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A randomized controlled trial of a community-based dementia care coordination intervention: effects of MIND at Home on caregiver outcomes

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Abstract

Objectives—To assess whether MIND at Home, a community-based, multicomponent, care coordination intervention, reduces unmet caregiving needs and burden in informal caregivers of persons with memory disorders.

Design—18-month randomized controlled trial of 289 community-living care recipient (CR)/caregiver dyads.

Setting—28 postal code areas of Baltimore, MD.

Participants—Informal caregivers (i.e., an unpaid individual who is regularly relied on by the CR for assistance).

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The remaining authors have no relevant conflicts or financial interests to disclose.

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Intervention—All dyads and the CR's primary care physician received the written needs assessment results and intervention recommendations. Intervention dyads then received an 18-month care coordination intervention delivered by non-clinical community-workers to address unmet care needs through individualized care planning; referral and linkage to dementia services; provision of caregiver dementia education and skill building strategies; and care progress monitoring by an interdisciplinary team.

Measurements—Primary outcome was total percent of unmet caregiver needs at 18 months. Secondary outcomes included objective and subjective caregiver burden measures, quality of life (QOL), and depression.

Results—Total percent of unmet caregiver needs declined in both groups from baseline to 18 months, but there was no statistically significant between-group difference. There were no significant group differences in most caregiver burden measures, depression, or QOL. There was a potentially *clinically-relevant* reduction in self-reported number of hours caregivers spent with the CR for MIND participants compared with controls.

Conclusions—No statistically significant impacts on caregiver outcomes were found after multiple comparison adjustments. Yet, MIND appeared to have had a modest, and clinically-meaningful, impact on informal caregiver time spent with CRs.

Keywords

Dementia; caregiver; care coordination; community-based; intervention

Objectives

Roughly two-thirds of the 5.4 million persons with dementia (PWD) in the United States live at home, cared for by approximately 15 million unpaid, informal caregivers (1). These caregivers, usually spouses or adult children, play a key role in how PWD are cared for in the United States – their contributions were estimated to save the healthcare system over \$216 billion in 2012 (1). Caregivers facilitate medical care, manage and monitor patient symptoms, provide physical and emotional support, and coordinate (sometimes financing) social and supportive care services (2). This critical but often taxing role places caregivers at increased risk for considerable stress and burden (3), medical and psychiatric comorbidities (4, 5), dementia (6), mortality (7), social isolation, and an estimated annual financial burden of over \$18,000 (1, 8). Caregiver burden, a multidimensional response to caregiving consisting of objective burden (the practical aspects of care, such as the amount of time spent caregiving) and subjective burden (a caregiver's perception of the impact of caregiving activities on themselves), has been shown to increase over the course of the disease (1, 3, 9). These negative outcomes in caregivers are consistent predictors of poorer outcomes in PWD, including earlier institutionalization and increased mortality (10, 11).

Ideally, the management of dementia should be both patient and family-centric, so that caregivers are afforded the support and resources necessary to provide quality care and quality of life for their loved ones and for themselves. However, dementia caregiver needs often go unevaluated and unmet (12-14). The most common unmet needs among dementia caregivers are potentially modifiable, and include education about dementia (e.g., prognosis;

symptom management; skills training; available resources) and attention to their own mental health and medical needs (13, 14).

Comprehensive care coordination models that take a family-centric approach and include dementia care oriented needs assessments, individualized care planning, and continuous monitoring over time represent a promising approach to improving dementia care and caregiver outcomes (15-18). There is some convergence of evidence in previous care coordination trials to support modest to moderate effects of these programs in reducing caregiver burden, unmet needs, and depression (16, 17, 19-21). However, the evidence base suggests that these programs have had limited impact in producing simultaneous and meaningful improvements for many PWD outcomes (18).

A recent randomized controlled trial, Maximizing Independence (MIND) at Home (22), used a comprehensive, multicomponent, home-based care coordination intervention to systematically identify and address dementia-related care needs of persons with memory disorders (i.e., dementia and mild cognitive impairment) and their caregivers through individualized care planning; referral and linkages to health and community services; provision of dementia education and skill building strategies to caregivers; and ongoing care monitoring by an interdisciplinary team comprised of non-clinical community workers (coordinators) linked to a nurse and a geriatric psychiatrist. The intervention was developed to be applicable to a diverse group and implementable in a range of community settings (e.g., social service agencies). In a previous report on patient outcomes, we found that those receiving MIND experienced an overall delay in time to transition from home, reduced unmet care needs, and improved quality of life (QOL) compared to a similar group receiving augmented usual care over an 18 month period (22).

This investigation uses the MIND trial data to examine the impact of MIND on caregiver outcomes. We hypothesized that over 18 months, caregivers receiving MIND would have reduced unmet caregiver needs, caregiver burden (subjective and objective), depression, and improved QOL relative to caregivers receiving augmented usual care.

Methods

These data are from the MIND at Home dementia care coordination pilot trial (clinicaltrials.gov; NCT01283750) carried out in Baltimore, Maryland. The trial design and methods have been described previously (22). This 18-month randomized controlled trial included elders with memory disorders living at home (n=303) and their informal caregivers (n=278).

The Johns Hopkins Medicine Institutional Review Board approved this study. Oral consent was obtained for telephone screening interviews, written consent was obtained from all participants at the initial in-home assessment, and assent was obtained from CR who lacked consent capacity.

Procedures and Measures

Care recipients (i.e. persons with memory disorders (CR)) lived in a geographically defined area (28 postal codes) in Baltimore, MD. Eligible CRs were age 70+ with a cognitive disorder (i.e., dementia or mild cognitive impairment), English-speaking, had a consenting study partner available, and had > 1 unmet care needs on the Johns Hopkins Dementia Care Needs Assessment (JHDCNA) (14, 23). Study partners were considered informal caregivers if they (1) had contact with the CR at least once per week, and (2) were relied on by the CR for assistance in daily activities. Recruitment methods included mailings to community agency client lists, referrals from community agencies, and study promotion through community outreach (e.g., press releases, advertisements, and promotion at community events). These analyses only include CRs who had a caregiver (n=289). 11 individuals served as caregivers for 2 different CRs in the study (n=278).

Flow of study participation is shown in **Figure 1**. First, a phone screen was administered to CRs and caregivers to explain the study, determine demographic eligibility, and screen for cognitive impairment using the Telephone Interview for Cognitive Status (TICS) and the Short Informant Questionnaire for Cognitive Disorders in the Elderly (IQCODE). Positive phone screens (e.g. TICS <31 and IQCODE >52 cut-offs) (24, 25) then received a detailed, in-home evaluation by a geriatric psychiatrist and/or registered nurse to confirm cognitive diagnosis (using DSM-IV-TR criteria) and to complete the JHDCNA. Data collected included CR medical and psychiatric history, a neurological and mental status exam, and information on function, behavior, support networks, service use, and home environment. Caregivers self-reported their medical diagnoses, health status, insurance coverage, and use of various types of health care and supportive services. Eligible dyads then received a baseline visit to collect quantitative assessments of clinical outcomes including caregiver burden, QOL, and depression.

Randomization

CR/caregiver dyads were randomized within 48 hours of the baseline visit to the intervention or augmented usual care group (1:2 allocation). We used stratified urn randomization to encourage balance on our stratification variable (CR living with/without caregiver). In cases where a caregiver served as the caregiver for 2 different CRs (n=11), randomization of CR/caregiver dyad #1 was completed and the same group assignment was then applied to CR #2 to avoid bias and “bleed over” effects.

Intervention conditions

Augmented usual care (control) group dyads, intervention group dyads, and all CR's primary care physicians received the written results of the JHDCNA following the baseline visit, including recommendations for each identified unmet need. Caregivers in both groups also received a brief resource guide developed for the study that provided program and contact information for local and national aging service organizations. This constituted augmented usual care for the control group (n=183) (16).

Intervention group dyads (n=106) received 18 months of care coordination by an interdisciplinary intervention team that included non-clinical community workers

(coordinators) as the frontline staff, a registered nurse, and a geriatric psychiatrist. The manualized care coordination protocol consisted of four key components: (1) identification of needs and individualized care planning based on the JHDCNA to address unmet needs and to match the priorities and preferences of the dyad and family; (2) provision of dementia education and skill building strategies; (3) coordination, referral, and linkage to health and community services; and (4) care monitoring. Coordinators followed an intervention manual containing detailed descriptions of each care need to be evaluated and suggested care strategies for each identified unmet need. **Table 1** lists the 4 caregiver need domains and examples of intervention recommendations.

Following randomization to the intervention group, coordinators scheduled an in-home visit with dyads to review the assessment results, prioritize identified unmet needs, and create an individualized care plan. Coordinators then assisted CRs and caregivers, primarily through telephone contacts, in meeting care plan goals. Needs were monitored over time and new strategies implemented when necessary. The protocol pre-specified two in-home visits (at baseline and 18-months), and monthly contacts to maintain engagement with the care team, but otherwise frequency and intensity of contacts was driven by need and family preferences. Coordinators were available to families without time restrictions and made an average of 2 contacts (mean 1.8, SD 24.1) per month to intervention group dyads for 18 months (excluding left messages) (22). The number of direct contacts with caregivers regarding solely caregiver needs was not captured systematically. When indicated, coordinators took a direct role to ensure follow-through with recommended interventions (e.g., attending outpatient visits, assisting with service program applications, and modeling management techniques). The intervention team held weekly meetings to review recommendations, discuss cases, provide clinical oversight, and ensure protocol adherence. A web application developed for this intervention, the Dementia Care Management System (DCMS), was used to monitor clinical progress, share information between the intervention team, make referrals, and track protocol fidelity and implementation.

The three coordinators (2 FTE bachelors-prepared, and 0.5 FTE with social work masters degree) were employees of two community-based social service agencies. They were hired purposely for the study and located at the agencies based on *a priori* design. None had prior formal training or certifications in geriatric case management or dementia care. Coordinator training was delivered over a 4-week period and included didactic dementia care management sessions, readings, modeling, clinical care observations, and proficiency assessments.

Measurements

Caregiver characteristics assessed included demographics, living arrangement (living with/without CR), employment status, medical comorbidity, and whether the caregiver was responsible for providing care to at least one other person age 18 and younger or 65 and older. CR characteristics assessed included demographics, Mini-Mental State Exam (MMSE) (26), diagnosis (i.e., dementia vs. mild cognitive impairment), Psychogeriatric Dependency Rating Scale-Behavior (PGDRS-B) to assess functional status (27), and the

Neuropsychiatric Inventory-Questionnaire (NPI-Q) to assess neuropsychiatric symptoms (28).

Caregiver Unmet Needs—The Johns Hopkins Dementia Care Needs Assessment (JHDCNA) is a multidimensional instrument for trained community evaluators to identify caregiver and CR dementia-related needs. It is formatted as a checklist to evaluate 15 CR need domains (71 items) and 4 caregiver domains (15 items; **Table 1**). The evaluator determines if the need is unmet, partially met, or fully met based on criteria specified in the intervention manual. The JHDCNA was developed as a manualized instrument by a multidisciplinary group of clinical dementia experts based on best practices and has demonstrated convergent and discriminant validity (13, 29). Total percent of unmet caregiver needs on the JHDCNA ($[\# \text{ of unmet need items} / \# \text{ of need items assessed}] * 100$) was calculated using the 15 items assessing caregiver needs. The percent of unmet needs in 4 need domains (caregiver education, resource referral, mental health, medical health) were also evaluated for treatment group differences ($[\# \text{ of unmet need items in domains} / \# \text{ of need items assessed in domain}] * 100$). A registered nurse, unmasked to group placement, rated the JHDCNA at baseline and 18-month visits.

Secondary outcome measures—Aspects of caregiver burden (objective and subjective), depression, and QOL were assessed by masked evaluators at baseline, 9 months, and 18 months. Objective caregiver burden was operationalized with 3 items that asked caregivers to estimate their time expenditures: (1) “How many hours in the past week did you spend *with* the CR?”; (2) “How many hours in the past week did you spend doing things *for* the CR (e.g., paying bills, picking up supplies)?”; (3) (for those currently employed) “How many hours in the past month did you miss from work due to your caregiver responsibilities for the CR?”. Subjective caregiver burden was measured by the 12-item Zarit Burden Interview (ZBI) on which scores range from 0 to 44 with higher scores being worse (30). Depression was measured by the 15-item Geriatric Depression Scale (GDS), with scores ranging from 0 to 15 and scores above 5 suggestive of depression (31). QOL was measured by the SF-12, which consists of physical and mental health components ranging from 0 to 100, with a lower score being worse (32). Additionally, single-item Likert burden ratings recorded perceived day-to-day difficulty caring for the CR (1 least difficult, 5 most difficult), self-rated overall health (1 poor health, 5 excellent health), and self-rated stress (1 not stressed, 5 extremely stressed).

Analysis

Descriptive statistics (Pearson chi-square and t-tests) were used to assess group differences at baseline. Mixed-effects linear regression models were used to estimate the effect of the intervention in each continuous outcome measure relative to control using intention-to-treat analysis. Terms for living with CR (the randomization stratification variable), baseline CR PGDRS-B total, baseline CR total daily medications, treatment group, time, and a group by time interaction were included in the model. Baseline PGDRS-B total and total medications were included as covariates due to their association with dropout/attrition over time and because CRs in the intervention group were taking significantly more medications at baseline than control participants.

The measurement of interest was the change in the control group minus the change in the intervention group from 0 to 18 months. For total percent of unmet needs from 0 to 18 months, groups were also modeled independently to assess the effect of time since the augmented usual care group also received the needs assessment and recommendations. Tests were considered significant at an alpha level of .05. Among secondary outcomes, false discovery rate was controlled using the Benjamini Hochberg procedure. SPSS 19.0, SAS 9.3, and R 2.15.2 software were used for analyses.

Results

At baseline, intervention (n=106) and augmented usual care control (n=183) dyads were similar in demographics, CR clinical measures, and caregiver outcome measures (**Table 2**). Over half (57%) of caregivers were age 70+. Most were female, lived with the CR, and were either the spouse or child of the CR. Amongst CRs, 88% were diagnosed with dementia with most being in the mild stages, and the average MMSE was 19 (33). CRs in the intervention group took a greater number of routine medications than those in the control group, but otherwise CRs had similar ratings of neuropsychiatric symptoms, unmet needs, and functional status.

96% of caregivers had > 1 unmet needs at baseline (**Figure 2**). The most prevalent unmet needs among caregivers were for resource referral, caregiver education, and caregiver mental health care. Caregivers had an average of 4.4 unmet needs (SD=2.2) out of the 15 need items assessed at baseline.

There were no statistically significant group differences in reduction of total percent of unmet needs from baseline to 18 months or in any of the four need domains: caregiver education, resource referral, mental health care, and medical health care (**Table 3**). However, the total percent of unmet needs decreased in both the augmented usual care and intervention groups when modeled independently using mixed effects linear regression models (augmented usual care group: $\beta=-3.38\%$, 95%CI -0.62 to -6.14, $t=-2.43$, 92 df, $p=0.017$; intervention group: $\beta=-4.43\%$, 95%CI -1.24 to -7.61, $t=-2.78$, 58 df, $p=0.007$).

There was a decrease in hours per week caregivers spent with CRs in the intervention group relative to the control group from baseline to 18 months (**Table 4**) and an increase in the control group, but this was not statistically significant after multiple comparison correction. Similarly, though not statistically significant, ZBI score estimates increased in the control group and decreased in the intervention group. There were no significant differences between groups over time in QOL, depression, time spent for CR, work hours missed, self-rated difficulty caring for CR, self-rated overall health, or self-rated stress (**Table 4**).

Discussion

In this evaluation of caregiver outcomes from the pilot MIND at Home intervention trial, we found no statistically significant intervention effects on caregiver outcomes. There was a reduction in the hours caregivers spent with care recipients (CRs). However, this model may still represent a valuable approach to care coordination for community-living persons with memory disorders cared for by informal caregivers given its demonstrated impact on

important CR outcomes such as delaying transition from home and improving CR QOL (22). Further, MIND is distinguished from other care coordination models through innovative features such as its (1) novel care team, in which trained non-clinical community workers serve as frontline care coordinators in the context of an interdisciplinary team; (2) implementation in a broad community context as opposed to within an integrated health care system (e.g., Veterans Affairs or university affiliated health care system); (3) focus on a clinically and racially diverse population with varied needs; (4) and content of the intervention itself (e.g., comprehensive needs assessment with linked interventions where dose and intensity is adjusted to CR and caregiver needs).

There were no significant differences in unmet caregiver needs between groups; however, both study groups had a significant reduction in total unmet needs over time. This possibly suggests that the detailed needs assessment results, intervention recommendations, and caregiver resource guide provided to every caregiver, CR, and CR's primary care physician after the initial evaluation benefitted both the intervention and control groups. It may be that providing caregivers a needs assessment and intervention recommendations in and of itself is beneficial and could serve as a low cost alternative intervention, but this would need further testing.

The intervention did not substantially improve or worsen subjective caregiver burden despite delaying CR transition from home. ZBI scores remained relatively stable for the intervention group, while scores increased by 10% in controls (**Table 4**). The Cohen's d effect size was .220. While not statistically significant, this may represent a modest, clinically-relevant finding since subjective caregiver burden tends to increase over time (1, 3, 34). MIND may not have adequately addressed key factors in subjective burden such as grief from the perceived continuous loss of a loved one or the caregiver's perception of the CR's suffering (35, 36), and could be augmented by incorporating grief and suffering counseling strategies in the future. Similar to other studies (15, 17), the intervention did not appear to affect caregiver depression, QOL, work hours missed, self-rated stress, self-rated difficulty caring for the CR, and self-rated overall health.

MIND caregivers spent on average about 6 *fewer* hours with CRs per week over the course of the study compared to the control group, while control group caregivers spent about 10 *more* hours per week on average with CRs. This is not surprising given the intervention's emphasis on promoting caregiver respite opportunities. Although not statistically significant, the effect size was 0.280, suggesting a modest impact. Thus MIND may have a practical, day-to-day, clinically significant impact (37) on time caregivers gained for themselves, as there were no between-group differences in the number of work hours missed over the study. This may be particularly important for early-stage dementia caregivers, since loss of personal time and feelings of missed opportunities are key stressors (38). While the reduction in hours spent with CRs could be a concern for neglect or represent fewer positive caregiver-CR interactions, we previously reported that for CRs, MIND significantly improved QOL, delayed transition from home, and reduced unmet care needs (22). Other intervention types such as caregiver-focused education/support programs (REACH II), and tailored activities programs (TAP) (39, 40) have also demonstrated reductions in self-

reported objective caregiver burden indicators. Future studies should examine how these additional hours are spent by caregivers.

The lack of group differences in caregiver outcomes could be due to several reasons. First, while attempting to empower caregivers, the intervention asks caregivers to take a larger role in the care of the CR which may have added additional stresses. It was reassuring to find that the intervention does not appear to have an additional negative impact on assessed caregiver outcomes. Second, caregiver intervention studies present a unique challenge because subjects are selected based on their caregiver status rather than specific symptoms (e.g., depression, burden) that can be targeted by an intervention (41). As a result, many caregivers without significant levels of depression or burden are included and potentially mask intervention impact. For example, while GDS scores above 5 are suggestive of depression (32), the mean baseline score in our sample was 2.8. Third, MIND was designed to be family-centric and individualized to each CR/caregiver dyad so the contact intensity, prioritization of needs, and care plans varied. As a consequence, it is possible that dyads and coordinators prioritized intervening on CR needs before caregivers needs. Incorporating more evidence-supported protocols to address unmet caregiver needs and pre-specifying a minimum number of caregiver-specific contacts may enhance effectiveness. Finally, the comparison group received a low grade intervention (i.e., JHDCNA needs assessment and recommendations), which may underestimate the impact of MIND compared to current practices.

This study has several limitations. This was an urban sample, which limits generalizability. However, caregiver demographics were comparable to national surveys (1). Unmet need data were collected by an unmasked nurse due to budget limitations. Like similar multicomponent interventions, the mechanisms of action are not yet well understood. Given the diversity of the sample and their needs, we see the intervention's individualized, multicomponent nature as a strength that allowed care plans to be tailored to each dyad's needs rather than a onsize-fits-all program. The frequency of contacts with caregivers regarding caregiver needs was not captured systematically, thus the actual "dose" caregivers received regarding their specific needs is not clear, nor is it clear whether caregiver benefits are primarily gained through intervening on caregiver-specific needs, CR needs, or both. Additionally, the intervention is labor intensive and is not currently a covered service for Medicare, limiting large-scale diffusion. Finally, the true impact of MIND may have been underestimated because the comparison group did not represent usual care.

Overall, we did not observe statistically significant effects on caregiver outcomes. Yet MIND may lead to modest but clinically meaningful benefits such as reducing the number of hours caregivers spend with CRs. The effect of MIND on caregiver outcomes might be augmented by strategically integrating additional evidence-supported protocols such as grief counseling, meditation and stress-relief strategies. In the broader context however, MIND at Home represents a promising and potentially affordable community-based dementia care coordination program that benefits CRs through delaying time to transition from home and improving quality of life. Future work should investigate which caregivers may have benefited most from MIND, if MIND can be enhanced to better impact caregiver outcomes,

and the potential cost-benefits of MIND given its impact on delaying CR transition from home.

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Figure 1.
Participant Flowchart

Figure 2.

Baseline domains with at least one unmet need among caregivers (% of participants)

Table 1**Johns Hopkins Dementia Care Needs Assessment (JHDCNA) – Caregiver Need Domains and Interventions**

Domain	Needs Included	Intervention Examples*
Caregiver Education	Illness education	Educate about dementia course and impact; provide written learning material; inform of educational events and other sources
	Caregiver skills counseling	Instruct and counsel on how to properly manage care (behavioral issues, communication, family conflicts, planning, safety, support)
	Local resource availability	Provide information on local dementia resources (clinicians, non-profits, senior centers, care services, support groups)
Resource Referral	Alzheimer's Association	Refer to local or national chapter after identifying educational, support, care, and safety needs
	Eldercare attorney	Refer to local eldercare attorney after identifying legal needs (e.g., estate planning, will, power of attorney, advanced directives)
	Office on Aging/Social Services	Refer to Maryland Dep of Aging or local agency after identifying financial, meal, transportation, housing, insurance needs
	Geriatric care management	Refer to geriatric care manager after identifying complex health and psychosocial needs
	Adult Protective Services	Contact APS if any signs of abuse, neglect, or exploitation
Mental Health Care	Emotional Support	Monitor stress levels; allow caregiver to express emotions; provide emotional support; empower caregiver; help with coping skills
	Respite	Plan and arrange regular respite care periods
	Mental health counseling	Refer to licensed mental health counselor to assist with personal concerns and symptoms of anxiety or depression, and to help increase self-awareness and improve problem solving
	Psychiatrist	Refer to psychiatrist if symptoms of psychiatric illness interfere with daily functioning and not responding to mental health counseling
Medical Health Care	Primary medical care	Refer to primary care physician when health problems are unaddressed or due for routine exam
	Medical specialist care	Refer to medical specialist (e.g., cardiologist) when needed
	Other health care	Refer to dentist, optometrist, physical therapist when needed

Note: Each need item was assessed as being either “fully met” (i.e. need has been addressed and potential benefits of available interventions have been achieved to the extent possible for the individual) or “unmet” (i.e. (1) it has not been addressed and potentially beneficial interventions are available, or (2) it has been or is being addressed but potential benefits of available interventions have not yet been achieved).

* Listed recommended interventions are not exhaustive. A copy of the full intervention protocol is available upon request.

Table 2Baseline Characteristics of Caregivers and Care Recipients (CR)^{*}

Characteristic	Control	Intervention	Total	χ^2	t	df	P-value
Caregivers:^a	(n=178)	(n=100)	(n=278)				
Age, mean (SD)	67.5 (13.0)	66.3 (14.1)	67.1 (13.4)		0.71	273	0.477
Female, % (No.)	74 (132)	75 (75)	75 (207)	0.02		1	0.877
Race, % (No.)				2.75		1	0.253
White	71 (127)	71 (71)	71 (198)				
Black	28 (50)	26 (26)	27 (76)				
Other	0.6 (1)	3.0 (3)	1.4 (4)				
Years Education, mean (SD)	15.4 (3.0)	15.6 (3.0)	15.4 (3.0)		-0.63	272	0.530
Relationship with CR, % (No.)				0.72		2	0.699
Spouse	46 (82)	41 (41)	44 (123)				
Child	46 (81)	49 (49)	47 (130)				
Other	8 (15)	10 (10)	9 (25)				
Assist Additional People, % (No.)							
Adults (< 65)	13 (23)	14 (14)	13 (37)	0.10		1	0.750
Children (> 18)	11 (20)	14 (14)	12 (34)	0.52		1	0.471
Currently Working, % (No.)	42 (75)	53 (52)	46 (127)	2.63		1	0.105
Living with CR, % (No.)	71 (130)	76 (80)	73 (210)	0.66		1	0.415
Medical Dx Categories, mean (SD)	1.7 (1.0)	1.8 (.96)	1.7 (.98)		-0.29	238	0.769
Primary Outcomes:	(n=183)	(n=106)	(n=289)				
Total Needs, mean % unmet (SD) [‡]	23.0 (12.1)	24.0 (10.8)	23.4 (11.7)		-0.75	285	0.452
Caregiver Education, mean % unmet (SD) [‡]	54.1 (32.8)	59.0 (31.8)	55.9 (32.5)		-1.20	284	0.219
Resource Referral, mean % unmet (SD) [‡]	34.9 (20.8)	36.2 (17.7)	35.4 (19.7)		-0.54	249	0.587
Mental Health, mean % unmet (SD) [‡]	17.3 (23.0)	16.8 (24.8)	17.1 (23.7)		0.18	285	0.858
Medical Health, mean % unmet (SD) [‡]	7.9 (16.6)	9.1 (18.7)	8.4 (17.4)		-0.56	285	0.574
Secondary Outcomes:	(n=183)	(n=106)	(n=289)				
Caregiver Burden (ZBI), mean (SD) [‡]	14.8 (8.5)	14.3 (9.1)	14.6 (8.7)		0.48	280	0.631
Depression (GDS), mean (SD) [‡]	2.7 (2.9)	2.9 (3.2)	2.8 (3.0)		-0.46	278	0.647
QOL - Physical (SF-12), mean (SD) [‡]	47.4 (11.5)	48.1 (10.8)	47.6 (11.2)		-0.53	281	0.595
QOL - Mental (SF-12), mean (SD) [‡]	48.2 (9.5)	48.3 (11.5)	48.2 (10.3)		-0.07	281	0.945
Difficulty Caring for CR, mean(SD)	2.7 (1.2)	2.7 (1.3)	2.66 (1.2)		-0.02	282	0.986
Hours Spent With CR/wk, mean(SD)	67.2 (59.3)	75.4 (62.2)	70.2 (60.4)		-1.10	282	0.276
Hours Spent For CR/wk, mean(SD)	22.0 (31.3)	21.9 (27.5)	22.0 (29.9)		0.02	280	0.981
Work Hours Missed/month, mean(SD)	12.2 (32.1)	11.7 (25.4)	12.0 (29.5)		0.10	135	0.922

Characteristic	Control	Intervention	Total	χ^2	t	df	P-value
Overall Health, mean(SD)	3.2 (1.0)	3.4 (1.0)	3.2 (1.0)		-1.50	284	0.136
Stress From Caring, mean(SD)	3.2 (1.1)	3.2 (1.2)	3.2 (1.1)		0.38	285	0.703
Care Recipients:	(n=183)	(n=106)	(n=289)				
Age, mean (SD)	83.6 (5.8)	84.2 (5.7)	83.8 (5.8)		-0.81	287	0.416
Female, % (No.)	62 (113)	65 (69)	63 (182)	0.05		1	0.828
Education, mean(SD)	13.2 (3.9)	13.0 (3.1)	13.1 (3.6)		0.58	254	0.566
MMSE, mean(SD) [†]	18.9 (7.7)	18.8 (8.0)	18.8 (7.8)		0.11	284	0.912
No. routine medications, mean(SD)	6.1 (2.9)	6.9 (3.4)	6.4 (3.1)		-2.14	287	0.033
Dementia,%(No.)				1.13		1	0.288
Yes	86 (158)	91 (96)	88 (254)				
No (MCI)	14 (25)	9 (10)	12 (35)				
NPI-Q, mean (SD) [‡]	7.4 (6.3)	7.4 (5.7)	7.4 (6.1)		.000	285	0.999
PGDRS-B, mean (SD) [‡]	9.6 (8.1)	10.5 (7.8)	9.9 (8.0)		-0.83	286	0.407
Total Needs, mean % unmet (SD) [‡]	10.2 (6.5)	9.7 (5.4)	10.0 (6.1)		0.62	288	0.533

Abbreviations: Dx = Diagnosis; ZBI = Zarit Burden Interview; GDS = Geriatric Depression Scale; QOL = Quality of Life; SF-12 = Short Form (12) Health Survey; MMSE = Mini-Mental State Exam; No. = Number; NPI-Q = Neuropsychiatric Inventory-Questionnaire; PGDRS-B = Psychogeriatric Dependency Rating Scale-Behavior

* Pearson chi-square and t-tests were used to assess baseline group differences

[†] Higher scores are better

[‡] Higher scores are worse

^a 11 participants serving as caregivers for 2 PWD only included once for demographics

Table 3
Effect of intervention and augmented usual care on caregiver unmet needs at baseline (BL) and 18 months *

		Time	Estimated Mean (SE)		Linear Mixed Model Results		
			Augmented Usual Care (n = 183)	Intervention (n = 106)	A in Augmented Usual Care – BL to 18 months (95%CI)	Statistic (df)	P value
Total Needs (% unmet)	Baseline	22.29 (0.91)	23.52 (1.19)	--			
	18 Months	18.86 (1.24)	19.11 (1.52)	-0.98 (-5.2 to 3.3)		t(151) = -0.46	0.649
Caregiver Education (% unmet)	Baseline	54.36 (2.53)	59.36 (3.32)	--			
	18 Months	41.86 (3.40)	39.88 (4.19)	-6.99 (-18 to 4.4)		t(149) = -1.22	0.226
Resource Referral (% unmet)	Baseline	34.96 (1.53)	37.24 (2.00)	--			
	18 Months	30.38 (2.08)	28.21 (2.56)	-4.46 (-12 to 2.7)		t(151) = -1.23	0.219
Mental Health Care (% unmet)	Baseline	15.13 (1.55)	14.22 (2.03)	--			
	18 Months	5.85 (2.12)	4.55 (2.61)	-0.39 (-7.9 to 7.2)		t(151) = -0.10	0.920
Medical Health Care (% unmet)	Baseline	7.14 (1.53)	8.19 (2.00)	--			
	18 Months	11.33 (2.10)	16.89 (2.58)	4.52 (-2.9 to 12)		t(151) = 1.21	0.230

* Intention-to-treat, mixed effects linear regression models adjusted for living with care recipient (CR), CR Psychogeriatric Dependency Rating Scale-Behavior at BL, and CR total daily medications at BL.

Table 4

Effect of intervention and augmented usual care on secondary outcomes at baseline (BL) and 18 months^{*}

	Time	Estimated Mean (SE)		Intervention (n = 106)	Linear Mixed Model Results		
		Augmented Usual Care (n = 183)			in Augmented Usual Care – in Intervention from BL to 18 months (95%CI)	Statistic (df)	Corrected P value [•]
Caregiver QOL (SF-12)[†]							
A. Physical Health	Baseline	48.11 (.84)		48.88 (1.11)	--		
	18 Months	47.00 (1.02)		49.31 (1.25)	1.53 (–1.1 to 4.2)	t(331) = 1.14	0.257
B. Mental Health	Baseline	48.64 (.82)		48.89 (1.08)	--		
	18 Months	47.54 (1.00)		48.45 (1.22)	–0.66 (–1.9 to 3.2)	t(331) = 0.50	0.617
Caregiver Burden (ZBI)[‡]	Baseline	14.51 (.67)		14.18 (.89)	--		
	18 Months	16.14 (.79)		13.90 (.99)	–1.91 (–3.9 to .05)	t(336) = –1.91	0.057
Depression (GDS)[‡]	Baseline	2.54 (.23)		2.85 (.31)	--		
	18 Months	3.01 (.28)		2.93 (.34)	–0.38 (–1.0 to .25)	t(321) = –1.19	0.237
Time Spent With CR (hr/wk)	Baseline	53.04 (4.04)		58.79 (5.35)	--		
	18 Months	63.88 (5.23)		52.72 (6.42)	–16.90 (–33 to –72)	t(341) = –2.05	0.041
Time Spent With CR (hr/wk)	Baseline	18.41 (2.33)		16.83 (3.08)	--		
	18 Months	12.73 (3.21)		14.31 (3.90)	3.16 (–8.5 to 15)	t(336) = 0.54	0.593
Work Missed (hr/mth)	Baseline	11.54 (2.53)		11.54 (3.16)	--		
	18 Months	7.70 (3.41)		6.29 (4.05)	–1.41 (–13 to 10)	t(118) = –0.25	0.806
Difficulty Caring For CR¹	Baseline	2.63 (.09)		2.60 (.12)	--		
	18 Months	2.56 (.11)		2.32 (.14)	–0.21 (–.55 to –.14)	t(341) = –1.18	0.241
Overall Health²	Baseline	3.25 (.08)		3.47 (.10)	--		
	18 Months	3.08 (.10)		3.46 (.12)	0.16 (–.10 to .42)	t(152) = 1.19	0.237
Stress From Caregiving³	Baseline	3.19 (.08)		3.13 (.11)	--		
	18 Months	2.86 (.10)		2.92 (.13)	0.11 (–.17 to –.39)	t(152) = 0.80	0.424

Abbreviations: QOL = Quality of Life; SF-12 = Short Form (12) Health Survey; ZBI = Zarit Burden Interview; GDS = Geriatric Depression Scale; CR = Care Recipient

^{*} Intention-to-treat, mixed effects linear regression models adjusted for living with care recipient (CR), CR Psychogeriatric Dependency Rating Scale-Behavior at BL, and CR total daily medications at BL.

[•] P values corrected with False Discovery Rate method to correct for multiple comparisons

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- Higher scores are better
- Higher scores are worse
- Likert Item (5 responses) with 1 being least difficult
- Likert Item (5 responses) with 1 being poor health
- Likert Item (5 responses) with 1 being never stressed