < .001$) and iADLs ($p = .005$) significantly declined. Although no differences were seen in the frequency of BSD between baseline and the sixth session ($p = .47$), caregivers' reactions to BSD significantly improved ($p = .003$). Caregiver burden ($p = .001$) and symptoms of depression ($p < .001$) also improved. The number of caregivers classified as having a higher risk of clinical depression at the sixth session was significantly reduced from baseline ($p < .001$). Of the CESD-R symptom groups, Dysphoria ($p < .001$), Sleep ($p = .002$), Thinking/Concentration ($p = .01$), Worthlessness ($p = .03$), and Agitation ($p = .04$) showed significant improvement

**Table 1.** Demographic and other descriptive information.

| Variable | n | M (SD) | Range |
|---|---|---|---|
| Age (years) | 120 | 67.48 (9.92) | 43–89 |
| Education (years) | 120 | 15.28 (2.37) | 10–20 |
| | n | % | |
| Gender (n male) | 31 | 25.4 | |
| Annual household income | | | |
| <$5000 | 0 | 0.0 | |
| $5,000–$9,999 | 1 | 0.9 | |
| $10,000–$14,999 | 2 | 1.8 | |
| $15,000–$24,999 | 11 | 9.7 | |
| $25,000–$49,999 | 24 | 21.2 | |
| $50,000–$74,999 | 29 | 25.7 | |
| ≥$75,000 | 46 | 40.7 | |
| Marital status (n married) | 100 | 86.2 | |
| Relationship to the PWD | | | |
| Spouse | 80 | 66.7 | |
| Child | 31 | 25.8 | |
| Other | 9 | 7.5 | |
| Gender of the PWD (n male) | 64 | 53.3 | |
| Race of the PWD | | | |
| White | 105 | 87.5 | |
| African American | 14 | 11.7 | |
| Other | 1 | 0.8 | |
| Geographic location of the PWD | | | |
| Urban | 74 | 62.2 | |
| Rural | 45 | 37.8 | |

Note. PWD, person with dementia.

(Table 3). The frequency with which caregivers were able to complete activities ($p = .18$) or have their needs met ($p = .13$) did not change.

### Predictors of change

A linear regression analysis predicting change in caregiver burden between baseline and the sixth session yielded a significant final overall model. Younger age, being married, female gender, and lower household income were associated with a greater reduction in caregiver burden F(1, 93) = 5.31, $p < .001$, adjusted $R^2 = .15$. Age ($p = .007$), marital status ($p = .007$), and gender ($p = .03$) significantly contributed to the overall model.

A linear regression analysis predicting change in caregivers' reactions to BSD between baseline and the sixth session yielded a non-significant final model in which only gender was retained, F(1, 81) = 2.80, $p = .10$, adjusted $R^2 = .02$.

A linear regression analysis predicting change in the symptoms of depression between baseline and the sixth session did not yield an overall model, as no predictors were retained. In contrast, a logistic regression analysis predicting risk of depression group membership at the sixth session, in caregivers who were initially classified as having a higher risk of clinical depression at baseline, yielded a robust final model (Table 4). Gender and geographic location significantly predicted group membership with a correct classification rate of 77.8% (Nagelkerke $R^2 = .43$, $p = .005$, Hosmer-Lemeshow $p = .98$). Males caring for a PWD residing in a rural area were more likely to convert to a lower risk of clinical depression. Only geographic area ($p = .01$) contributed significantly to the overall model; however, gender had a much larger odds ratio than geographic area (OR = 5.17 and 0.04, respectively).

### Six-month follow-up

Seventy-nine caregivers completed the 6-month follow-up. Mean comparison analyses for ADLs, iADLs, and all

**Table 2.** Means comparisons between baseline and sixth session for primary measures.

| Type of test | Variable | Baseline | | Sixth session | | | | |
|---|---|---|---|---|---|---|---|---|
| | | n | M (SD) | n | M (SD) | t | p | 95% CI |
| t-test | Katz ADL total score | 119 | 4.60 (1.55) | 119 | 4.13 (1.87) | 4.54 | <.001 | [0.26, 0.66] |
| | Lawton IADL Scale total score | 110 | 2.53 (2.05) | 110 | 2.21 (1.98) | 2.85 | .005 | [0.10, 0.54] |
| | *RMBPC total reaction | 102 | 1.05 (0.56) | 102 | 0.91 (0.59) | 3.05 | .003 | [0.05, 0.25] |
| | *RMBPC total frequency | 114 | 1.55 (0.58) | 114 | 1.58 (0.66) | −0.72 | .47 | [−0.11, 0.05] |
| | CWBS short form activities total | 116 | 32.48 (5.52) | 116 | 31.85 (6.01) | 1.34 | .18 | [−0.30, 1.56] |
| | CWBS short form needs total | 120 | 32.78 (5.07) | 120 | 32.23 (5.07) | 1.54 | .13 | [−0.16, 1.26] |
| | *ZBI 4-item version | 120 | 8.91 (3.31) | 120 | 8.02 (3.36) | 3.36 | .001 | [0.37, 1.42] |
| | | n | M (SD) | n | M (SD) | Z | p | |
| Wilcoxon signed-rank test | *CESD-R | 108 | 14.94 (12.77) | 106 | 12.08 (10.49) | −3.74 | <.001 | |
| | | n (%) | | n (%) | | $\chi^2$ | p | Cramer's V |
| Chi-squared test | Depressed (n yes) | 32 (33.0) | | 20 (20.6) | | 20.11 | <.001 | .46 |

Note. CI, confidence interval; ADL, activities of daily living; IADL, instrumental activities of daily living; RMBPC, revised memory and behavior problems checklist; CWBS, Caregiver Well-Being Scale; ZBI, Zarit Burden Interview 4-Item Version; CESD-R, Center for Epidemiologic Studies Depression Scale-Revised; depressed, CESD style score > 15.
*Higher scores equate to greater impairment.

**Table 3.** Means comparisons between baseline and sixth session for Center for Epidemiologic Studies Depression Scale-Revised symptom groups.

| Type of test | CESD-R symptom group | Baseline | | Sixth session | | | | |
|---|---|---|---|---|---|---|---|---|
| | | n | M (SD) | n | M (SD) | t | p | 95% CI |
| t-test | Fatigue | 114 | 1.99 (1.91) | 114 | 1.78 (1.72) | 1.32 | .19 | [−0.11, 0.53] |
| | | n | M (SD) | n | M (SD) | Z | p | |
| Wilcoxon signed-rank test | Dysphoria | 120 | 3.53 (2.95) | 116 | 2.72 (2.63) | −3.53 | <.001 | |
| | Anhedonia | 121 | 1.43 (1.95) | 118 | 1.19 (1.52) | −1.43 | .15 | |
| | Appetite | 122 | 0.51 (1.29) | 117 | 0.44 (1.01) | −0.45 | .66 | |
| | Sleep | 118 | 2.91 (2.65) | 118 | 2.25 (2.29) | −3.09 | .002 | |
| | Thinking/concentration | 119 | 1.91 (2.08) | 118 | 1.44 (1.67) | −2.74 | .01 | |
| | Worthlessness | 117 | 1.10 (1.78) | 118 | 0.81 (1.28) | −2.22 | .03 | |
| | Agitation | 122 | 1.62 (1.86) | 116 | 1.28 (1.44) | −2.11 | .04 | |
| | Suicidal ideation | 120 | 0.16 (0.82) | 118 | 0.13 (0.59) | −0.99 | .32 | |

Note. CESD-R, Center for Epidemiologic Studies Depression Scale-Revised; CI, confidence interval. Higher scores indicate greater impairment.

**Table 4.** Stepwise Wald logistic regression model predicting depression group membership at sixth session for participants depressed at baseline.

| Final predictors | Statistics | | | | | | Final overall model | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | B | SE | Wald | p | OR | 95% CI | Nagelkerke $R^2$ | p | Hosmer-Lemeshow | Classification rate[a] |
| Gender | 1.64 | 1.11 | 2.19 | .14 | 5.17 | [0.59, 45.61] | .43 | .005 | .98 | 77.8% |
| Geographic location | −3.19 | 1.24 | 6.60 | .01 | 0.04 | [0.004, 0.47] | | | | |

Note. Depression, depressed versus not depressed using Center for Epidemiologic Studies Depression Scale-Revised style score cutoff of > 15; SE, standard error; OR, odds ratio; CI, confidence interval; Gender, male versus female; Geographic location, urban versus rural.
[a]Cut value = .48.

**Table 5.** Means comparisons between baseline and 6-month follow up for primary measures.

| Type of test | Variable | Baseline | | Six-month | | | | |
|---|---|---|---|---|---|---|---|---|
| | | n | M (SD) | n | M (SD) | t | p | 95% CI |
| t-test | Katz ADL total score | 76 | 4.59 (1.56) | 76 | 3.70 (2.10) | 5.10 | <.001 | [0.55, 1.24] |
| | Lawton IADL Scale total score | 69 | 2.58 (2.18) | 69 | 1.88 (1.97) | 4.75 | <.001 | [0.40, 0.99] |
| | *RMBPC total reaction | 65 | 1.08 (0.60) | 65 | 0.84 (0.54) | 3.89 | <.001 | [0.12, 0.37] |
| | *RMBPC total frequency | 75 | 1.62 (0.61) | 75 | 1.51 (0.69) | 1.70 | .09 | [−0.02, 0.24] |
| | CWBS short form activities total | 74 | 32.80 (5.51) | 74 | 33.04 (5.70) | −0.44 | .66 | [−1.34, 0.85] |
| | CWBS short form needs total | 77 | 32.96 (4.88) | 77 | 32.87 (4.97) | 0.20 | .85 | [−0.84, 1.02] |
| | *ZBI 4-item version | 76 | 9.13 (3.22) | 76 | 7.84 (3.50) | 3.52 | <.001 | [0.56, 2.02] |
| | | n | M (SD) | n | M (SD) | Z | p | |
| Wilcoxon signed-rank test | *CESD-R | 108 | 14.94 (12.77) | 66 | 8.39 (6.63) | −4.06 | <.001 | |
| | | n (%) | | n (%) | | $\chi^2$ | p | Cramer's V |
| Chi-squared test | Depressed (n yes) | 19 (31.7) | | 7 (11.7) | | 5.79 | .02 | .31 |

Note. CI, confidence interval; ADL, activities of daily living; IADL, instrumental activities of daily living; RMBPC, revised memory and behavior problems checklist; CWBS, Caregiver Well-Being Scale; ZBI, Zarit Burden Interview 4-Item Version; CESD-R, Center for Epidemiologic Studies Depression Scale-Revised; depressed, CESD style score > 15.
*Higher scores equate to greater impairment.

primary outcome variables between baseline and the 6-month follow-up are presented in Table 5. The results were highly similar to those yielded from the primary analyses, suggesting sustained post-intervention benefits. ADLs and iADLs significantly declined (p values < .001). Caregivers' reactions to BSD significantly improved (p < .001), despite the lack of change in the frequency with which these behaviors occurred (p = .09). Initial improvements in caregiver burden and symptoms of depression were maintained (p values < .001). The number of caregivers classified as having a higher risk of clinical depression at 6-month follow-up remained reduced from baseline (p = .02). The frequency with which caregivers were able to complete activities (p = .66) or have their needs met (p = .85) did not change.

### Caregiver satisfaction survey

At the sixth session, the majority of caregivers (98.1%) found the intervention helpful. Similar sentiments were expressed at 6-month follow-up (91.8%). At both the sixth session and 6-month follow-up, almost all caregivers indicated the intervention met their needs (96.2% and 90%, respectively), with a majority indicating it had a positive impact on their mood (84.9% and 77.1%, respectively) and the PWD for whom they provide care (60.9% and 59.1%, respectively). Only one caregiver indicated they would be unlikely to recommend the intervention to others. At both time points, most caregivers indicated they would be willing to pay to participate in the intervention (81.5% and 77.1%, respectively).

Caregivers were asked two open ended questions in this survey: 'What did you find most helpful about this program?' and 'What would you change about the program?' We identified four themes related to aspects that caregivers found most helpful: 1) being able to express how they felt about their situation, 2) a sense of feeling heard and validated, 3), practical benefits derived from learning the causes and symptoms of dementia and available community resources, and 4) mobilization and strengthening of their support network. Thematic analysis of answers to the second question did not result in discovery of coherent themes.

## Discussion

Caregiver burden often has a detrimental impact on caregivers' health and QoL. As the prevalence of dementia increases (Mayeux & Stern 2012), so will the number of caregivers and the associated socio-economic impact. This study demonstrated the efficacy of implementing a modified evidenced-based intervention for caregivers of community dwelling PWDs.

Symptoms of depression, caregiver burden, and the caregivers' ability to effectively manage their reactions to BSD significantly improved at the sixth session, the study's primary endpoint. Caregivers experienced improvements despite deterioration of PWDs' ADLs and iADLs. These results suggest a positive impact on multiple aspects of caregiver health and well-being, which may be attributed to the multi-component nature of FAMILIES and its capacity to address a diversity of person-specific needs.

Though not synonymous constructs, there is overlap between the symptoms of depression and caregiver burden. Caregivers with more responsibilities, who experience more severe and/or chronic stress, role strain, and uncertainty about the future are more vulnerable to depression (Feast, Orrell, Russell, Charlesworth, & Moniz-Cook, 2017; Pinquart & Sörensen, 2003a). Elevated depressive symptoms can have a negative impact on the emotional and cognitive resources needed to effectively balance caregiving and other life demands. This can, in turn, exacerbate caregiver burden. It is therefore possible that improvements in the symptoms of depression and caregiver burden had synergistic effects, thereby contributing to a broader positive impact on well-being.

Caregivers experienced improvement in the majority of the symptoms comprising the construct of depression and thus the overall experience of feeling 'depressed'. This suggests that improved depression stemmed from systemic improvements in emotional, psychological, and behavioral symptoms and was not artificially driven by change in an isolated component of depression. Our results also suggest that FAMILIES was successful in reducing the number of caregivers who at baseline had a higher risk of clinical depression. Being male and living in a rural area were specifically associated with a greater likelihood of converting from a higher to lower risk of clinical depression. Men are less likely to have or use an emotional support system (Coe & Neufeld, 1999) and individuals in rural areas have less access to support services (National Rural Health Alliance, 2010). The greater isolation and limited support that can be seen in male caregivers and those living in a rural areas may have resulted in increased baseline vulnerability to clinical depression, thereby affording greater opportunity for improvement.

Caregivers' capacity to effectively cope with and manage BSD is likely to have a reciprocal impact on their mental health and experience of caregiver burden. It is well-understood that BSD cause significant caregiver distress (Fauth & Gibbons, 2014; Huang, Lee, Liao, Wang, & Lai, 2012) and that BSD can precipitate institutionalization and predict earlier time to death (de Vugt et al., 2005; Chan, Kasper, Black, & Rabins, 2003). Medications prescribed to ameliorate BSD often have limited efficacy, can exacerbate cognitive deficits, and increase the risk of falls, aspiration, cerebrovascular events, and mortality (Maust et al., 2015; Schneider, Dagerman, & Insel, 2006). In contrast, non-pharmacological interventions that focus on coping skills and behavioral management strategies have limited adverse side effects and can be cost-saving (Long, Moriarty, Mittelman, & Foldes, 2014). FAMILIES interwove patient-centered psychoeducation about dementia and its symptom manifestations, with evidence-based coping, behavioral symptom management training, and a focus on strengthening caregiver support networks. The reduction seen in the severity of caregivers' reactions to BSD suggest that they were successful in applying the knowledge learned and skills developed via the intervention. Importantly, caregivers demonstrated increased efficacy in responding to BSD despite a lack of change in the frequency of symptom occurrence. This suggests that FAMILIES was the principal factor underlying the observed improvements, given its focus on dementia education and caregiver coping, as opposed to direct symptom amelioration. Ultimately, it appears that as caregivers gained increased confidence in their ability to employ new coping and behavioral management skills, and received greater caregiving support, they experienced a subsequent reduction in caregiver burden and depressive symptoms.

The factors that contribute to caregiver burden vary among caregivers of different demographic backgrounds (Covinsky et al., 2003; Roth, Haley, Owen, Clay, & Goode, 2001; Lee, Czaja, & Schulz, 2010). Less is known about the factors that moderate outcomes of caregiver interventions. In contrast to previously published findings (Navaie-Waliser et al., 2002), PWD level of independence in ADLs and iADLs did not predict change in caregiver burden or other outcomes. Rather, we found that caregivers who were married and female were most likely to experience a greater

improvement in caregiver burden. Studies have shown that women disproportionately use emotion-focused coping strategies (Iavarone, Ziello, Pastore, Fasanaro, & Poderico, 2014) and are subject to the dominant societal expectations that they assume the role of caregiver, even at the expense of their own goals, physical health, and psychological resources (Rose-Rego, Strauss, & Smyth, 1998; Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000). Although being married or partnered often mitigates the risk of poor health outcomes, caregivers married to and living with a PWD do not receive the same amount or type of practical or emotional support as those who are married and living with someone without dementia. Through FAMILIES, spousal caregivers learned task-focused and non-avoidant coping skills, shown to be effective in reducing caregiver burden (Aschbacher et al., 2005). Another central aim of FAMILIES was to strengthen the caregivers' support network, thereby lessening the daily demands placed upon them. These core components of the intervention were ideally matched to the specific needs of many women and/or married caregivers, which may account for their greater reduction in caregiver burden.

Having a lower household income was associated with improvements in caregiver burden, suggesting that caregivers who might not have the resources to afford and participate in dementia care services may actually benefit the most from doing so. This finding is critically important given that community dwelling caregivers of PWDs with lower incomes (Mavandadi et al., 2017), as well as people of color, those with less education, less caregiving support (Davis, Weaver, & Habermann, 2006), or their own health problems (Gitlin, Corcoran, Winter, Boyce, & Marcus, 1999) are less likely to complete caregiver intervention programs. Disparities in the ease of access to dementia care services and the strain placed on caregivers' resources can affect their capacity to engage in, complete, and thus benefit from dementia care services. If such barriers can be overcome, caregivers with fewer resources may experience heightened benefits from participating in caregiver interventions.

In order for a clinical intervention to be successful, it needs to have enough appeal for individuals to enroll and then find personally rewarding. FAMILIES allowed caregivers the opportunity to develop individualized goals and treatment plans given their unique needs. Satisfaction survey responses show that caregivers found this person-center approach as valuable, having met their needs, and having positively impacted their well-being. Caregivers also found FAMILIES to have a positive impact on the well-being of the PWD for whom they provide care.

A common shortcoming of caregiver interventions is the limited long-term efficacy of initially favorable outcomes or the lack of known long-term efficacy given limited follow-up. Results from studies evaluating the long-term benefits of NYUCI stand as exceptions. Implementation of the NYUCI for spousal caregivers of PWDs with AD resulted in sustained improvements in caregivers' social support networks, depressive symptoms, and capacity to effectively manage their reactions to BSD (Roth et al., 2005; Mittelman et al., 1995; Mittelman, Roth, Coon, et al., 2004; Mittelman, Roth, Haley, et al., 2004; Mittelman et al., 2006; Gaugler et al., 2013). Similar long-term benefits were realized despite our modifications to the NYUCI. Caregivers maintained improvements in caregiver burden, symptoms of depression, and their ability to effectively respond to BSD at 6-month follow-up. These benefits were sustained despite further decline in PWDs' ADLs and iADLs and a lack of change in the frequency of manifested BSD. Together, these results are a cause for optimism when considering the longitudinal implications of sustained post-intervention improvements in health and the potential subsequent economic benefits.

## Limitations

Because FAMILIES was principally implemented to meet the unique needs of a broad population of caregivers of PWDs, no control group was utilized. The results of our study are, however, supported by results from several randomized controlled studies of the NYUCI. Given these consistencies and that our modifications to the core structure of the evidenced-based NYUCI were minimal, we believe that our results can be viewed as an important extension of previous findings. A second limitation is the number of caregivers who terminated early. That said, there were no significant differences between caregivers who completed the sixth session and those who terminated early. This suggests that the observed improvements were not an artificial byproduct of attrition of more severely affected caregivers. Despite concerted efforts to recruit non-White caregivers, the percentage of enrolled African American participants (11.7%) was below the percentage of African Americans in Virginia (19.2%). This reflects longstanding discrepancies in healthcare utilization between White and non-White people in the Southeast region of the country and is a common problem across healthcare research. Future work needs to be completed to improve outreach and access to healthcare resources to non-White caregivers.

## Conclusions

Caregivers who participated in FAMILIES experienced significant improvements in caregiver burden, symptoms of depression, and their ability to effectively react to BSD. Different demographic factors were associated with different outcomes. The positive benefits of the intervention were sustained at 6-month follow-up. Our findings indicate that the Virginia implementation of the modified NYUCI, which reduced the number of sessions and extended eligibility to all informal caregivers of community dwelling PWDs, regardless of dementia etiology or their relationship to the PWD, had a broad, positive, and sustained impact. Given the relatively low costs of conducting this intervention, even modest government funding directed at supporting implementation of FAMILIES could have significant positive implications on the health and well-being of caregivers and PWDs, as well as the healthcare system at large.

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