

External Validity of the New York University Caregiver Intervention: Key Caregiver Outcomes Across Multiple Demonstration Projects

Elizabeth B. Fauth¹, Mark A. Jackson¹,
Donna K. Walberg², Nancy E. Lee²,
Leisa R. Easom³, Gayle Alston³, Angel Ramos³,
Kristen Felten⁴, Asenath LaRue⁵,
and Mary Mittelman⁶

Abstract

Purpose of the Study: The Administration on Aging funded six New York University Caregiver Intervention (NYUCI) demonstration projects, a counseling/support intervention targeting dementia caregivers and families. Three sites (Georgia, Utah, Wisconsin) pooled data to inform external validity in nonresearch settings. This study (a) assesses collective changes over time, and (b) compares outcomes across sites on caregiver burden, depressive symptoms, satisfaction with social support, family conflict, and quality of life.

Manuscript received: December 11, 2015; **final revision received:** April 7, 2017;
accepted: May 6, 2017.

¹Utah State University, Logan, USA

²Minnesota Board on Aging, St. Paul, USA

³Georgia Southwestern State University, Americus, USA

⁴Wisconsin Department of Health Services, Madison, USA

⁵University of Wisconsin–Madison, USA

⁶New York University Medical Center, New York City, USA

Corresponding Author:

Elizabeth B. Fauth, Utah State University, 2905 Old Main Hill, Logan, UT 84322-2905, USA.

Email: beth.fauth@usu.edu

Design and Methods: Data included baseline/preintervention ($N = 294$) and follow-up visits (approximately 4, 8, 12 months). **Results:** Linear mixed models showed that social support satisfaction increased ($p < .05$) and family conflict decreased ($p < .05$; Cohen's $d = 0.49$ and 0.35 , respectively). Marginally significant findings emerged for quality of life increases ($p = .05$) and burden decreases ($p < .10$). Depressive symptoms remained stable. Slopes did not differ much by site. **Implications:** NYUCI demonstrated external validity in nonresearch settings across diverse caregiver samples.

Keywords

caregiving, dementia, intervention

Caregiving for family members with dementia can be rewarding (Carbonneau, Caron, & Desrosiers, 2010; Kramer, 1997) but is also associated with stress that affects caregivers' physical and mental health (Pearlin, Mullan, Semple, & Skaff, 1990; Pinquart & Sörensen, 2003). Meta-analyses of 78 articles suggest that interventions are effective at improving caregiver outcomes such as burden, depressive symptoms, and overall life satisfaction, particularly if the interventions include both psychotherapeutic (i.e., counseling) and educational components (Sörensen, Pinquart, & Duberstein, 2002). Interventions that reduce caregiver stress can affect caregiver physical health directly and/or indirectly via these improved mental health processes (Basu, Hochhalter, & Stevens, 2015). Zarit and Femia (2008) discuss characteristics of successful interventions with examples drawn from specific interventions in the literature. Interventions that are multidimensional and target the heterogeneous goals and needs of caregivers, offer flexibility and adaptability to the curriculum or approach, pay attention to the dosage of the intervention, and match their research design to effectively document the desired outcomes are noted as particularly successful approaches.

Between 2008 and 2013, the Administration on Aging (AoA) Supportive Services Program (ADSSP) provided funding to replicate empirically validated caregiver interventions, including the Savvy Caregiver (Hepburn, Lewis, Sherman, & Tornatore, 2003), REACH II (Elliott, Burgio, & Decoster, 2010; Nichols et al., 2008), and the New York University Caregiver Intervention (NYUCI; Mittelman, Epstein, & Pierzchala, 2003). Caregiver support services in California, Florida, Georgia, Minnesota, Utah, and Wisconsin were awarded funding to translate the NYUCI in their areas. Translation projects were awarded from independent applications, and although each site was required to empirically assess program effectiveness,

sites were not, a priori, required to participate in a coordinated cross-site research comparison. In a post hoc decision, however, three sites (Georgia, Utah, and Wisconsin) agreed to pool data for the purposes of (a) assessing collective changes over time and (b) comparing outcomes across sites.

The current article provides a unique opportunity to describe how an intervention program that was originally embedded within a structured randomized control trial in an urban setting (the original NYUCI) translates to multiple real-world settings, where there is more “noise” (variability) introduced both within and between sites. When state or regional service providers across the United States (e.g., Divisions of Aging Services, Area Agencies on Aging) seek to implement empirically validated programs, they will need to be aware of results from highly controlled studies with high levels of internal validity (as is presented below, from the original NYUCI). They should also be aware, however, of program outcomes from settings that might be more similar to their own, for example, when the target population of caregivers is rural, include nonspouses, or vary in ethnicity from the original NYUCI. Describing outcomes from these pooled data across participating demonstration projects addresses external validity of NYUCI.

The NYUCI Program: Description of the Program and Prior Research

The NYUCI began in 1987 and enrolled 406 participants over a 10-year time frame with high retention rates. The study involved only spousal caregivers of persons with dementia living in the New York City metropolitan area. Participants were randomly assigned to the NYUCI treatment group or to a usual-care control group (who received advice, information about resources, and support services as needed). Details of the NYUCI protocol are published (Mittelman et al., 2003), with a brief overview of the research design and intervention included here.

The program includes identical assessment of caregivers preintervention (baseline) and at 4, 8, 12 months follow-up (and for the original study, every 6 months thereafter, continuing after nursing home placement and up until 2 years after the death of the person with dementia). The assessment battery includes demographic characteristics, physical health of the caregiver and care recipient, sources of caregiver assistance, behavioral symptoms and dementia severity of the care recipient, caregiver burden, depressive symptoms, family conflict, satisfaction with social support, and quality of life (QoL). These interviews are conducted face to face by trained NYUCI interventionists/counselors, and they inform both program evaluation and caregiver needs.

Over 4 to 6 months with the same counselor, caregivers receive one individual counseling session, followed by four family counseling sessions (caregivers choose who it is that they invite), and one final individual session. Sessions occur in caregivers' homes or at counselors' service delivery centers based on the preference of the caregiver. In the first individual session, the caregiver and counselor discuss expectations, the importance of including family members in support of the caregiver and person with dementia, decide on family members to be invited to participate, and review the intervention timeline. During family sessions, the caregivers and their family members discuss the impact of the disease and the experiences of caregiving, and the family focuses on building a support network for the caregiver and care receiver. In the final individual session, the counselor and caregiver review the family sessions and focus on integrating the experiences into a plan for the future. Caregivers are encouraged to join a support group after the first follow-up evaluation and receive ad hoc counseling as needed, generally via telephone calls to their assigned counselor if they have specific questions or concerns. Follow-up evaluations provide opportunities to assess change and have further counseling.

Randomized control trials of the original NYUCI identified that the intervention was associated with (a) improved caregiver satisfaction with social support (Drentea, Clay, Roth, & Mittelman, 2006; Roth, Mittelman, Clay, Madan, & Haley, 2005), (b) reduced depressive symptoms (Mittelman et al., 1995; Mittelman, Roth, Coon, & Haley, 2004) both before and after institutionalization (Gaugler, Roth, Haley, & Mittelman, 2008), and (c) decreased distress ratings of behavioral symptoms of the person with dementia (Mittelman, Roth, Haley, & Zarit, 2004). Participating caregivers reported better health and fewer illnesses longitudinally (Mittelman, Roth, Clay, & Haley, 2007) and delayed institutional placement of care recipients (Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Mittelman, Haley, Clay, & Roth, 2006). Long, Moriarty, Mittelman, and Foldes (2014) used NYUCI data for economic projections of dollars saved, associated with prevented or delayed institutionalization.

The Three Country Study—a randomized control study testing NYUCI in the United States, England, and Australia—replicated the decrease in depressive symptoms over 2 years for the NYUCI treatment group and found increases in symptoms for the control group (Mittelman, Brodaty, Wallen, & Burns, 2008). A modified version of the intervention in Minnesota with adult-child caregivers (NYU-AC) found similar results. Caregivers receiving NYU-AC were less reactive to behavioral symptoms in the person with dementia (Gaugler, Reese, & Mittelman, 2016), showed a 3-year reduction in depressive symptoms, and showed increased QoL compared with control

group caregivers (Gaugler, Reese, & Mittelman, 2015). These caregivers also kept their parents at home significantly longer than caregivers in the control group (Gaugler, Reese, & Mittelman, 2013). Collectively, these studies support the effectiveness of NYUCI in randomized control studies with high levels of internal validity.

AoA Demonstration Projects: NYUCI Across Multiple Sites

The AoA funded six NYUCI demonstration projects; awardees were California (CA Dept. of Aging), Florida (FL Dept. of Elder Affairs), Georgia (Rosalynn Carter Institute for Caregiving and GA Southwestern State University), Minnesota (MN Board on Aging), Utah (UT Division of Aging and Adult Services), and Wisconsin (WI Department of Health Services). Funding for these projects was purposefully focused on service delivery. The assessment component in the demonstration projects was intended to document program effectiveness within each site and inform the individualized counseling, and the studies were *not* designed with the original intention of conducting comparative analyses. However, discussions among participating sites during the period of implementation led to a collaboration and pooled data, the purpose of which is to report information helpful in discerning external validity across diverse locations and samples. To do so, we report the extent to which outcomes changed over time (across all available sites) and/or if significant differences emerged in outcomes between sites.

The California site did not share data for pooled analyses, as their data management agreement did not permit pooling with external collaborators. Despite requests to amend the original approved protocols, the Institutional Review Board (IRB) overseeing the Florida data collection restricted the agencies from pooling the data because consent from participants had not been collected for these purposes. Minnesota used measures of caregiver outcomes that were different from those used by the other sites, prohibiting the pooling of Minnesota data. Thus, the current manuscript includes data from Georgia, Utah, and Wisconsin. We note, however, that outcomes from the Minnesota translation project are published elsewhere. The Minnesota translation project reported decreased depressive symptoms and distress. The project also identified that attending a greater number of counseling sessions was associated with delayed institutionalization of the person with dementia (Mittelman & Bartels, 2014).

The three demonstration sites using the NYUCI protocol and pooling data for the current analyses differed from the original study design/protocol in a number of ways: First, although the original NYUCI utilized spousal

caregivers, in the current study only Wisconsin utilized a spousal sample, while the other sites include spouses and adult-offspring caregivers (see Table 1). Second, the sample in the original NYUCI was drawn from a largely White, urban population; however, all subsamples in our investigation were more likely to include rural caregivers, and Georgia specifically targeted service delivery to a sample subset of African American caregivers. Finally, the original study with high levels of internal validity included a randomized control design with a usual-care comparison group. As AoA demonstration funding focused on service delivery, it would not support the assessment of a control group. Thus, while we compare NYUCI outcomes collectively and across sites, we cannot determine how these pooled data compare with a control or usual-care group.

Method

Participants

Recruitment of caregivers took place through state and local aging agencies, public resource centers, and the Alzheimer's Association state/regional chapters, although the sites varied to some extent in their recruitment approaches. Most caregivers in Georgia were recruited when they contacted participating Area Agencies on Aging. Utah identified caregivers in a similar way and via caregivers' phone calls to the Alzheimer's Association. Wisconsin followed similar procedures and added outreach to health care facilities, senior services programs, and community organizations.

Inclusion criteria varied only slightly by site. All sites required the care recipient to have a diagnosis of Alzheimer's disease or other dementia, and excluded caregivers who were not primary caregivers, or those with a serious mental illness that would prevent participation in counseling sessions, or those that did not have at least one family member available to attend family counseling sessions. All sites also required the care dyad to live in the community (not be institutionalized) at baseline but not necessarily in the same home. Utah and Wisconsin also explicitly stated that they limited participation to English-speaking participants. Wisconsin was the only state to require that caregivers were spouses. Georgia required that caregivers endorsed having some burden in their role and the need for assistance.

Baseline preintervention data come from a total sample of 294 caregivers. Table 1 provides rates of attrition and sample characteristics. Georgia had the highest rates of attrition. The counselors/interventionists in Georgia could not identify one or more particular reasons for lack of interest in follow-up, but speculated that with service delivery as their main focus there was a low level

Table 1. Sample Demographic Characteristics of Caregiver (CG) and Person with Dementia (PWD).

	All sites	Utah	Georgia	Wisconsin
Baseline N	294 (100.0%)	88 (100.0%)	132 (100.0%)	74 (100.0%)
Follow-Up 1 n (% retention from baseline)	152 (51.7)	55 (62.5)	54 (40.9)	43 (58.1)
Follow-Up 2 n (% retention from baseline)	74 (25.2)	36 (40.9)	11 (8.3)	27 (36.5)
Follow-Up 3 n (% retention from baseline)	44 (15.0)	24 (27.3)	5 (3.8)	15 (20.3)
CG kin relationship (%)*				
Adult child	9.6	13.6	12.1	0
Spouse	89.8	83.0	87.9	100.0
Other	0.7	2.3	0	0
CG married (%)*	90.2	90.0	84.8	100.0
CG female (%)	66.9	68.2	63.1	71.6
CG age (M)*	70.8 (SD = 11.5)	69.1 (SD = 11.8)	69.2 (SD = 12.3)	75.2 (SD = 8.3)
PWD female (%)	38.4	35.2	45.9	29.7
PWD age (M)	76.1 (SD = 9.7)	75.5 (SD = 7.9)	75.6 (SD = 11.6)	77.7 (SD = 7.9)
CG ethnicity: % identifying as Hispanic	2.6	5.7	1.5	0
CG race (%)*				
White	88.4	96.6	76.5	100
American Indian or Alaska Native	0	0	0	0
Asian	0	0	0	0
Black/African American	8.5	0	18.9	0
Native Hawaiian/Pacific Islander	1.0	1.1	1.5	0
Other	2.0	2.3	3	0
CG education (%)*				
Graduate school	14.5	21.6	11.7	10.8

(continued)

Table 1. (continued)

	All sites	Utah	Georgia	Wisconsin
Completed college	21.4	28.4	15.6	23
Some college	24.8	35.2	15.6	28.4
Completed high school	25.9	13.6	32.0	29.7
Some high school	7.6	1.1	12.5	6.8
Junior high school	3.8	0	7.8	1.4
<7 years of school	2.1	0	4.7	0
CG %working*	17.2	23.9	18.6	6.8
PWD global deterioration (M)	4.8 (SD = 1.12)	4.6 (SD = 1.3)	4.9 (SD = 1.1)	4.8 (SD = 0.9)
CG clinically depressed ^a (%)	31.6	38.6	24.2	36.5
Reasons for attrition				
Lack of interest from CG or family members in attending family counseling	25 (17%)	7 (21%)	11 (14%)	7 (22%)
Closure of service provider or other scheduling difficulties for follow-up assessments ^b	23 (16%)	9 (27%)	—	14 (45%)
Institutionalization of PWD	9 (6%)	6 (18%)	3 (4%)	—
Death of PWD	9 (6%)	4 (12%)	5 (6%)	—
CG or PWD declining health	17 (12%)	5 (15%)	5 (6%)	7 (22%)
CG death or moved from area	3 (2%)	—	2 (3%)	1 (3%)
Other/unknown/lost to follow-up	58 (41%)	2 (6%)	52 (67%)	2 (7%)

Note. All values except attrition information are baseline (preintervention) data. CG = caregivers; PWD = persons with dementia.

^aClinical depression cutoff scores are 10 for Geriatric Depression Scale, based on Lyness, et al., 1997

^bA UT Alzheimer's Association branch office closure forced these participants to leave the study, as the remote geographic location did not allow for counselors in other areas to continue working with these participants.

*Indicates that chi-square (categorical variable) or ANOVA (continuous variable) differed by site at a level of $p < .05$.

of interest from participants in being assessed after the completion of the counseling sessions.

Procedures

After receiving AoA funding, the sites were trained individually prior to providing services to caregivers (training by the original author, Dr. Mittelman, occurred face to face). Counselors/interventionists were encouraged to read *Counseling the Alzheimer's Caregiver: A Resource for Health Care Professionals* (Mittelman et al., 2003), and training included the provision of documentation on NYUCI procedures, sessions, assessment, and so on (see *A Guide to Implementing the NYU Caregiver Intervention*; Mittelman & Epstein, 2009). Throughout the duration of the funding period, regular phone meetings occurred across participating demonstration sites to address questions and maintain fidelity to the program.

The NYUCI protocol and assessment schedule are described in the introduction, with further details available (e.g., Mittelman & Epstein, 2009; Mittelman et al., 2003); however, we review these procedures again here. Counseling sessions occurred face to face in the home or at an agency office, but on rare occasions family meetings were held via telephone or online video conferencing. Counseling sessions occurred for most caregivers over 4 months (occasionally extended to 6 months), and the length of individual and family sessions (as determined by the caregiver) ranged from 30 to 120 min. The range on the intervention is large; however, this is because the length of time spent with a counselor depended on the needs of the caregiver, and meeting length was purposefully flexible.

The content and focus of sessions are determined by the caregiver's needs and the specific family concerns and dynamics. In the initial individual session, the counselor clarified the outcomes of the baseline assessment, going over the concerns and difficulties of the caregiver, as well as identifying family members to be included in the intervention. Over the following four family sessions, family members came together to better understand the needs of the person with dementia and the needs of the caregiver. They discussed ways to be emotionally supportive to the caregiver, with the goal of developing an effective and supportive network for the caregiver. In the follow-up individual session, the counselor reviewed the effectiveness of the family sessions, identified remaining needs, and helped establish a plan for the future, including encouraging caregivers to attend a support group and/or utilize existing resources.

Per NYUCI protocol, caregivers completed the assessment battery at baseline (preintervention), Follow-Up 1 (4 months), Follow-Up 2 (8 months),

and Follow-Up 3 (12 months postbaseline). However due to a misinterpretation of the assessment schedule, the first follow-up assessment in Wisconsin was scheduled 4 months after the last counseling session, such that the initial follow-up occurred at an average of 10.79 ($SD = 2.67$) months after baseline assessment. Thus, what was labeled in the protocol as “4-month” assessment is actually close to 10 months postbaseline for WI, with “8-month” and “12-month” assessments occurring on average at 15 and 19 months. To adjust for this inter- and intrasite variability in assessment timing and estimations of the linear change over time, an elapsed time variable was used in all growth curve models (see analytic plan).

Measures

Caregiver burden. The Zarit Burden Interview (ZBI; Zarit, Reever, & Bach-Peterson, 1980) is a self-report instrument with 22 items measuring caregiver burden on a scale of 0 (*never*) to 4 (*nearly always*). A summed score reflects greater levels of burden. Cronbach's alpha in the combined sample at baseline was .90 (UT $\alpha = .92$; GA $\alpha = .88$ WI $\alpha = .88$).

Depressive symptoms. The Geriatric Depression Scale (GDS; Yesavage et al., 1983) assesses the presence of depressive symptoms in caregivers. The GDS contains 30 items that are rated dichotomously (0 = *no*; 1 = *yes*) to produce a summed score. Cronbach's alpha in the combined sample at baseline was as follows: $\alpha = .88$ (UT $\alpha = .89$; GA $\alpha = .92$; WI $\alpha = .79$).

Satisfaction with social support. Caregivers reported satisfaction with social support using three items from the Social Network Questionnaire (Stokes, 1983). Item responses range from 1 (*very satisfied*) to 6 (*very dissatisfied*). Item-level scores were reverse coded and averaged, such that higher scores indicate greater satisfaction. Cronbach's alpha in the combined sample at baseline was as follows: $\alpha = .84$ (UT $\alpha = .84$; GA $\alpha = .85$; WI $\alpha = .74$).

Family conflict. The Family Conflict Scale (Semple, 1992) contains 12 items assessing family conflict specifically related to dementia care on a scale of 0 (*none*) to 3 (*quite a bit*). Higher summed scores indicate greater conflict. Cronbach's alpha in the combined sample at baseline was .92 (UT $\alpha = .93$; GA $\alpha = .93$; WI $\alpha = .79$).

QoL. Caregivers rated their overall QoL with a single item: “How would you rate your overall quality of life today?” Participants rated their QoL both textually (by writing a number) and graphically (by indicating the

appropriate value on a Visual Analog Scale [VAS]) on a scale of 0 to 100. De Boer and colleagues (2004) report that single-item VAS QoL measures have acceptable validity and reliability, and can adequately capture change over time.

Deterioration in care recipients. Although global functional impairment of care recipients was not an outcome targeted by NYUCI, we include a model of changes over time for descriptive purposes only. The Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982) was used in all states except Utah, where the Mini-Mental State Examination (MMSE) was used instead (Folstein, Folstein, & McHugh, 1975). The Global Deterioration Scale measures care recipients' impairment on a seven-stage scale ranging from 1 (*no cognitive decline; normal function*) to 7 (*very severe cognitive decline; late-stage dementia*). The MMSE is a cognitive performance test containing 30 items indicating success or failure to complete a cognitive task, with higher summed scores indicating higher cognitive function. Reisberg and colleagues (2011) administered both scales to a large sample of persons with dementia and report appropriate conversion scores between the MMSE and Global Deterioration Scale, thus to facilitate pooling data, Utah participants' Global Deterioration scores reflect this conversion from the MMSE.

Analytic Plan

Data on demographic characteristics and baseline, 4-, 8-, and 12-month assessments were pooled following approval of each participating IRB. Informal information/notes collected by counselors during individual and family counseling sessions were not IRB approved for data sharing, as family members were not part of the consent for research process—their volunteer participation was only to attend counseling. Mixed models for all outcomes (random slope–random intercept; IBM SPSS Version 22) were used to compare linear slope models with corresponding quadratic models. The best-fitting “base” model was determined via comparisons of the Akaike information criterion (AIC) score (such that lower scores are more desirable). In the next step, models were rerun to include the covariate of *Site* (GA, UT, WI), which permitted the identification of significant differences across initial (baseline) levels and rates of change over time (per month). Wisconsin was the reference category in these analyses. This site was chosen at random; however, it provides a unique comparison opportunity because it was the only site that included exclusively spouses in the sample, making Wisconsin's sample potentially more similar to the original NYUCI study. Additional follow-up analyses were conducted using Utah as a reference group to identify if site

differences were biased only because of the choice of reference group. The follow-up analysis also allowed us to compare Utah with Georgia, which is not feasible when WI is the reference group. In addition, for models where the fixed effect of change over time was significant, follow-up models were run with basic demographic characteristics included to determine if covariates explained variance in change over time. Covariates included caregiver gender, age, race/ethnicity, and education; kin relationship with the care receiver was excluded because it shared variance with age and gender. Full-information maximum likelihood (FIML) was used to impute missing data for all models.

The original intention as outlined by NYUCI was to assess caregivers at baseline, 4, 8, and 12-month postbaseline, but as described above, Wisconsin initiated the first follow-up assessment 4 months postcounseling (not post-baseline). To account for differences in assessment timing, *Time* was modeled as *Time elapsed from baseline in months*. This elapsed time variable was not rounded; someone completing a Follow-Up 1 at 4 months and 15 days postbaseline would have a Follow-Up 1 *Time* score of 4.5. Someone with his or her first follow-up at 6 months 5 days postbaseline would have a Follow-Up 1 time score of 6.17. Thus, we account for variability in assessment dates both across sites and within sites.

Results

Demographic Characteristics of the Sample: Collectively and by Site

Demographic characteristics (pooled and separate by site) are presented in Table 1. ANOVA was used to compare sites on continuous variables, and chi-square tests were used to compare sites across categorical variables. Sites did not differ statistically on caregiver gender, $\chi^2(2, N = 284) = 1.60, p = .45$; the percentage of caregivers above the clinical cutoff for depression at baseline, $\chi^2(2, N = 240) = .33, p = .85$; the gender of the person with dementia, $\chi^2(2, N = 284) = 5.63, p = .06$; or the average age of the person with dementia, $F(2, 272) = 1.32, p = .27$. Groups did not differ on Global Deterioration Scale score at baseline $F(2, 233) = 1.80, p = .17$, and the average at baseline was 4.8 ($SD = 1.12$), where a 4 indicates mild and 5 indicates moderate dementia. Just less than one third of caregivers were above the clinical cutoff for depression (GDS 10+; Lyness et al., 1997) at baseline (31.6%).

Across the three sites, the majority of caregivers were spouses (89.8%); however, sites differed in caregiver kin relationship distribution, $\chi^2(4, N = 293) = 15.60, p < .01$; marital status, $\chi^2(2, N = 256) = 12.36, p < .01$; and

average age, $F(2, 267) = 7.91, p < .001$. These differences are driven by the fact that Wisconsin's sample was all spousal caregivers, whereas Utah and Georgia had comparatively lower proportions of spousal caregivers (83.9% and 87.9%, respectively). The percentage of participants identified as Hispanic was low across all states (2.6% of the total sample) but higher in Utah (5.7%) than in other states, $\chi^2(3, N = 532) = 10.44, p < .05$. Similarly, while the majority of the pooled sample was White (88.4%), Georgia had a much higher percentage (18.9%) of Black or African American participants compared with other sites, $\chi^2(6, N = 294) = 37.83, p < .01$. Of the pooled sample, 86.6% completed high school or higher. Utah had the highest levels of education of all four sites, followed by Wisconsin, then Georgia, $F(12, 290) = 51.03, p < .001$. Utah also had the highest percentage of working caregivers (23.9%), followed by Georgia (18.6%), then Wisconsin (6.8%), $\chi^2(2, N = 291) = 8.60, p < .05$.

Key Outcomes From Pooled Data: Collective Results

For all outcomes, the linear rate of change produced a better fit (lower AIC) than the quadratic models, thus results reflect *Time* as linear. Fixed effects (linear slope estimates) of elapsed time (see Table 2) suggest that, collectively across all sites, burden changed at an average rate of -0.13 points per month ($p = .10$; marginally significant). Caregivers' depressive symptoms did not change over time at a rate that was statistically different from 0 (Est. = $-0.05, p = .16$). We note, however, that stability in depressive symptoms is not likely due to a measurement "ceiling or floor" effect. At baseline, nearly one third of caregivers were above the cutoff described in the GDS as "clinically significant" depressive symptoms (see Table 1). GDS scores ranging from 9 to 11 indicate "moderate depression," and the parameter estimate for initial level across pooled data in our sample was 9.15, indicating that average initial levels of depressive symptoms across all sites were fairly high.

Satisfaction with social support increased at a rate of 0.03 per month ($p < .01$; statistically significant), suggesting that caregivers became increasingly satisfied with their social networks. Family conflict scores decreased over time by 0.11 per month ($p < .05$; statistically significant). QoL increased at a rate of 0.22 per month ($p = .05$; marginally significant). Results from the descriptive model tracking care recipient dementia severity suggested that severity increased at an average rate of 0.06 per month ($p < .01$).

In sum, two of the caregiver outcome models had statistically significant change over time (satisfaction with social support increased and family conflict decreased). Although no control group was available, we computed within-group effect sizes for this change over time using means and standard

Table 2. Pooled Data Best-Fitting Base Models With Fixed Effects.

Dependent variable	AIC ^a	Intercept		Linear time	
		Estimate	<i>p</i>	Estimate	<i>p</i>
Burden	3,914.92	33.729	.000	-0.132	.099
Depressive symptoms	3,137.68	9.146	.000	-0.046	.155
Satisfaction with social support	1,655.55	4.647	.000	0.029	.000
Family conflict	3,193.36	7.938	.000	-0.134	.029
Quality of life	4,340.97	66.845	.000	0.221	.053
Global Deterioration Scale	1,113.73	4.805	.000	0.060	.000

Note. AIC = Akaike information criterion.

^aModel fit statistics were used to compare a linear model and a quadratic model. The AIC value for the best-fitting model pertaining to each outcome variable is presented here, along with the fixed effects. Compared with a quadratic model, the best-fitting model was determined to be linear for all dependent variables.

deviations from baseline and 12-month data. We accounted for the within-group dependence in means by adjusting the effect via the pre-post correlation (Morris & DeShon, 2002). The Cohen's *d* for the statistically significant models indicated moderate effect sizes. Over 12 months, the average increase in satisfaction with social support was associated with $d = 0.49$, and average decrease in family conflict was associated with $d = 0.35$.

Key Outcomes by Site

To compare states' baseline and rate of change across outcomes, Site and Site \times Time interactions were added to the best-fitting base models for all dependent variables (as described above, WI was the reference category; see Table 3 for model results). Utah participants reported higher baseline burden than Wisconsin (Est. = 10.44, $p < .01$) but changed at a similar rate over time. Despite using "endorsing some care-related burden" as a participation criterion, Georgia started off with similar levels of burden at baseline but decreased in burden at a more rapid rate than Wisconsin (Est. = -0.51, $p < .05$). Utah and Wisconsin demonstrated statistically similar baseline levels and rates of change in depressive symptoms, but Georgia demonstrated higher baseline depressive symptoms (Est. = 2.02, $p < .05$) and decreased depressive symptoms over time (Est. = -0.24, $p < .05$). Levels of depressive symptoms in Wisconsin and Utah were essentially stable over time. Baseline satisfaction with social support in Utah and Georgia was lower in comparison with Wisconsin, although the difference for UT was statistically significant and for

Table 3. Estimates of Fixed Effects for CG and PWD Outcomes Across States.

Parameter	Estimate	SE	df	t	Significance
Dependent variable: CG burden					
Intercept	28.98	1.66	246.61	17.41	.000
Time (months postbaseline)	-0.03	0.12	40.06	-0.29	.771
Wisconsin baseline ^a	0 ^a	0.00			
Utah baseline	10.44	2.24	236.69	4.66	.000
Georgia baseline	2.87	2.31	243.98	1.24	.217
Wisconsin × Time ^a	0 ^a	0.00			
Utah × Time	-0.09	0.17	66.19	-0.55	.586
Georgia × Time	-0.51	0.24	107.80	-2.10	.038
Dependent variable: CG depressive symptoms					
Intercept	7.99	0.71	242.55	11.19	.000
Time (months postbaseline)	0.00	0.05	60.19	0.02	.982
Wisconsin baseline ^a	0 ^a	0.00			
Utah baseline	1.42	0.96	235.26	1.48	.141
Georgia baseline	2.02	0.99	241.21	2.03	.043
Wisconsin × Time ^a	0 ^a	0.00			
Utah × Time	-0.02	0.07	93.05	-0.28	.783
Georgia × Time	-0.24	0.10	145.74	-2.46	.015
Dependent variable: CG satisfaction with social support					
Intercept	5.01	0.13	297.20	38.34	.000
Time (months postbaseline)	0.01	0.01	84.89	1.64	.106
Wisconsin baseline ^a	0 ^a	0.00			
Utah baseline	-0.71	0.17	282.21	-4.03	.000
Georgia baseline	-0.32	0.16	296.05	-1.96	.051
Wisconsin × Time ^a	0 ^a	0.00			
Utah × Time	0.03	0.01	152.05	2.08	.039
Georgia × Time	0.02	0.02	222.60	0.96	.337
Dependent variable: CG family conflict					
Intercept	4.43	1.20	227.24	3.69	.000
Time (months postbaseline)	0.01	0.11	33.48	0.07	.942
Wisconsin baseline ^a	0 ^a	0.00			
Utah baseline	5.40	1.55	219.47	3.48	.001
Georgia baseline	4.02	1.59	223.44	2.53	.012
Wisconsin × Time ^a	0 ^a	0.00			
Utah × Time	-0.27	0.14	45.29	-1.95	.058
Georgia × Time	-0.03	0.18	63.78	-0.19	.851

(continued)

Table 3. (continued)

Dependent variable: CG quality of life					
Intercept	69.05	2.27	241.96	30.39	.000
Time (months postbaseline)	0.37	0.16	60.39	2.27	.027
Wisconsin baseline ^a	0 ^a	0.00			
Utah baseline	-4.12	3.05	231.06	-1.35	.178
Georgia baseline	-1.48	3.22	241.96	-0.46	.646
Wisconsin × Time ^a	0 ^a	0.00			
Utah × Time	-0.29	0.25	105.72	-1.16	.250
Georgia × Time	-0.37	0.34	161.34	-1.09	.280
Dependent variable: PWD Global Deterioration Scale ^b					
Intercept	4.79	0.13	238.46	36.84	.000
Time (months postbaseline)	0.05	0.01	53.77	4.75	.000
Wisconsin baseline ^a	0 ^a	0.00			
Utah baseline	-0.10	0.18	241.05	-0.57	.572
Georgia baseline	0.12	0.17	239.38	0.67	.504
Wisconsin × Time ^a	0 ^a	0.00			
Utah × Time	0.03	0.02	74.57	1.74	.087
Georgia × Time	-0.04	0.04	134.96	-0.94	.351

Note. CG = caregivers; PWD = persons with dementia.

^aWisconsin is the reference group.

^bWe did not hypothesize that the intervention would affect care recipient dementia severity, so Global Deterioration is not a "key outcome" in these analyses. The model is presented here for descriptive purposes, only, tracking changes in the care recipient over the course of the study.

Georgia it was marginally significant (UT Est. = -0.71, $p < .01$; GA Est. = -0.32, $p = .051$). Utah increased in satisfaction with social support at a slightly higher rate than Wisconsin (Est. = 0.03, $p < .05$). Baseline family conflict in Utah and Georgia was higher than that in Wisconsin (UT Est. = 5.40, $p < .01$; GA Est. = 4.02, $p < .05$), and Utah decreased in family conflict at a greater rate (though marginally significant; Est. = -0.27, $p < .10$). Utah and Georgia did not differ statistically from Wisconsin in average baseline levels or rates of change of QoL. Descriptive findings for the model of care recipient Global Deterioration suggested that dementia severity did not differ by state at baseline; UT care recipients deteriorated faster but results were marginally significant (Est. = 0.03, $p < .10$). The linear rates of change for each caregiver outcome (and for dementia severity) are presented in Figure 1 for both the pooled and collective data, as well as across each participating site.

To examine the intraindividual variability in slope (collectively and by site), we extracted the best linear unbiased predictions (BLUP) for each individual and for each outcome. We then computed the means and standard deviations for each across the pooled data and separately for each site. While

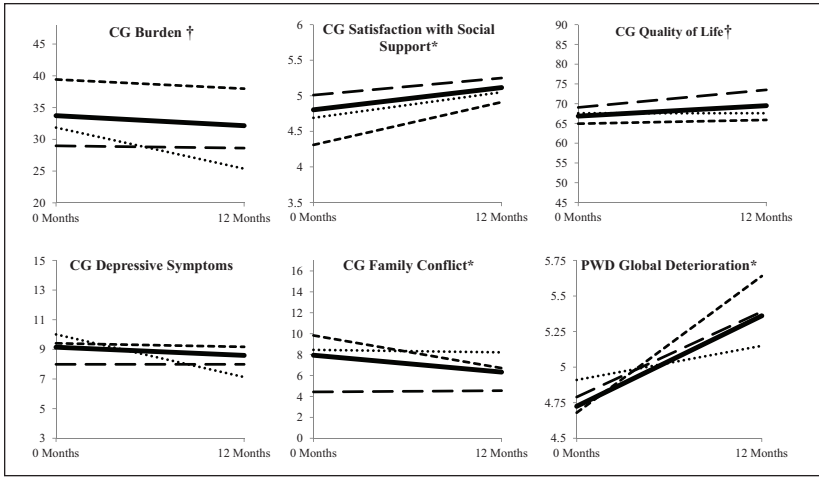


Figure 1. Estimates of linear time effects on CG and PWD outcomes by site. Note. For each outcome, the y-axis range was decreased to facilitate figure legibility by bounds set to 1 standard deviation from the pooled-sample baseline means. Possible ranges were as follows: Burden (0-88), satisfaction with social support (1-6), QoL (0-100), depressive symptoms (0-30), family conflict (0-36), and PWD global deterioration (1-7). CG = caregivers; PWD = persons with dementia.

†Indicates that the average linear rate of change (across sites) was marginally significant ($p < .10$).
 *Indicates that the average linear rate of change across all sites was statistically significant ($p < .05$).

there is not a test of statistical significance for this, we report these BLUP means and standard deviations descriptively in Table 4, so that one can see (particularly from the *SD* column) the range (or lack thereof) in the standard deviations by site. This indicates that some sites may have had more or less random (intraindividual) fluctuation around the fixed effect (mean) slope. In family conflict, for example, there is a larger standard deviation in individual change over time (random slopes) for Utah than there is for Wisconsin. This indicates more intraindividual variability in change over time for Utah and less variability in individuals' change over time for Wisconsin. Besides this example, however, standard deviations for individual rates of change did not appear to be too different by site.

Analyses were run with UT as the reference group, instead of WI, to determine if site differences (or lack thereof) were biased only because of the choice of reference group. Based on this follow-up model, Wisconsin and Georgia had lower burden than UT at baseline (WI Est. = -10.44 , $p < .001$; GA Est. = -7.57 , $p = .001$). There were no differences in depression baseline levels, although GA decreased in depressive symptoms more than UT (Est. = 0.225 ; $p < .05$). Satisfaction with social support was higher for WI and GA at

Table 4. Best Linear Unbiased Predictions (BLUP) for Slope: Means and Standard Deviations Across and Within Sites.

Dependent variable	Site	Individual slope	Individual slope
		<i>M</i>	<i>SD</i>
Burden	All sites	-0.134	0.117
	Utah	-0.095	0.112
	Georgia	-0.171	0.113
	Wisconsin	-0.164	0.111
Satisfaction with social support	All sites	0.027	0.022
	Utah	0.032	0.025
	Georgia	0.025	0.022
	Wisconsin	0.020	0.017
Depressive symptoms	All sites	-0.039	0.076
	Utah	-0.036	0.060
	Georgia	-0.060	0.091
	Wisconsin	-0.0270	0.082
Family conflict	All sites	-0.124	0.183
	Utah	-0.155	0.211
	Georgia	-0.118	0.190
	Wisconsin	-0.071	0.086
Quality of life	All sites	0.210	0.159
	Utah	0.220	0.153
	Georgia	0.186	0.162
	Wisconsin	0.216	0.166
Global deterioration score in person with dementia	All sites	0.061	0.039
	Utah	0.066	0.043
	Georgia	0.058	0.035
	Wisconsin	0.057	0.037

Note. BLUP = best linear unbiased predictions.

baseline (WI Est. = 0.705; $p < .001$; GA Est. = 0.384; $p < .05$), and the slope estimate for WI was lower than UT (Est. = -0.029; $p < .05$). For family conflict, WI was lower than UT at baseline (Est. = -5.398; $p < .01$), and there were no slope estimates that statistically differed from UT, although WI slope was marginally significant (Est. = -0.268; $p = .058$). There were no site differences in baseline levels of rate of change for QoL or the descriptive global deterioration score models when UT was used as the reference. These analyses confirmed that, regardless of whether WI or UT was used as the reference group, the site differences were mostly in baseline levels of caregiver outcomes. Sites only differed in the rate of change for a few models: GA differed

from WI but not UT in rate of change in burden, GA differed from both WI and UT in rate of change in depressive symptoms, and UT differed in rate of change for satisfaction with social support compared with WI.

Analyses with additional covariates besides Site (demographic characteristics of the caregiver) were conducted on caregiver outcome variables with a statistically significant fixed effect for slope. These included the satisfaction with social support and family conflict models. Results are presented in Table 5. For satisfaction with social support, Site remained a statistically significant predictor of both baseline level and change over time, in that Utah started off at baseline with lower satisfaction with social support compared with Wisconsin and increased in satisfaction with social support more so than Wisconsin (both estimates were statistically significant at $p < .05$). Race and ethnicity did not predict differences in baseline levels, but Non-White caregivers increased their satisfaction with social support more so than White caregivers (marginally significant at $p = .051$). Caregivers who had a high school education or less started off at baseline with lower satisfaction with social support compared with caregivers with more than a high school education, although this was marginally significant (at a level of $p = .088$). Education did not predict changes in social support satisfaction over time. Age was significant: Older caregivers started off at baseline with higher satisfaction with social support ($p = .02$) and increased in satisfaction with social support more than younger caregivers ($p = .046$). Demographic characteristics of the caregiver did not explain much of the variance in baseline level and rate of change over time for family conflict. The only parameters that were significant were that Utah caregivers started off with higher family conflict at baseline compared with Wisconsin, and older caregivers started off with lower family conflict at baseline. None of the covariates predicted differences in rate of change over time in family conflict.

Because Georgia had a high attrition rate, especially at the final wave of follow-up, we also ran all analyses again without GA included to determine if the attrition rates were affecting the rate of change over time identified in the models. The interpretation of the models did not change when GA was excluded—the same slope parameters were statistically significant (or non-significant) as described above, and effect sizes for satisfaction with social support and family conflict remained in the moderate range. Because we felt that the GA participants added value to this study of external validity (especially because this site contributed the highest level of ethnic diversity), we felt it was important to keep GA data in the models and present the results on all three demonstration project sites.

Table 5. For Outcome Models With Significant Fixed Effects for Change Over Time: Additional Covariates.

Parameter	Satisfaction with social support				Family conflict					
	Est.	SE	df	t	Significance	Est.	SE	df	t	Significance
Intercept	4.00	0.51	250.47	7.80	.00	24.58	4.90	186.14	5.02	.00
Time (months)	-0.03	0.06	177.31	-0.48	.63	0.58	0.56	68.12	1.03	.31
Utah baseline ^a	-0.69	0.18	248.44	-3.80	.00	3.22	1.56	191.22	2.06	.04
Georgia baseline ^a	-0.14	0.19	258.35	-0.75	.46	2.21	1.88	190.44	1.17	.24
Gender ^b	0.06	0.15	246.71	0.42	.68	0.56	1.38	188.48	0.41	.68
Race/ethnicity ^c	0.00	0.23	249.65	-0.01	.99	-0.05	2.05	186.84	-0.02	.98
Education ^d	-0.26	0.15	251.02	-1.71	.09	-0.27	1.42	189.84	-0.19	.85
Age	0.01	0.01	250.18	2.29	.02	-0.27	0.06	186.70	-4.62	.00
Utah x Time ^a	0.03	0.01	152.62	2.39	.02	-0.20	0.15	41.99	-1.31	.20
Georgia x Time ^a	-0.01	0.02	224.69	-0.32	.75	-0.05	0.23	65.67	-0.21	.83
Gender x Time ^b	0.01	0.01	138.05	0.57	.57	-0.06	0.16	75.27	-0.39	.70
Race/ethnicity x Time ^c	-0.06	0.03	204.35	-1.96	.05	-0.39	0.30	78.20	-1.28	.20
Education x Time ^d	0.01	0.01	92.82	0.52	.60	0.22	0.16	40.81	1.34	.19
Age x Time	0.001	0.00	169.89	2.01	.05	-0.003	0.01	72.07	-0.50	.62

Note. All variables included here describe characteristics of the caregiver, not care recipient.

^aWisconsin was the reference group for Site.

^bFemale was the reference group.

^cNon-White was the reference group.

^dGreater than high school education was the reference group.

Discussion

These analyses pooled data across multiple states (sites) involved in the AoA demonstration projects to replicate NYUCI in diverse community settings. Results support the external validity of past NYUCI findings in non-research-focused environments. For example, in the randomized control design of the original NYUCI, Roth and colleagues (2005) found that caregivers receiving NYUCI reported improved satisfaction with social support. Although we lack a control group, the current analyses also indicate average increases satisfaction with social support over time when compared with baseline levels. Current analyses indicate several other improvements in caregiver socioemotional well-being. Family conflict decreased, and two other marginally significant results were noted: burden decreased ($p = .10$) and QoL increased ($p = .05$). Care recipients demonstrated significant deterioration throughout the same period. Post hoc analyses of all five caregiver outcome models using global deterioration scores as a covariate did not change the interpretation of the models depicted here. Thus, collectively, caregivers enrolled in NYUCI experienced socioemotional stability or improved outcomes (particularly social support and family conflict) in the face of increased dementia severity in their family members.

Effect sizes for increased satisfaction with social support and decreased family conflict in the current study were in the moderate range (Cohen's $d = 0.49$ and 0.35 , respectively). We cannot directly infer the clinical significance of these improvements, as neither of these scales are used for diagnostic purposes, nor do they have established clinical cutoffs. However, these same scales have reported predictive validity for clinically relevant outcomes (institutionalization and adjustment to institutionalization). In reports of prior NYUCI intervention, Mittelman and colleagues (2006) reported that (a) changes in response to behavioral symptoms, (b) changes in depression, and (c) changes in satisfaction with social support collectively accounted for 61.2% of the NYUCI intervention effect on placement in a nursing home. Gaugler, Zarit, and Pearlin (1999) found that family conflict was related to poorer adjustment to the care recipients' nursing home placement for female spousal caregivers.

While many key findings from the current analyses echo the original NYUCI reports, some results from the current analyses are different. The current study identified that perceptions of social/external factors improved (satisfaction with social support and family conflict), while the more self/internal factors (burden, depressive symptoms, QoL) showed stability (depressive symptoms) and improvement, albeit only at the marginally significant level (burden and QoL).

In contrast, for the original NYUCI, Mittelman and colleagues report improvements in internal outcomes, specifically there was a decrease in depressive symptoms in the original NYUCI treatment group (Mittelman et al., 1995; Mittelman, Roth, Coon, & Haley, 2004), with declines in depressive symptoms appearing at approximately 10 months postbaseline. It may be that the demonstration sites were simply more effective at utilizing the family intervention to improve family and social-related outcomes and less effective than the original NYUCI at targeting the individual well-being of the caregiver. It would be interesting in future studies to assess whether effective family counseling sessions are key in improving family and social outcomes and whether the individual counseling sessions are key in improving internal outcomes for the caregiver. There were, in terms of frequency, more family sessions provided than individual sessions in the program. However, because NYUCI research has shown that social support is a mediator for the outcome of depression (Roth et al., 2005) family counseling sessions should contribute to both external *and* internal caregiver outcomes. Also, the original NYUCI had the same number of individual and family sessions offered as the demonstration projects, thus the number and type of sessions may not be driving factors in this discrepancy from the original NYUCI.

We speculate that our inability to detect average decreases in depressive symptoms for caregivers in the demonstration project is potentially due to shorter follow-up than the original study. The original NYUCI detected improvements in depressive symptoms at around 10 months, and participants were followed 18 months and beyond. In the demonstration projects' pooled data, participants were followed up only through 12 months. We note that our sample also had higher rates of attrition than the original NYUCI. With fewer participants contributing data to later waves of measurement, we may have lost some sensitivity to detect changes that emerge over the longer term.

Differences and Similarities Across Results by Site

Site comparisons revealed few systematic differences in *rates of change* over time, although there were some differences by site in baseline levels. In Georgia (where site comparisons indicated higher baseline depressive symptoms and where rates of attrition were high), caregivers decreased in burden and depressive symptoms more than participants from other states. Utah caregivers increased in satisfaction with social support at a higher rate and decreased in family conflict more rapidly (marginally significant at $p = .06$). Utah participants also reported significantly higher baseline levels of family conflict and caregiver burden, and significantly lower QoL and satisfaction with social support. Preintervention baseline differences may be due

to selection procedures: Utah caregivers sought intervention by initiating contact with the Alzheimer's Association Utah Chapter (or partnering Agency on Aging offices), and Georgia required that caregivers endorse at least some level of caregiver burden for participation; thus, caregivers may have been more distressed at study onset at these sites. ANOVA and chi-square comparisons of demographic characteristics revealed differences in the sites for race/ethnicity, education, age, and so on. These characteristics seemed to predict some variance in social support satisfaction change over time, but they did not predict differences in rate of change for family conflict. In sum, the sample differences across sites in caregiver characteristics did not predict many differences in longitudinal outcomes. The *lack of* site differences in rates of change over time for most models, despite the differences in samples, suggests that the stability or improvements for caregivers were fairly homogeneous across sites.

Limitations and "Lessons Learned"

Limitations of our study are noted. The current analyses lack a control group, and we cannot conclude that the NYUCI intervention *caused* the observable changes. Additional limitations include the fairly low rates of ethnic/racial diversity in the pooled data, particularly the lack of, or low levels of participants who identify as Hispanic/Latino/a, Asian, Native American, and Native Hawaiian or Pacific Islander, which may affect generalizability of findings at the national level. Lower ethnic/racial diversity of the sample (particularly for UT and WI) can be attributed, to some extent, to differences in diversity at the state population level. Census data (U.S. Census Bureau, 2017) report that in 2015, the total U.S. population was 77.1% White; % White in GA = 61.6%, UT = 91.2%, and WI = 87.6%. In other words, Georgia has a more ethnically/racially diverse population than the national average, and UT and WI are less ethnically/racially diverse, providing possible explanations for the lower rates of total ethnic/racial diversity in our pooled sample. With the exception of Georgia, where both African American caregivers and counselors were recruited (in GA, 60% of counselors were African American), the other demonstration states reported the need to more actively recruit non-White caregivers and counselors.

In addition, the range of time devoted to counseling sessions was 30 to 120 min. We emphasize that the length of time per session is guided by the needs of the caregiver and his or her family, and not by a set curriculum or time. The intervention itself is not "time spent with counselor." Someone with a 120-min session should not be perceived as receiving more "dosage" of the intervention than someone with a 30-min session. On a practical level,

this flexibility and adaptability in delivering caregiver support is a characteristic of successful interventions (as described by Zarit & Femia, 2008); however, on a program evaluation level, we acknowledge that it introduces or may be a proxy for possible interindividual variability.

Finally, while the focus on service delivery was primary for the demonstration projects, this elicited practical complexity in program evaluation in addition to what is described above. The variability in timing of follow-up occasions for Wisconsin (with first follow-up occurring closer to 10 months postbaseline as compared with 4 months for the other states), while adjusted statistically in our model of “elapsed time” (see Method section), may have also attenuated some of the longitudinal results for this state. Similarly, while all states reported fairly significant levels of attrition, Georgia had a much higher attrition rate, resulting in possible attrition bias where only the most committed caregivers remained for follow-up. Caregivers may be less inclined to participate in assessments once the counseling sessions are complete, therefore future NYUCI replications should utilize determined and directed approaches for retention, explaining to caregivers that assessment occasions are not just about evaluation but also offer an additional informal opportunity for follow-up counseling to address new or unresolved issues. Additional “learning experiences” of all six sites (including FL, CA, and MN) are described in an Implementation Guide that further discusses their individual approaches in delivering the NYUCI across diverse settings (Easom, Alston, & Dean, 2013).

Summary and Impact

Collective results across three demonstration sites with samples varying in age, kin relationship to the care receiver, education, race/ethnicity, and so on suggest that NYUCI has external validity in nonresearch, community settings. Caregivers in the current pooled sample had improved satisfaction with social support and decreased family conflict compared with preintervention levels. Despite some differences across states in sample, assessment timing, measurement, and baseline levels of some outcome variables, there were few site differences in key outcomes over time.

In the current (and most likely future) fiscal state, where social programs are often underfunded or operating on small, restricted budgets, it is likely that major funding sources (e.g., state and federal agencies) will *only* support spending dollars on empirically validated interventions. Thus, it is not only important for these agencies and their funders to know the impact of a program in a controlled research setting with high levels of internal validity, but it is also important to know whether the programs translate, or generalize, to

agencies outside of the research setting. Existing service providers still need to maintain integrity to the interventions and protocols—we do not mean to suggest that nonresearch service providers can allow the structure of a program to fall apart, simply because it is “the real world.” Each site in this study, for example, needed to conform to the protocol of the NYUCI manual and received extensive training before initiating the intervention. However, each site and the agencies or care partners therein also came to the study with their own existing network for recruiting caregivers in need for support. Sites varied in the ethnic, racial, and cultural characteristics of the caregivers and the counselors. In the “real world,” nuances and idiosyncrasies exist in service provider structure, climate, personnel, and clients (Burgio, et al., 2009). Indeed, *despite the preexisting variability* in the sites included in the current study, NYUCI caregivers demonstrated improved outcomes (increased satisfaction with social support and decreased family conflict).

In conclusion, we emphasize the value of evidence-based caregiver interventions (Sörensen et al., 2002; Zarit & Femia, 2008) and the importance in evaluating effectiveness of intervention translations at the community level across spouses and adult children caregivers, within more diverse populations, and across a variety of geographic areas. Being able to evaluate these demonstration projects across at least three sites provided needed information on the external validity of the NYUCI. However, issues related to pooling data across all six *potential* sites highlight the need for funding sources to require standard assessment across future multisite demonstration projects, with plans for pooling data and comparing outcomes across all sites a priori, so that collective trends and site comparisons can be facilitated in future intervention translations.

Acknowledgments

We would also like to acknowledge the following organizations in their development and delivery of the program: Alzheimer’s Association: Georgia, Utah, and Greater Wisconsin Chapters, as well as the Georgia Department of Aging Services, Southern Crescent Area Agencies on Aging, Northeast Georgia Area Agencies on Aging, Veterans Administration, University of Utah, Wisconsin State Unit on Aging, Aging and Disability Resources Centers of Barron, Chippewa, Dunn, Eau Claire, Risk, and Washburn Counties, Wisconsin; Greater Wisconsin Agency on Aging Resources, and the Wisconsin Alzheimer’s Institute, University of Wisconsin-Madison.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This project was supported in part by grant numbers 90AE0339, 90AE0343, and 90AE0332 from the U.S. Administration on Aging/Administration for Community Living, U.S. Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

References

- Basu, R., Hochhalter, A. K., & Stevens, A. B. (2015). The impact of the REACH II intervention on caregivers' perceived health. *Journal of Applied Gerontology, 34*(5), 590-608.
- Burgio, L. D., Collins, I. B., Schmid, B., Wharton, T., McCallum, D., & DeCoster, J. (2009). Translating the REACH caregiver intervention for use by area agency on aging personnel: The REACH OUT program. *The Gerontologist, 49*, 103-116.
- Carbonneau, H., Caron, C., & Desrosiers, J. (2010). Development of a conceptual framework of positive aspects of caregiving in dementia. *Dementia, 9*, 327-353. doi:10.1177/1471301210375316
- De Boer, A. G. E. M., Van Lanschot, J. J. B., Stalmeier, P. F. M., Van Sandick, J. W., Hulscher, J. B. F., De Haes, J. C. J. M., & Sprangers, M. A. G. (2004). Is a single-item visual analogue scale as valid, reliable and responsive as multi-item scales in measuring quality of life? *Quality of Life Research, 13*, 311-320.
- Drentea, P., Clay, O. J., Roth, D. L., & Mittelman, M. S. (2006). Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease. *Social Science & Medicine, 63*, 957-967. doi:10.1016/j.socscimed.2006.02.020
- Easom, L., Alston, G., & Dean, A. (2013). *NYUCI implementation guide*. Americus, GA: Rosalynn Carter Institute for Caregiving. Retrieved from <http://www.rosalynncarter.org/UserFiles/NYUCI%281%29.pdf>
- Elliott, A. F., Burgio, L. D., & Decoster, J. (2010). Enhancing caregiver health: Findings from the resources for enhancing Alzheimer's caregiver health II intervention. *Journal of the American Geriatrics Society, 58*, 30-37. doi:10.1111/j.1532-5415.2009.02631.x
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*, 189-198. doi:10.1016/0022-3956(75)90026-6
- Gaugler, J. E., Reese, M., & Mittelman, M. S. (2013). Effects of the NYU Caregiver Intervention-Adult Child on residential care placement. *The Gerontologist, 53*, 985-997. doi:10.1093/geront/gns193
- Gaugler, J. E., Reese, M., & Mittelman, M. S. (2015). Effects of the Minnesota adaptation of the NYU Caregiver Intervention on depressive symptoms and quality of life for adult child caregivers of persons with dementia. *The American Journal of Geriatric Psychiatry, 23*, 1179-1192.

- Gaugler, J. E., Reese, M., & Mittelman, M. S. (2016). Effects of the Minnesota adaptation of the NYU Caregiver Intervention on primary subjective stress of adult child caregivers of persons with dementia. *The Gerontologist, 56*, 461-474. doi:10.1093/geront/gnu125
- Gaugler, J. E., Roth, D. L., Haley, W. E., & Mittelman, M. S. (2008). Can counseling and support reduce burden and depressive symptoms in caregivers of people with Alzheimer's disease during the transition to institutionalization? Results from the New York University caregiver intervention study. *Journal of the American Geriatrics Society, 56*, 421-428. doi:10.1111/j.1532-5415.2007.01593.x
- Gaugler, J. E., Zarit, S. H., & Pearlin, L. I. (1999). Caregiving and institutionalization: Perceptions of family conflict and socioemotional support. *International Journal of Aging and Human Development, 49*(1), 1-25. doi: 10.2190/91A8-XCE1-3NGX-X2M7
- Hepburn, K. W., Lewis, M., Sherman, C. W., & Tornatore, J. (2003). The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiver training program. *The Gerontologist, 43*, 908-915. doi:10.1093/geront/43.6.908
- Kramer, B. J. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist, 37*, 218-232. doi:10.1093/geront/37.2.218
- Long, K. H., Moriarty, J. P., Mittelman, M. S., & Folds, S. S. (2014). Estimating the potential cost savings from the New York University Caregiver Intervention in Minnesota. *Health Affairs, 33*, 596-604. doi:10.1377/hlthaff.2013.1257
- Lyness, J. M., Noel, T., Cox, C., King, D. A., Conwell, Y., & Caine, E. D. (1997). Screening for depression in elderly primary care patients: A comparison of the Center for Epidemiologic Studies—Depression Scale and the Geriatric Depression Scale. *Archives of Internal Medicine, 157*, 449-454. doi:10.1001/archinte.1997.00440250107012
- Mittelman, M., & Bartels, S. J. (2014). THE CARE SPAN: Translating research into practice: Case study of a community-based dementia caregiver intervention. *Health Affairs, 33*, 4587-4595. doi:10.1377/hlthaff.2013.1334
- Mittelman, M., Ferris, S., Shulman, E., Steinberg, G., Ambinder, A., Mackell, J., & Cohen, J. (1995). A comprehensive support program: Effect on depression in spouse-caregivers of AD patients. *The Gerontologist, 35*, 792-802. doi:10.1093/geront/35.6.792
- Mittelman, M. S., Brodaty, H., Wallen, A. S., & Burns, A. (2008). A three-country randomized controlled trial of a psychosocial intervention for caregivers combined with pharmacological treatment for patients with Alzheimer disease: Effects on caregiver depression. *The American Journal of Geriatric Psychiatry, 16*, 893-904. doi:10.1097/JGP.0b013e3181898095
- Mittelman, M. S., & Epstein, C. (2009). *A guide to implementing the NYU Caregiver Intervention*. Retrieved from http://www.mnlivewellathome.org/Memory_Concerns/Memory%20Care%20Support.aspx
- Mittelman, M. S., Epstein, C., & Pierzchala, A. (2003). *Counseling the Alzheimer's caregiver: A resource for health care professionals*. Chicago, IL: American Medical Association Press.

- Mittelman, M. S., Ferris, S. H., Shulman, E., Steinberg, G., & Levin, B. (1996). A family intervention to delay nursing home placement of patients with Alzheimer disease. *Journal of the American Medical Association, 276*, 1725-1731. doi:10.1001/jama.1996.03540210033030
- Mittelman, M. S., Haley, W. E., Clay, O., & Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology, 67*, 1592-1599. doi:10.1212/01.wnl.0000242727.81172.91
- Mittelman, M. S., Roth, D. L., Clay, O. J., & Haley, W. E. (2007). Preserving health of Alzheimer's caregivers: Impact of a spouse caregiver intervention. *American Journal of Geriatric Psychiatry, 15*, 780-789. doi:10.1097/JGP.0b013e31805d858a
- Mittelman, M. S., Roth, D. L., Coon, D. W., & Haley, W. E. (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease. *American Journal of Psychiatry, 161*, 850-856. doi:10.1176/appi.ajp.161.5.850
- Mittelman, M. S., Roth, D. L., Haley, W. E., & Zarit, S. H. (2004). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. *The Journals of Gerontology, Series B: Psychological Sciences & Social Sciences, 59*, P27-P34. doi:10.1093/geronb/59.1.P27
- Morris, S. B., & DeShon, R. P. (2002). Combining effect size estimates in meta-analysis with repeated measures and independent-group designs. *Psychological Methods, 7*, 105-125.
- Nichols, L. O., Chang, C., Lummus, A., Burns, R., Martindale-Adams, J., . . . Czaja, S. (2008). The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. *Journal of the American Geriatrics Society, 56*, 413-420.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*, 583-594. doi:10.1093/geront/30.5.583
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*, 250-267. doi:10.1037/0882-7974.18.2.250
- Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *The American Journal of Psychiatry, 139*, 1136-1139.
- Reisberg, B., Jamil, I. A., Khan, S., Monteiro, I., Torossian, C., Ferris, S., . . . Wegiel, J. (2011). Staging dementia. In M. Y. Abou-Saleh, C. L. E. Katona, & A. Kumar (Eds.), *Principles and practice of geriatric psychiatry* (pp. 162-169). Hoboken, NJ: John Wiley.
- Roth, D. R., Mittelman, M. S., Clay, O. J., Madan, A., & Haley, W. E. (2005). Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychology and Aging, 20*, 634-644. doi:10.1037/0882-7974.20.4.634

- Semple, S. J. (1992). Conflict in Alzheimer's caregiving families: Its dimensions and consequences. *The Gerontologist*, *32*, 648-655. doi:10.1093/geront/32.5.648
- Sörensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, *42*, 356-372. doi:10.1093/geront/42.3.356
- Stokes, J. P. (1983). Predicting satisfaction with social support from social network structure. *American Journal of Community Psychology*, *11*, 141-152. doi:10.1007/BF00894363
- U.S. Census Bureau. (2017). *Quick facts: V2015*. Retrieved from <https://www.census.gov/quickfacts/table/PST045216/00>
- Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M. B., . . . Leirer, V. O. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, *17*, 37-49. doi:10.1016/0022-3956(82)90033-4
- Zarit, S., & Femia, E. (2008). Behavioral and psychosocial interventions for family caregivers. *The American Journal of Nursing*, *108*(9), 47-53.
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, *20*, 649-655. doi:10.1093/geront/20.6.649

Author Biographies

Elizabeth B. Fauth is an associate professor of family, consumer, and human development at Utah State University. She studies dementia caregiving, quality of life for people with dementia, and disablement processes in late life. She is the coordinator of the gerontology certificate program at Utah State, and she teaches graduate and undergraduate classes in adult development and aging.

Mark A. Jackson received his PhD from Utah State University in 2015 and has just recently accepted a position conducting data analysis.

Donna K. Walberg is the project director of the Alzheimer's Disease Support Services Program for the Minnesota Board on Aging.

Nancy E. Lee is the Family Memory Care State Coordinator for the Aging and Adult Service Division/Minnesota Board on Aging.

Leisa R. Easom is the executive director of the Rosalynn Carter Institute for Caregiving (RCI) and Pope Eminent Scholar at Georgia Southwestern State University (GSW). She was a professor of nursing and served as the Chair in the GSW School of Nursing from 2007 to 2010.

Gayle Alston serves as the director of the Rosalynn Carter Institute for Caregiving Training Center for Excellence.

Angel Ramos is the data manager for the Rosalynn Carter Institute for Caregiving.

Kristen Felten is a dementia specialist for the Office on Aging at the Wisconsin Department of Health Services.

Asenath LaRue has recently retired from the University of Wisconsin–Madison where she served as a senior scientist. She used her training in neuropsychology to conduct research on preclinical Alzheimer’s disease (AD) and interventions for persons with AD and their caregivers. She served as a research partner for Wisconsin’s Memory Care Connections project.

Mary Mittelman is a research professor at the Department of Psychiatry and at the Department of Rehabilitation Medicine at NYU Langone Medical Center in the NYU School of Medicine. She serves as director of the Psychosocial Research and Support Program at the Center for Cognitive Neurology, which focuses on nondrug therapies for people with dementia and their families. She has many research publications on her New York University Caregiver Intervention.