

Original Research Article

The Effects of a Comprehensive Psychosocial Intervention on Secondary Stressors and Social Support for Adult Child Caregivers of Persons With Dementia

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Abstract

Background and Objectives: Many evaluations of nonpharmacologic interventions for family members of persons with Alzheimer's disease or related dementias (ADRDs) exist, but few consider effects on outcomes that are pertinent to caregivers' roles and relationships. The current study evaluated the efficacy of the New York University Caregiver Intervention-Adult Child (NYUCI-AC) on perceptions of family conflict, role conflict (effects of family caregiving and time, family, and social life), and perceived social support for adult child caregivers of relatives with ADRD over a 3-year period.

Research Design and Methods: A single-blinded randomized controlled trial design was used. One-hundred and seven adult child caregivers were enrolled in the NYUCI-AC and randomly assigned to a treatment or contact control group. Assessments were scheduled to be completed every 4 months during the first year of participation and every 6 months thereafter for up to 3 years. Individual growth curve models were utilized to ascertain the effects of the NYUCI-AC on change in family conflict, role conflict, and perceptions of social support.

Results: Among the entire sample, role conflict significantly ($p < .05$) declined and satisfaction with instrumental assistance increased over the course of the study, whereas family conflict slightly increased over the initial study period and then declined slightly. The findings indicated that the NYUCI-AC did not exert statistically significant effects on changes in family conflict, role conflict, or perceptions of social support over the 3-year study period.

Discussion and Implications: Although the clinical content of some dementia caregiver interventions is tailored to the specific needs of each caregiver and family, the outcomes selected to judge the efficacy of these interventions might not follow similar principles. Incorporating clinical content and evaluation outcomes that are family-centered will help to advance the state of the art of dementia caregiving interventions.

Translational Significance: This 3-year evaluation of the NYU Caregiver Intervention-Adult Child, or NYUCI-AC, a comprehensive psychosocial support program for adult child caregivers of persons with dementia, found no effects on changes in family conflict, role conflict, or social support among caregivers. These findings suggest that dementia caregiver programs should take into account the relationship of the caregiver to the person with dementia, as adult child caregivers generally have different needs than spouse/partner caregivers. In addition, reliable and valid family-centric outcome measures are essential to accurate assessment of psychosocial interventions for caregivers.

Keywords: Alzheimer's disease, Family caregiving, Family conflict, Intervention, Multicomponent, Role conflict

The costs and implications of family care for persons with Alzheimer's disease or related dementias (ADRDs) are well documented (Alzheimer's Association, 2017; Brodaty & Donkin, 2009; Liu & Gallagher-Thompson, 2009). A limitation in current dementia caregiving research is the lack of focus on outcomes of importance to families. Specifically, outcomes that are directly pertinent to family caregivers' lives (e.g., relationships with other family members) should receive greater attention alongside the more classic outcomes of stress and depression when considering the effects of caregiver interventions (Gitlin & Hodgson, 2015). Similarly, a core mechanism in prominent conceptual models of ADRD caregiving stress is that of proliferation, where the emotional challenge and distress related to providing day-to-day care of a relative with dementia is thought to spread to life domains beyond the immediate care situation, such as one's family relationships or other similar responsibilities. These are considered "secondary stressors" (Pearlin, Mullan, Semple, & Skaff, 1990). Although a handful of descriptive efforts have sought to examine predictors of secondary stressors such as family conflict, little is known about the effects of interventions in modifying or reducing them. To address these gaps, the current study evaluated the efficacy of the New York University Caregiver Intervention-Adult Child (NYUCI-AC) on perceptions of family conflict, role conflict (effects of family caregiving on time, family, and social life), and social support for adult child caregivers of relatives with ADRD over a 3-year period.

Background

Although much of the research on family caregiving focuses on "primary" caregivers (defined as those family members who provide the most help and/or deem themselves most responsible for the care of a relative with ADRD), dementia care provision often takes place in the context of multiple family relationships (Gwyther, 1995). Earlier research suggested that the presence of family conflict among caregivers is linked with other outcomes, such as depression (Gaugler, Zarit, & Pearlin, 1999; Li & Sprague, 2002; Lieberman & Fisher, 1999; Semple, 1992). To date, few if any controlled evaluations have examined the influence of dementia caregiver interventions on family conflict. One study that did measure family conflict found no intervention effect, which the authors suggested might have been due to the fact that the intervention was targeted at one caregiver and the level of conflict was reported as very low prior to the intervention (Ducharme et al., 2011). In addition to a relative lack of attention to family conflict, variability in intervention efficacy across different kin relationships (e.g., spouse, adult child) is often not considered nor well described in ADRD caregiver interventions (among other mechanisms; see Andr n & Elmst hl, 2008; Belle et al., 2006; Gitlin et al., 2001,

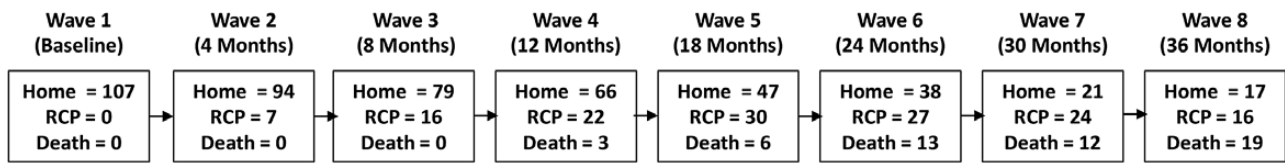
2003; Signe & Elmst hl, 2008; S rensen, Pinguart, Habil, & Duberstein, 2002; Zarit & Boutselis, 1987; Zarit, 2018).

Systematic reviews have suggested that the quality of evidence of multicomponent interventions that emphasize building social support with family members as low. While few intervention studies considered social support as an outcome (Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016), the original NYUCI was a notable exception and demonstrated improved social support for spousal dementia caregivers (Drentea, Clay, Roth, & Mittelman, 2006). A Cochrane review included two trials of telephone counseling intervention approaches for dementia caregivers that did yield evidence of efficacy in improving caregivers' social support (Lins et al., 2014); a review of computer-mediated interventions reported three studies that considered social support as an outcome, only one of which demonstrated improvement in that domain (McKechnie, Barker, & Stott, 2014). A 5-month study of a videophone intervention (Czaja, Loewenstein, Schulz, Nair, & Perdomo, 2013) and a smaller 6-month evaluation of a mindfulness-based stress reduction program (Whitebird et al., 2013) both had positive effects on dementia caregivers' social support. Although researchers have not considered role conflict as an outcome in dementia caregiver interventions, conceptual models imply the importance of this domain for adult child caregivers of relatives with ADRD.

Conceptual Model

The stress process model is based on the mechanism of *proliferation*, or the spread of stress from primary objective domains (e.g., care demands) to primary subjective stressors (perceptions of overload or role entrapment due to care responsibilities) (Pearlin et al., 1990). As primary, care-specific stress accumulates and intensifies, the stress process model postulates that this stress will spread and negatively influence other life domains, such as family relationships or balance between competing role responsibilities. Various resources, both external (social support) and internal (coping) may operate to slow the proliferation of stress from primary to secondary stressors and eventually to global domains of mental or physical health of the family caregiver as well as the person with dementia.

Relying on this conceptual framework, the present study sought to determine whether a comprehensive psychosocial intervention, the NYUCI-AC, was efficacious in reducing adult child caregivers' family conflict and role conflict and improving their perceptions of social support over a 3-year period. Because of their multiple life responsibilities at the time of providing care to an aging parent with ADRD, adult children may be at particular risk for increased tension with family members (other siblings, spouses, their own children) and role conflict related



Home = Care recipient resides in the community

RCP = Care recipient is in residential care

NOTE: Waves 2 to 7 exclude those caregiver who did not complete interviews but did provide resident dispositional status only

Figure 1. Dispositional status of participants in the New York University Caregiver Intervention-Adult Child study (36 months, N = 107).

to dementia care. As prior intervention evaluations have often not considered secondary stressors as outcomes among adult child caregivers of parents with dementia, the current study aimed to fill a gap in the literature. We hypothesized that caregivers who received the NYUCI-AC when compared to usual care controls (i.e., those who did not receive the multiple counseling components of the NYUCI-AC) would indicate significant decreases in family conflict and role conflict and increases in perceived social support over a 3-year period.

Methods

Procedure and Sample

A prospective, single-blind, randomized controlled study design was utilized (IRB# 0508S72389). One-hundred and seven adult child caregivers of individuals with ADRD were enrolled from the Minneapolis/St. Paul region or beyond. Eligibility criteria were as follows: the care recipient had to have a physician diagnosis of ADRD and lived at home in the community at baseline. Adult child caregivers self-identified as the person most responsible for caring for the person with ADRD (i.e., the “primary caregiver”), visited the person with ADRD at least once a week, and had not had professional counseling for caregiving issues in the year prior to participating in the NYUCI-AC evaluation. Enrollment occurred from January 2006 to August 2009. Recruitment efforts focused on community outreach, including advertisements and flyers as well as educational presentations. After the completion of screening, consent, and the baseline questionnaire/survey, adult child caregivers were randomly assigned to the NYUCI-AC treatment group (n = 54) or a contact control condition (n = 53) using a random group assignment list.

A blinded rater administered baseline and follow-up questionnaires/surveys. Data collection was designed to occur initially, every 4 months during the first year of participation, and every 6 months afterwards for up to 3 years. Adult child caregivers were given the option to complete the questionnaires/surveys in-person, over the telephone, or via e-mail. Participation in the study ended in instances where the caregiver died, refused to continue with participation, or 2 years following the death of a care recipient. Caregivers were followed for a maximum of 3.79 years due to completion of mail surveys later than scheduled. For

additional design details, see [Gaugler, Reese, & Mittelman, 2013](#); [Gaugler, Reese, & Mittelman, 2015](#); [Gaugler, Reese, & Mittelman, 2016](#); [Gaugler, Reese, & Mittelman, 2017](#)). Figure 1 shows the number of adult child caregivers who completed follow-up interviews at each interval of the NYUCI-AC.

Intervention

As with the original NYUCI protocol, the NYUCI-AC included three clinical components: individual and family counseling, support group participation, and ad hoc counseling. During the first 4 months of participation in the intervention, adult child caregivers were asked to complete six individual and family sessions. In the original NYUCI, these six sessions includes one individual session followed by four family sessions (which include the primary caregiver and one or more family members) and then another individual session. However, NYUCI-AC participants were reluctant to include other family members in the counseling sessions ([Gaugler et al., 2017](#)). For this reason, the NYUCI-AC counseling protocol was adapted to include two individual, followed by three family, and a final individual session ([Gaugler et al., 2017](#)). The clinical content of the NYUCI-AC sessions were tailored to meet the needs of adult child caregivers as indicated in the intake questionnaires/surveys or from prior counseling sessions. A key emphasis of the NYUCI-AC was the provision of information and psychosocial support to help caregivers manage care recipients’ dementia symptoms as well as enhance social support from family members or other resources.

Following the completion of the 1-/4-month questionnaire/assessment, adult child caregivers were referred to local support groups (e.g., support groups provided by area agencies on aging or the local Alzheimer’s Association chapter). Based on the requests of adult child caregiver participants and the lack of availability of local adult child caregiver support groups at the time, NYUCI-AC counselors designed and moderated an adult child-specific support group as well. Continuing support and guidance via ad hoc counseling was offered in-person, over the telephone, or by e-mail. Ad hoc sessions were also used to address crises as they emerged for adult child caregivers. The NYUCI-AC counselors were both Master’s-level psychotherapists.

The counselors provided “check-in” calls to adult child caregivers in the contact control group every 4 months. To further establish rapport, a biannual project newsletter was offered to all caregivers in the study. If adult child caregivers in the contact control group required information, referral, or brief consultation due to a crisis, study counselors provided this support.

Measures

Context of care

Table 1 provides information on sociodemographic and background characteristics of adult child caregivers and persons with ADRD. Whether residential care placement or care recipient death occurred was collected during each follow-up assessment from adult child caregivers.

Primary objective stressors

The overall severity of dementia was measured with the *Global Deterioration Scale* (GDS) (Reisberg, Ferris, de Leon, & Crook, 1982). To measure services provided by the caregiver, we summed the number of care tasks the adult child caregiver provided during a typical week to the person with ADRD (these tasks included grooming, dressing, and toileting; bathing; shopping; cooking and food preparation; helping the care recipient eat; assisting with mobility; housekeeping; transportation; financial or legal assistance; social and recreational activities; outdoor cleaning; administering medications; management of psychotic symptoms; management of additional behavioral problems; training and supervision of paid help; consulting with health care professionals; supervision for safety and security) (Rice et al., 1993). Self-rated health of caregivers was measured with a single subjective item (1 = excellent; 2 = good; 3 = fair; 4 = poor) (Duke University Center for the Study of Aging and Human Development, 1978).

Resources

The size and composition of adult child caregivers’ social networks (e.g., number of close friends or relatives) was measured with *The Stokes Social Network List* (Stokes, 1983). Caregivers also indicated the number of community-based and psychosocial services they were currently using (*service utilization*; e.g., adult day services, in-home health, personal care, support groups, and other psychosocial services).

Primary subjective stress

The frequency of and adult child caregivers’ reactions to relatives’ behavior problems was assessed with the 24-item *Revised Memory and Behavior Problems Checklist* (RMBPC, $\alpha = .80$) (Teri et al., 1992). Item responses ranged from 0 = “never occurred” to 4 = “occurred daily or more often.” Example items included: “asking the same question over and over,” “losing or misplacing things,” “waking

you or other family members up at night,” “engaging in behavior that is potentially dangerous to self or others,” “appearing sad or depressed,” and “talking about feeling lonely.” In addition, caregivers’ reactions to the occurrence of each of the 24 behavior problems were summed ($\alpha = .87$; item responses ranged from 0 = “not at all” to 4 = “extremely”). Feelings of being trapped in care responsibilities was measured on a three item scale (*role captivity*, $\alpha = .81$) and included the following: “Wish you were free to lead a life of your own?,” “Feel trapped by your parent’s illness?,” and “Wish you could just run away?” Perceptions of emotional and physical fatigue were assessed on a four-item scale (*role overload*; $\alpha = .79$) (Pearlin et al., 1990). Items included: “You are exhausted when you go to bed at night;” “You have more things to do than you can handle;” “You don’t have time just for yourself;” and “You work hard as a caregiver but never seem to make any progress.” Item responses ranged from 4 = “very much/completely” to 1 = “not at all” on both measures.

Secondary stressors

A measure of *family conflict* was adapted from the Caregiver Reaction Inventory developed by Given and associates ($\alpha = .87$) (Given et al., 1992). Items included: “It is difficult to get help;” “I feel abandoned;” “My family left me alone;” “Our family works together;” and “Other family members dump caring on me.” Item responses are scored on a 5-item scale with 5 = “strongly agree” and 1 = “strongly disagree.” A measure of *role conflict* was also included to ascertain the effects of caregiving on other aspects of adult child caregivers’ lives. The five item measure assessed areas such as the effects of caregiving on time, family, and social life ($\alpha = .81$) (Mui, 1995). Item responses ranged from 0 = “It’s not a problem” to 2 = “It’s a serious problem.”

Social support

Three individual items were administered at each time point to measure adult child caregivers’ perceptions of social support: how satisfied the adult child caregiver was with her/his overall social network, the emotional support provided by her/his social network, and the assistance offered by her/his social network. Item responses for each item ranged from 1 = “very satisfied” to 6 = “very dissatisfied.”

Analysis

Significant baseline differences between the NYUCI-AC treatment and control groups were determined with a series of bivariate comparisons (chi-squares, independent sample *T* tests (see Table 1). If a baseline covariate significantly varied ($p < .05$) between groups, it was adjusted for in subsequent longitudinal models that examined the effects of the NYUCI-AC on family conflict, role conflict, and social support. Whether residential care placement and care recipient death occurred were included as covariates to provide additional control for the effects of these transitions.

Table 1. Baseline Descriptive Information and Bivariate Comparisons, NYU Caregiver Intervention-Adult Child Treatment and Control Groups (*N* = 107)

Variable	Total (<i>N</i> = 107)	Control (<i>n</i> = 53)	Treatment (<i>n</i> = 54)
Context of Care			
Caregiver age (in years) ^a (<i>df</i> = 104)	<i>M</i> = 50.46 <i>SD</i> = 8.24	<i>M</i> = 49.68 <i>SD</i> = 9.36	<i>M</i> = 51.23 <i>SD</i> = 6.95
Caregiver is female ^{*,b}	94.3%	100%	88.7%
Caregiver is Caucasian ^b	94.4%	94.3%	94.4%
Caregiver household annual income ^{c,d}	<i>M</i> = 6.95 <i>SD</i> = 1.33	<i>M</i> = 6.90 <i>SD</i> = 1.30	<i>M</i> = 7.00 <i>SD</i> = 1.36
Caregiver completed high school or more	100%	100%	100%
Caregiver is employed	100%	100%	100%
Caregiver is married ^e (<i>df</i> = 1)	71.0%	69.8%	72.2%
Caregiver number of children ^e	<i>M</i> = 1.68 <i>SD</i> = 1.57	<i>M</i> = 1.90 <i>SD</i> = 1.77	<i>M</i> = 1.46 <i>SD</i> = 1.33
Care recipient number of children ^e	<i>M</i> = 3.57 <i>SD</i> = 1.93	<i>M</i> = 3.54 <i>SD</i> = 1.92	<i>M</i> = 3.59 <i>SD</i> = 1.97
Care recipient lives alone ^e (<i>df</i> = 1)	17.0%	13.5%	20.4%
Care recipient is on Medicaid ^e (<i>df</i> = 1)	25.5%	26.9%	24.1%
Dementia Severity			
Global Deterioration Scale score ^a (<i>df</i> = 98)	<i>M</i> = 4.89 <i>SD</i> = 0.90	<i>M</i> = 4.97 <i>SD</i> = 0.87	<i>M</i> = 4.80 <i>SD</i> = 0.92
Revised Memory Problem Checklist-Frequency ^a (<i>df</i> = 105)	<i>M</i> = 38.64 <i>SD</i> = 12.00	<i>M</i> = 38.38 <i>SD</i> = 12.01	<i>M</i> = 38.89 <i>SD</i> = 12.09
Caregiver Stress			
Role overload ^a (<i>df</i> = 105)	<i>M</i> = 7.39 <i>SD</i> = 2.06	<i>M</i> = 7.52 <i>SD</i> = 2.04	<i>M</i> = 7.26 <i>SD</i> = 2.09
Role captivity ^a (<i>df</i> = 105)	<i>M</i> = 7.60 <i>SD</i> = 2.39	<i>M</i> = 7.35 <i>SD</i> = 2.50	<i>M</i> = 7.85 <i>SD</i> = 2.28
Revised Memory Problem Checklist-Reaction ^a (<i>df</i> = 105)	<i>M</i> = 26.17 <i>SD</i> = 14.17	<i>M</i> = 25.07 <i>SD</i> = 14.00	<i>M</i> = 27.25 <i>SD</i> = 14.38
Support Resources			
Stokes Social Network: Number of close friends ^{*,c}	<i>M</i> = 3.96 <i>SD</i> = 3.17	<i>M</i> = 4.65 <i>SD</i> = 3.59	<i>M</i> = 3.28 <i>SD</i> = 2.54
Stokes Social Network: Number of close relatives ^a (<i>df</i> = 104)	<i>M</i> = 4.11 <i>SD</i> = 3.29	<i>M</i> = 4.25 <i>SD</i> = 3.11	<i>M</i> = 3.98 <i>SD</i> = 3.48
Number of community-based and psychosocial services used ^a	<i>M</i> = 0.96 <i>SD</i> = 1.19	<i>M</i> = 1.09 <i>SD</i> = 1.26	<i>M</i> = 0.83 <i>SD</i> = 1.11
Secondary Stressors			
Role conflict ^a	<i>M</i> = 4.44 <i>SD</i> = 2.43	<i>M</i> = 4.42 <i>SD</i> = 2.43	<i>M</i> = 4.46 <i>SD</i> = 2.45
Family conflict ^{*,*,a}	<i>M</i> = 2.79 <i>SD</i> = 1.00	<i>M</i> = 2.53 <i>SD</i> = 1.00	<i>M</i> = 3.03 <i>SD</i> = 0.95
Perceived Social Support			
Overall satisfaction with social network ^{*,*,a,f} (<i>df</i> = 105)	<i>M</i> = 2.54 <i>SD</i> = 1.47	<i>M</i> = 2.12 <i>SD</i> = 1.27	<i>M</i> = 2.94 <i>SD</i> = 1.55
Satisfaction with emotional support ^{*,c,f}	<i>M</i> = 2.39 <i>SD</i> = 1.44	<i>M</i> = 2.14 <i>SD</i> = 1.39	<i>M</i> = 2.63 <i>SD</i> = 2.39
Satisfaction with assistance ^{a,f} (<i>df</i> = 105)	<i>M</i> = 3.40 <i>SD</i> = 1.60	<i>M</i> = 3.22 <i>SD</i> = 1.50	<i>M</i> = 3.57 <i>SD</i> = 1.69

Note: *df* = Degrees of freedom; *M* = Mean; *SD* = Standard deviation.

^aIndependent samples *T* test. ^bFisher's exact test. ^cMann-Whitney *U* test. ^d1 = None, 2 = Under \$5,000, 3 = \$5,000 to \$9,999, 4 = \$10,000 to \$14,999, 5 = \$15,000 to \$24,999, 6 = \$25,000 to \$49,999, 7 = \$50,000 to \$74,999, 8 = \$75,000 or more. ^ePearson chi-square test. ^f1 = Very satisfied, 2 = Moderately satisfied, 3 = Slightly satisfied, 4 = Slightly dissatisfied, 5 = Moderately dissatisfied, 6 = Very dissatisfied.

p* < .05; *p* < .01; ****p* < .001.

Individual growth curve models were used to determine whether the NYUCI-AC reduced family conflict and role conflict and improved social support over time (Jackson, 2010; Raudenbush & Bryk, 2002; Singer & Willett, 2003). The Level 1, unconditional growth curve models determined the significance of variations over time in individual trajectories of the family conflict, role conflict, and social support outcomes. A key consideration is whether interindividual differences in change are statistically significant ($p < .05$) when fitting linear, quadratic, and/or cubic parameters in the unconditional models prior to the Level 2 modeling procedures (Shek & Ma, 2011). The linear, cubic, and quadratic Level 1 growth models tested over the 3-year data collection period were as follows:

$$Y_{ij} = \pi_{0i} + \pi_{1i}(\text{Time}) + \pi_{2i}(\text{Time}^2) + \pi_{3i}(\text{Time}^3) + \varepsilon_{ij}$$

Y_{ij} is caregiver i 's value of family conflict, role conflict, or social support on occasion j . π_{0i} is caregiver i 's true initial status, or the value of family conflict, role conflict, or social support when $\text{Time}_{ij} = 0$. π_{1i} represents caregiver i 's true rate of change/linear change throughout the study period on family conflict, role conflict, or social support scores throughout the period under study; π_{2i} represents caregiver i 's quadratic change; and π_{3i} represents cubic change on a family conflict, role conflict, or social support scores throughout the period under study. ε_{ij} reflects the portion of caregiver i 's family conflict, role conflict, or social support that is unexplained on occasion j .

The between subjects, or Level 2, models determined whether NYUCI-AC group membership (intervention or control) significantly influenced linear, quadratic or cubic rates of change in family conflict, role conflict, or social support scores throughout the period under study. The linear, quadratic, and cubic Level 2 growth curve model were as follows:

$$Y_{ij} = \pi_{0i} + \pi_{1i}\text{Time}_{ij} + \pi_{2i}\text{Time}_{ij}^2 + \pi_{3i}\text{Time}_{ij}^3 + \varepsilon_{ij}$$

$$\pi_{0i} = \gamma_{00} + \gamma_{01}\text{NYUCI} - \text{AC}_i + \zeta_{0i}$$

$$\pi_{1i} = \gamma_{10} + \gamma_{11}\text{NYUCI} - \text{AC}_i + \zeta_{1i}$$

$$\pi_{2i} = \gamma_{20} + \gamma_{21}\text{NYUCI} - \text{AC}_i + \zeta_{2i}$$

$$\pi_{3i} = \gamma_{30} + \gamma_{31}\text{NYUCI} - \text{AC}_i + \zeta_{3i}$$

Within the Level 2 models, γ_{00} , γ_{10} , γ_{20} , and γ_{30} are the initial status, linear rate of change, quadratic change, and cubic change for caregivers assigned to the NYUCI-AC control group, respectively. γ_{01} , γ_{11} , γ_{21} , and γ_{31} reflect the effects of assignment to the NYUCI-AC treatment condition initial status, linear rate of change, quadratic, and cubic change on family conflict, role conflict, or social support scores, respectively. ζ_{0i} , ζ_{1i} , and ζ_{2i} , and ζ_{3i} represent the Level 2 residuals, respectively, and are the portions of initial status and linear, quadratic, or cubic rates of change that are unexplained in the Level 2 growth curve models. As with standard regression models, the Level 2 models can incorporate other covariates as part of the larger composite model (Singer & Willett, 2003). IBM SPSS version 24 was used to estimate all growth curve models (IBM Corporation, 2016; Shek & Ma, 2011).

Adult child caregivers had 6.21 data collection points/completed assessments available, on average: $SD = 1.81$ (see Figure 1). Family conflict, role conflict, and social support data were still collected on caregivers after a relative's admission to a residential care setting or a relative's death; the individual growth curve model approach estimated trajectories for missing data points based on all available data for participants in the sample. Caregivers who were enrolled in the later stages of the evaluation could only be followed for a maximum of 2 years; right censoring in the follow-ups beyond 2 years occurred in part because of time of enrollment rather than care recipient's disposition.

Results

Descriptive Data

Descriptive data over the 3-year follow-up period on the family conflict, role conflict, and social support measures are presented in Table 2.

Table 2. Occasion Means, Secondary Stressors and Social Support

	Baseline	4 Months	8 Months	12 Months	18 Months	24 Months	30 Months	36 Months
Variable	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>
Role Conflict	4.44 (2.43)	4.57 (2.36)	4.22 (2.36)	3.99 (2.42)	4.05 (2.68)	4.15 (2.67)	3.94 (2.81)	4.20 (3.32)
Family Conflict	2.79 (1.00)	2.88 (0.99)	2.81 (0.99)	2.82 (1.03)	2.94 (1.01)	2.86 (1.07)	2.75 (0.95)	2.73 (1.03)
Overall Satisfaction with Social Network	4.49 (1.45)	4.51 (1.40)	4.65 (1.31)	4.62 (1.34)	4.57 (1.39)	4.41 (1.53)	4.83 (1.26)	4.71 (1.27)
Satisfaction with Emotional Support	4.63 (1.43)	4.65 (1.32)	4.72 (1.32)	4.74 (1.35)	4.74 (1.46)	4.61 (1.50)	4.96 (1.17)	4.71 (1.39)
Satisfaction with Assistance	3.62 (1.58)	3.64 (1.53)	3.97 (1.44)	3.67 (1.57)	3.84 (1.61)	4.04 (1.69)	4.13 (1.58)	3.93 (1.65)

Note: *M* = Mean; *SD* = Standard deviation.

Level 1 Growth Curve Models

The results of Level 1 unconditional models that featured significant growth curve parameters are presented in [Supplementary Table 1](#). No parameters were statistically significant in the linear or cubic family conflict Level 1 models; however, both the linear and quadratic parameters ($B = .16$, $B = -.06$; $p < .05$, respectively) were statistically significant in the quadratic Level 1 model. Specifically, as shown in [Table 2](#), family conflict gradually increased in the first year of participation, but then declined. Thus, linear and quadratic change parameters for the Level 2 family conflict growth curve models were selected. Among the role conflict Level 1 models, no parameters emerged significant in the quadratic or cubic models; however, the linear rate of change parameter in the linear model was statistically significant ($B = -.23$, $p < .05$) and was selected as the main outcome of interest in the Level 2 role conflict growth curve models. Average role conflict scores across the 3-year project period demonstrated a decline over the 3-year study period (see [Table 2](#)). No parameters in the Level 1 linear, quadratic, and cubic parameters for overall satisfaction with social support and satisfaction with emotional assistance were statistically significant, and thus no Level 2 models were conducted for these outcomes. Only the linear parameterization of satisfaction with instrumental assistance was statistically significant ($B = .15$, $p < .05$) in the Level 1 linear model, and was retained in the Level 2 growth curve modeling procedures. As shown in [Table 2](#), mean scores of satisfaction with instrumental assistance gradually increased.

Level 2 Growth Curve Models

As shown in [Supplementary Table 2](#), several of the baseline covariates (e.g., caregiver gender, satisfaction with social network, and whether the care recipient was institutionalized and some point during the NYUCI-AC) had significant associations with family conflict, role conflict, and satisfaction with instrumental assistance ($p < .05$). NYUCI-AC treatment group assignment was not significantly associated with any family conflict, role conflict, or satisfaction with instrumental assistance growth curve parameters over 36 months.

Discussion

The NYUCI-AC has demonstrated effectiveness in reducing residential long-term care placement for persons with ADRD, adult child caregivers' negative reactions to disruptive behavior problems, and depressive symptoms ([Gaugler et al., 2013, 2015, 2016](#)). However, the outcome analysis presented here suggests that the NYUCI-AC was not effective in improving social support or reducing secondary stressors such as role conflict and family conflict among adult child caregivers.

Although these findings are disappointing, our recently published process evaluation ([Gaugler et al., 2017](#))

provides a partial explanation for these results. Almost half (46%) of the adult child caregivers chose not to utilize any family sessions. On average, adult child caregivers in the NYUCI-AC utilized an average of 1.22 family sessions. As we reported in the process evaluation of the NYUCI-AC, adult child caregivers of relatives with greater cognitive and functional dependencies were more likely to participate in family sessions. Adult daughters, caregivers who had more children themselves, and adult child caregivers who indicated more close relatives were also more likely to participate in family sessions ([Gaugler et al., 2017](#)). Based on anecdotal feedback from the NYUCI-AC study counselors, many adult children resisted including other family members in the counseling sessions as they did not feel it would help them at the time. In other instances, adult child caregivers simply preferred focusing on issues they believed were best addressed in individual counseling sessions. There may have been other barriers not included in our assessment that hindered adult children from including other family members in counseling sessions, such as logistical challenges or long standing conflicts among siblings and other relatives.

A major objective of the parent NYUCI is to build and enhance social support from family and friends among spousal dementia caregivers. In the NYUCI-AC, aspects of the counseling sessions that were well-received by adult child caregivers included the information provided about ADRD, learning skills to cope with problematic behavior of care recipients, and how to effectively communicate with others about their relative's dementia (as ascertained by a reliable review checklist that determined how adult child caregivers perceived the usefulness of various NYUCI-AC counseling components) ([Gaugler et al., 2017](#)). In contrast, strategies to obtain more help and support from other family members were less well-received. This suggests that the individualized focus of the NYUCI-AC facilitated the management of distress but did not help adult child caregivers to interact with family and friends to: (a) enhance social support and decrease family conflict; and (b) offset the challenges of other roles that could potentially conflict with dementia caregiving. For these reasons, the original NYUCI can be considered a *psychosocial* intervention, while the modified NYUCI-AC was transformed into more of a *psychoeducational* intervention that emphasized improvement of coping skills, provision of education, and acquisition of caregiving strategies for adult child caregivers.

Our results also emphasize that outcomes measured must reflect the intended clinical effects of the intervention (Zarit, 2017). Meaningful effects on outcomes for the primary caregiver that relate to relationships with other family members involved in the caregiving dynamic (e.g., family conflict, support) likely require these relatives' active involvement in clinical delivery. This did not occur consistently in the NYUCI-AC, because of adult child caregiver preference to refrain from family counseling. It

is also important to note that measures deployed in the NYUCI-AC evaluation assessed aggregate conflict and support. In this regard, we were not able to gauge whether individual members of the adult child caregiver's family or broader social network were supportive. As noted earlier, adult child caregivers who referred to more relatives as "close" were more likely to participate in family sessions, suggesting the need for a granular assessment of conflict and support within adult child caregivers' social networks when evaluating the effects of an intervention such as the NYUCI-AC. Thus, the lack of findings on family conflict as well as the previously reported finding that more frequent participation in family sessions was linked to increased caregiver distress (see [Gaugler et al., 2017](#)) are unsurprising.

Our overall conceptualization of family caregiving continues to focus on individual units of analysis (i.e., the family caregiver herself or himself). This is often due to expediency; methodological training across many behavioral and social science disciplines is predicated on individual-level analyses and it is often difficult to recruit and enroll an entire family "system." Nonetheless, until methodological techniques are applied that capture family function in the context of a relative's dementia, it is likely our understanding of potential benefits of interventions will remain at least partially obscured. Promising developments in dyadic analysis address this issue in part ([Lyons et al., 2017](#); [Lyons, Zarit, Sayer, & Whitlatch, 2002](#); [Monin, Levy, Doyle, Schulz, & Kershaw, 2017](#)), but a comprehensive family systems approach that informs not only clinical intervention content but also outcomes analysis remains an elusive ideal in the ADRD caregiving literature. Had we adopted such methodological advances in the NYUCI-AC and evaluated outcomes for more than one family member, we would have achieved greater insight into how and why family sessions did or did not influence family-level outcomes. We thus consider the null findings presented here an important "lesson learned" for future dementia caregiver interventions. Although the NYUCI-AC was essentially an individual-level intervention targeted to adult children with few other family members participating, interventions that adopt a more expansive clinical approach require methodological techniques that move beyond individual units of analysis.

The overall changes that occurred in the adult child caregiving sample suggested some degree of adaptation to secondary stress apart from the receipt of comprehensive, psychosocial counseling. As other longitudinal studies of dementia caregiving have suggested, the classic model of "wear and tear" that is thought to exert a cumulative, adverse influence on dementia caregivers over time ignores the considerable resilience and coping strategies that such families often employ ([Gaugler, Kane, Kane, Clay, & Newcomer, 2005](#); [Gaugler, Kane, & Newcomer, 2007](#); [Gaugler, 2010](#)). Although we did not measure resilience

or positive aspects of caregiving in the current study, our impression was that participants learned to successfully manage and balance multiple role responsibilities in addition to family care and were also better able to engage with and utilize the support provided by other family members.

Several additional limitations attenuate our inferences. The sample lacks generalizability, as it was small, almost all female, Caucasian, and well educated. The lack of variance in the slopes for several outcomes may further explain the null findings. A subset of participants only provided 2 years of follow-up data due to study closure, which had an impact on the 3-year modeling approach. Among these adult child caregivers, 19 (59.4%) were in the NYUCI-AC treatment condition and the remaining 13 (40.6%) were in the control group. For other limitations, see [Gaugler et al. \(2013, 2015, 2016, 2017\)](#).

Although the content and delivery of many dementia caregiver interventions (including models such as the NYUCI and NYUCI-AC) are essentially "person-centered" in that the clinical content is tailored to the specific needs of each caregiver and family, one could argue that the outcomes selected to judge the efficacy of these interventions (e.g., burden, depression, etc.) do not adhere to similar principles. Moreover, outcomes that spouse caregivers deem important may differ from those of greatest concern to adult child caregivers. In addition to selecting outcome measures that better reflect the main concerns of dementia caregivers when designing intervention evaluation approaches (e.g., Goal Attainment Scaling, in which participants explicitly indicate their goals for treatment—see [Rockwood et al., 2003](#)), family-level measures that reflect the heterogeneous expectations of participants should be incorporated to better ascertain their potential for improving the ADRD caregiving experience for family systems.

Supplementary Material

Supplementary data are available at *Innovation in Aging* online.

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Conflict of Interest

None reported.

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