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Collaborative Care Management Reduces Disparities in Dementia Care Quality for Caregivers with Less Education

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Abstract

BACKGROUND—Lower educational attainment among informal caregivers' may be associated with poorer outcomes for patients with dementia.

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Conflict of Interest Checklist

Elements of Financial/Personal Conflicts	*Author 1 Arleen F. Brown		Author 2 Stefanie D. Vassar		Author 3 Karen I. Connor		Author 4 Barbara G. Vickrey	
	Yes	No	Yes	No	Yes	No	Yes	No
Employment or Affiliation		X		X		X		X
Grants/Funds		X		X		X		X
Honoraria		X		X		X		X
Speaker Forum		X		X		X		X
Consultant		X		X		X		X
Stocks		X		X		X		X
Royalties		X		X		X		X
Expert Testimony		X		X		X		X
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For "yes", provide a brief explanation:

Author Contributions:

Arleen Brown, MD, PhD: Study concept and design, analysis and interpretation of data, and preparation of manuscript.

Stefanie D. Vassar, MS: Analysis and interpretation of data, and preparation of manuscript.

Karen I. Connor, RN, MBA, PhD: Acquisition of subjects and/or data, and preparation of manuscript.

Barbara G. Vickrey, MD, MPH: Study concept and design, acquisition of subjects and/or data, analysis and interpretation of data, and preparation of manuscript.

OBJECTIVE—To examine educational gradients in dementia care and whether the effect of a dementia collaborative care management intervention varied by the educational attainment of the informal caregiver.

DESIGN—Analysis of data from a cluster-randomized controlled trial.

SETTING—Eighteen clinics across 3 healthcare organizations in Southern California.

PARTICIPANTS—Dyads of Medicare recipients, ages 65 years and older with a diagnosis of dementia, and an eligible caregiver.

INTERVENTION—Collaborative care management for dementia.

MEASUREMENTS—1) Caregiver educational attainment, 2) adherence to four dimensions of guideline-recommended processes of dementia care: Assessment, Treatment, Education/Support, and Safety pre- and post-intervention, and 3) the adjusted intervention effect (IE) for each dimension stratified by caregiver education. Each IE was estimated by subtracting the difference between pre- and post-intervention scores for the usual care participants from the difference in the intervention participants.

RESULTS—At baseline, caregivers with lower educational attainment had lower guideline-recommended processes of dementia care for the Treatment and Education dimensions than those with more education. However, less educated caregivers had significantly more improvement after the intervention on the Assessment, Treatment, and Safety dimensions. The IEs for those who had not graduated from high school compared to college graduates were 44.4 vs. 29.5 for the Assessment dimension ($P<0.001$), 36.9 vs. 15.7 for the Treatment dimension ($P<0.001$), and 52.7 vs. 40.9 for the Safety Dimension ($P<0.001$).

CONCLUSIONS—Collaborative care management was associated with reductions in disparities in dementia care quality among caregivers with lower educational attainment relative to more educated caregivers.

Keywords

Dementia; Caregivers; Care Management

INTRODUCTION

Educational disparities in health are well documented, yet remain poorly understood.^{1, 2} There is a strong and persistent positive gradient between educational attainment and health outcomes; it is estimated that an additional four years of education reduces 5-year mortality by 1.8 percentage points, lowers the probability of reporting fair or poor health by 2.2 percentage points, and reduces the risk of heart disease by 2.2 percentage points.¹ Once established in early adulthood, educational attainment is generally perceived as stable over the lifecourse. However, there is an emerging literature suggesting that educational disparities in health may be attenuated through clinical and behavioral interventions that promote adherence to recommended care. For example, in the Diabetes Control and Complications Trial (DCCT), a study of intensive glycemic control in adults with type 1 diabetes mellitus, the intervention was effective across all levels of educational attainment, but was more effective in improving glycemic control among participants without a high school degree than those who had a post graduate degree.³ Attenuation of the educational gradient in health has also been observed in response to care management interventions to improve glycemic control among patients with type 2 diabetes⁴ and interventions to support functional status among older adults.⁵

For vulnerable older adults, such as those with dementia, the informal caregiver's educational attainment may also influence health. Dementia is characterized by decline in memory and cognitive function that results in progressive functional decline and loss of independence. Most community-dwelling adults with this condition require substantial assistance from informal caregivers (henceforward referred to as caregivers) as the condition advances.⁶ In 2011, it was estimated that over 15 million adults in the U.S. provided unpaid care to a family member or friend with dementia.⁷ The unpaid care provided by the caregivers of adults with dementia may include assistance with activities of daily living, managing complex medication regimens, coordinating clinical care, and addressing behavioral problems.^{8–11} Further, when their caregivers have unmet need for assistance, adults with dementia have increased risk for hospitalization, institutionalization, and death. Several studies suggest that interventions that target the medical, social, psychological, or knowledge needs of caregivers can improve both patient and caregiver outcomes.^{11–16} To our knowledge, however, no studies have examined whether successful interventions can attenuate disparities in dementia care quality across education levels of informal caregivers.

The Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) study was a randomized trial of Chronic Care Model-based¹⁷ collaborative care management intervention among Medicare beneficiaries with dementia and their caregivers.¹⁸ Patient-caregiver dyad participation in the ACCESS intervention was associated with substantial improvement in quality of care for patients with dementia. The current study used data from ACCESS to determine whether there was a positive gradient between caregiver educational attainment and higher adherence to guideline-recommended processes of dementia care at baseline and to examine whether participation in a multifaceted intervention mitigated observed disparities associated with caregiver educational attainment. We hypothesized 1) that there would be an educational gradient in process of care and 2) that this gradient would be attenuated for participants in the care management intervention.

METHODS

Subjects and setting

Subjects participated in the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) study, a cluster-randomized controlled trial that enrolled Medicare recipients ages 65 years and older who were receiving care at one of 18 clinics across the three participating healthcare organizations.¹⁸ Within each healthcare organization, clinics were matched by patient volume and were randomized to either the intervention arm (9 clinics) or usual care arm (9 clinics). Administrative databases were used to identify patients with at least one diagnostic code for dementia for one or more outpatient visits or hospitalizations¹⁹ or a cholinesterase inhibitor prescription during the prior year. Primary care physicians (PCP) were sent a list of their patients who had been identified for the study to confirm the dementia diagnosis and severity level (mild or more advanced) and were asked to identify any other eligible subjects from their practices. PCPs were also asked to remove any names of persons they thought should not be in the study for any reason. Patients also had to have an available informal caregiver to be eligible for the study. Between August 2001 and November 2002, 408 patient-caregiver dyads were enrolled.

Twelve patient-caregiver dyads who had a change in caregiver between baseline and 12- or 18-month follow up were excluded from this study's analytic sample, yielding 396 patient-caregiver dyads in these analyses, 386 of whom had medical records available. The 12-month follow-up survey had 349 respondents and the 18-month follow-up survey had 278 respondents; all follow-up respondents had medical record data. Institutional review boards of all healthcare organizations and the University of California at Los Angeles approved the study protocols.

Data Collection—Caregivers were mailed surveys in English or Spanish at 12 and 18-months after enrollment. A payment of \$20 was enclosed with the survey mailing and nonrespondents received up to two follow-up mailings and a telephone call. Medical record abstractions were performed by nurse abstractors who obtained data from outpatient and inpatient records from 12 months prior to the patient's enrollment date or over the entire pre-enrollment period, as appropriate for the guideline. Details of the medical record abstraction are provided in Appendix A1

Intervention—The ACCESS study intervention has been described previously.¹⁸ Briefly, patient-caregiver dyads in the intervention arm were assigned a healthcare organization care manager (primarily social workers) who administered an initial structured assessment at a home visit, identified problems based on the assessment findings, and initiated care plan actions tailored to the needs of the patient and caregiver. In-home reassessments were conducted every 6 months through 18 months of follow-up, and care managers provided ongoing follow-up via telephone throughout the intervention period. Community agency based care managers also provided agency-specific care services and collaborated with the healthcare organization care managers. Providers at the intervention clinics attended up to five educational modules on relevant dementia care.²⁰ Patients, caregivers, and providers in the usual care group did not receive any of the intervention protocol, and patients received care as usual.

Quality Measures Process of Care Dimensions—A Steering Committee that included physicians from each healthcare organization, representatives from the community agencies, a caregiver for a patient with dementia, and investigators identified 22 dichotomous (yes or no) dementia care indicators.^{18, 21} Of these 22 indicators, 14 were assessed by medical record abstraction 12 months before enrollment and over the entire enrollment period, and the other eight care indicators were assessed by caregiver surveys completed at baseline and at 12 and 18 months after enrollment. The 22 indicators were categorized *a priori* into four process-of-care dimensions: Assessment (all 8 obtained from medical record review), Treatment (2 from medical record review, 5 from caregiver survey), Education and Support (2 medical record review, 2 caregiver survey), and Safety (2 medical record review, 1 caregiver survey). (Appendix Table 1) At each time point, the mean percentage adherence to indicators for which the dyad was eligible was calculated for each of these four dimensions of dementia care.

Independent Variables

Caregiver Education—The main independent variable examined was self-reported caregiver education, categorized as college graduate, some college or 2-year college degree, high school graduate or GED, or did not graduate high school (the reference group). Because fewer than 7% of caregivers had not graduated from high school, we conducted sensitivity analyses in which this category was combined with the “high school graduate or GED” category. The results did not differ substantially from the main results, so we present education in the four original categories.

Covariates—Patient-level covariates included age, gender, education (< high school vs ≥ high school), ethnicity (white vs non-white), comorbid health conditions (Charlson Index),²² dementia severity (11-item Blessed-Roth Dementia Scale),²³ and one or more visits to a primary care physician, geriatrician or neurologist in the six months prior to baseline. Caregiver characteristics included caregiver age, gender, ethnicity (white vs nonwhite), whether the caregiver was living with the person with dementia, a social support score (2-items),²⁴ caregiver mastery, and the caregiver's satisfaction with the patient's healthcare. Caregiver mastery was assessed using 4 standard items.²⁵ Caregivers were asked to rate

their level of agreement (strongly agree, agree, disagree, or strongly disagree) with statements about their perceived mastery of caregiving tasks over the past 4 weeks. Internal consistency of the caregiver mastery scale was very high (Cronbach's alpha =0.88). Baseline values of the caregiver mastery score (4-items)²⁵ and the caregiver's satisfaction with the patient's healthcare²⁶ were included in the models as covariates. Patients' health conditions were abstracted from the medical record; all other independent covariates were from the caregiver survey.

ANALYSES

Analyses were conducted using Stata statistical software version 11 (Statacorp LP, College Station, TX). Bivariate analyses were conducted to compare the intervention and usual care groups on patient and caregiver demographic and clinical characteristics, using 2-sample t-test for continuous variables, chi-square test for categorical variables and Wilcoxon 2-sample rank-sum tests for skewed numerical variables. Differences at baseline in each of the four mean care process dimension adherence scores (Assessment, Treatment, Education/Support; and Safety) across the 4 categories of caregiver education were measured for the entire sample using one-way ANOVA. Associations between each of the four process measures and independent variables were conducted using Pearson correlations. As in prior analyses, baseline values of independent variables with associations with any baseline adherence measure with p-values ≤ 0.20 were included in multivariate models.²¹

The dependent variable in each model was the post-intervention level of each care process dimension, and separate models were constructed for each of the four dimensions of dementia care at follow-up. Partial models were first constructed that included the baseline level for the process dimension, an indicator for intervention status, and interaction terms between intervention status and the 4-category caregiver education variable. Full models were then constructed that added the other patient and caregiver characteristics to the model as adjusters. There was little difference between the partial and fully adjusted models; therefore the fully adjusted models are presented. Adjusted values for the four categories of caregiver education were calculated for the fully adjusted models using the mean of each covariate. To account for the complex sample design and clustering of patient-caregiver dyads within clinics, generalized estimating equations were constructed using Stata survey analysis procedures ("svy:reg" procedure using clinic as the cluster variable). All models also included two indicator variables to adjust for healthcare organization.

The intervention effect (IE) was estimated by subtracting the difference between baseline and follow up scores for the usual care participants from those of the intervention participants. The standard errors for each IE was estimated using bootstrapping with 1000 repetitions.²⁷ The IE estimates across the four education categories were compared using a test of trend.

Intention-to-treat analyses were conducted at the dyad level. Twenty three percent of patient-caregiver dyads randomized to the intervention arm declined to participate in care management. As a sensitivity analysis, these dyads were included in the usual care group, and the analyses were repeated, with no substantial difference in study results. In separate sensitivity analysis, the 2000 U.S. Census median household income for the residential census tract of the caregiver was incorporated into the models as a proxy for individual caregiver income.

RESULTS

At baseline, the intervention and usual care groups did not differ ($p>0.05$) by patient and caregiver sociodemographic or clinical characteristics (Table 1) Overall, 6% of caregivers

had not graduated from high school, 17% were high school graduates or had received a GED, 36% had attended some college, and 41% were college graduates. The educational attainment of the patients was lower than that of the caregivers and did not differ between intervention and usual care groups.

Caregiver Education Gradient at Baseline

In unadjusted analyses, there was higher adherence to two of the four care dimensions among more educated caregivers at baseline (Table 2). For the Treatment dimension, 23% of those without a high school education, compared to 32% of those with a college degree were in adherence ($P=0.005$). In the Education/Support dimension, 35% of those without a high school degree were adherent to this indicator, compared to 56% of those in the highest education category ($P<0.001$). The Assessment dimension and the Safety dimension of care did not differ by caregiver education at baseline, prior to the intervention.

Overall 18-Month Follow-Up

In adjusted analyses, across all four levels of caregiver education, the 18-month post-intervention follow-up Assessment, Treatment, and Safety Dimension scores in the intervention arm were significantly higher than the corresponding scores of the intervention arm at baseline, the usual care arm at baseline, and the usual care arm at follow-up (Figure). The figure also illustrates the trend toward higher post-intervention scores with lower caregiver educational attainment (solid black bars). The one exception was the Education and Support Dimension, in which the strong positive gradient by caregiver education at baseline in both intervention and usual care groups (Table 2) is not evident at follow up for the usual care group (dark hatched bars), though the trends among the intervention group are comparable to the trends for the other dimensions.

Intervention Effects (IEs)

The adjusted IEs were significant and positive for all four dimensions across all levels of caregiver education (Figure). As previously reported for the entire sample of 408 dyads,¹⁸ the intervention was associated with higher adherence to all process indicators (see also Appendix Table A3). For the Assessment dimension, the IE for dyads where the caregiver had not graduated from high school (44.4), was significantly higher than the IE for high school graduates (31.9), those with some college education (33.1), and those with a college degree (29.5), $P<0.001$ for all comparisons. For the Treatment dimension, the IE for dyads in which the caregiver did not have a high school degree was significantly higher than those in which the caregiver had attended some college (23.8) or had a college degree (29.5), $P<0.001$ for all comparisons. For the Safety dimension, dyads in which the caregiver did not graduate high school had higher adjusted IEs (52.7) than those whose caregivers had attended college without graduating (42.8) or had a college degree (40.9), $P<0.001$ for all comparisons. For the Education / Support dimension, the IE was comparable for dyads in which the highest caregiver educational attainment was less than high school, high school graduate, or college graduate, though lower for dyads in which the caregiver had attended, but not graduated from, college.

DISCUSSION

These analyses confirmed the hypothesis of an educational gradient among caregivers of dementia patients: at baseline, caregivers with higher educational attainment provided higher quality care for two of four processes, suggesting that the educational gradient in health observed among individuals also applies in caregiver dyads. We also confirmed the hypothesis of a reduction in the caregiver education gradient in the intervention condition with the finding that although participants of all educational levels appeared to benefit from

participation in a multifaceted dementia care management intervention, less educated caregivers had significantly more improvement from the intervention on the Assessment, Treatment, and Safety dimensions of care quality, compared to college graduates.

Educational attainment may influence health through varied mechanisms.^{1, 2} For example, higher educational attainment may contribute to higher level reasoning and problem solving skills that result in better access to information and more effective use of that information. Education may also promote health through transmission of healthy behaviors between parents and children and through the formation of other social networks that support healthy behaviors. Exploring the mechanisms through which education may be associated with processes of care was beyond the scope of this work; however, this is an area that deserves further study.

There are some limitations to our analyses. It is possible that the educational disparities in our largely white cohort from Southern California may not reflect the variation observed in the general population of individuals who provide care for individuals with dementia in the U.S. The cohort had few racial/ethnic minority patients, and the effect modification observed between education and participation in the intervention may have differed between whites, Latinos, and African Americans due to disparities in educational opportunities for middle aged and older adults in the U.S. or differences in the socioeconomic gradient for racial/ethnic minority groups.²⁸ Given the increasing diversity of the aging population, it will be important to understand if there is variation in the education and process relationships by race or ethnicity. Finally, we had a relatively small sample size and may have had inadequate power to detect modest, but potentially meaningful interaction effects.

The Healthy People 2020 Initiative identifies improved recognition and care for dementia as important national goals²⁹. The results from the above analyses suggest that lower caregiver educational status may contribute to poorer processes of care for patients with dementia and that participation in a collaborative care management intervention can mitigate disparities in dementia care quality that are associated with caregiver education. Thus, identifying settings in which low patient or caregiver educational attainment are associated with lower quality of care and reducing these educational gradients through promotion of strategies such as care management, may contribute to the achievement of these important national goals.

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Appendix A1

Medical record abstractions were performed by nurse abstractors who completed a 3-day training session before beginning data collection. All nurse abstractors were able to abstract a test medical record using an abstraction tool with at least 90% accuracy relative to the project manager's gold standard abstraction. Abstractors were blinded to the randomization status of the patient and were not aware of the study hypotheses or the characteristics of the intervention. Outpatient and inpatient medical records were abstracted on-site at each health care organization. Data were abstracted from 12 months prior to the patient's enrollment date or over the entire pre-enrollment period, as appropriate for the guideline. Interrater reliability was assessed using a random subset of 33 medical records from 1 health care organization. Kappa statistics ranged from 0.50 to 1.0, with a mean of 0.73 and a median of 0.74, for measures that were assessed from medical records.

Table A1

Dementia Indicators Within Each Quality of Care Dimension

Assessment (8 indicators)	
Activities of daily living	
Cognitive status (MMSE or other formal test)	
Medical conditions including sleeplessness	
Behavioral problems or depression	
Primary caregiver and adequacy of support systems	
-	Decision-making capacity
-	Need for surrogate
-	Patient and family culture and decision-making process
Treatment (7 indicators)	
-	A care plan developed *
-	Caregiver involved in care plan development *
-	Caregiver advised to implement predictable routine of daily activities *
-	Caregiver input obtained about whether behavior symptom is perceived as a problem

- Two or more nonpharmacologic approaches for behavior problems recommended to caregiver *
- Monitoring for outcome and side effects documented, if patient is taking behavior medication
- Caregiver understands behavior or depression medication's benefits, side effects, and indications well *

Education and Support (4 indicators)

- Caregiver support group, dementia-related financial planning referral, and respite care discussed or recommended *
 - Alzheimer's Association, Caregiver Resource Center, Meals on Wheels, or health plan social services department discussed or recommended *
 - Advance directive discussed or completed and documented
 - Need to identify decision-making surrogates or to assess decision-making capacity documented
-

Safety (3 indicators)

- Safe Return Program (for wandering) discussed or recommended *
 - Monitoring for abuse documented
 - Driving status reported to county health department or nondriving status documented
-

* Indicates measure was obtained from the caregiver survey; all other measures were obtained by medical record abstraction. Indicators and dimension grouping were determined by a Steering Committee that included physicians from each healthcare organization, representatives from the community agencies, a caregiver representative, and study investigators.

Table A2

Patient and Caregiver Characteristics by Caregiver Educational Attainment (n = 396)

Characteristic	Caregiver Educational Attainment				p-value
	Did not graduate from high school (N = 24)	High school graduate (N = 68)	Some college or 2 year degree (N = 141)	College degree or graduate school (N = 163)	
Patients					
Female, n (%)	10 (41.7)	31 (45.6)	73 (51.8)	103 (63.2)	0.03
Age, mean $\pm$ SD	80.7 $\pm$ 6.7	78.5 $\pm$ 6.9	79.9 $\pm$ 6.8	80.9 $\pm$ 6.3	0.10
Married or living with someone, n (%)	17 (70.8)	55 (80.9)	82 (58.6)	79 (48.5)	<0.001
Non-white race/ethnicity, n (%)	10 (41.7)	10 (14.7)	20 (14.2)	12 (7.4)	<0.001
Educational attainment, n (%)					
Did not graduate high school	14 (58.3)	16 (23.5)	29 (20.6)	14 (8.6)	<0.001
High school graduate or GED	8 (33.3)	36 (52.9)	41 (29.1)	49 (30.1)	
Some college or 2-year degree	2 (8.3)	5 (7.4)	36 (25.5)	34 (20.9)	
College graduate	0 (0.0)	11 (16.2)	35 (24.8)	66 (40.5)	
Duration of dementia diagnosis, mean $\pm$ SD	2.4 $\pm$ 2.2	2.9 $\pm$ 2.9	2.8 $\pm$ 3.1	2.5 $\pm$ 2.3	0.69
Duration of dementia symptoms, mean $\pm$ SD	4.5 $\pm$ 3.1	4.4 $\pm$ 3.2	4.2 $\pm$ 3.7	4.3 $\pm$ 3.2	0.98
Dementia severity score, mean $\pm$ SD [†]	6.3 $\pm$ 3.7	5.5 $\pm$ 3.8	5.8 $\pm$ 3.8	6.1 $\pm$ 3.7	0.61
Charlson comorbidity index, median (IQ range) [‡]	3 (2–4.5)	2 (1–4)	2 (1–4)	2 (1–3)	0.01
Reported behavior problem in past year, n (%)	13 (54.2)	32 (47.1)	79 (56.0)	79 (48.5)	0.50
Caregivers					

Characteristic	Caregiver Educational Attainment				p-value
	Did not graduate from high school (N = 24)	High school graduate (N = 68)	Some college or 2 year degree (N = 141)	College degree or graduate school (N= 163)	
Female, n (%)	16 (66.7)	49 (72.1)	102 (72.3)	108 (66.3)	0.65
Age, mean $\pm$ SD	67.8 $\pm$ 13.9	70.7 $\pm$ 11.4	65.4 $\pm$ 12.5	63.0 $\pm$ 13.7	0.001
Married or living with someone, n (%)	19 (79.2)	60 (88.2)	117 (82.9)	134 (82.7)	0.67
Income					
Median household income for residential census tract (IQR), \$US	53,908 (45,614 – 67,551)	55,841 (49,266 – 68,696)	62,833 (48,594 – 73,389)	70,193 (57,404 – 86,349)	<0.001
Non-white race/ethnicity, n (%)	10 (41.7)	11 (16.2)	20 (14.2)	9 (5.5)	<0.001
Relationship to person with dementia, n (%)					
Spouse	17 (70.8)	53 (77.9)	79 (56.0)	69 (42.6)	<0.001
Son/son-in-law or daughter/daughter-in-law	6 (25.0)	11 (16.2)	52 (36.9)	84 (51.9)	
Other	1 (0.5)	4 (5.9)	10 (7.1)	9 (5.6)	
Lives with person with dementia, n (%)	22 (91.7)	59 (86.8)	101 (71.6)	96 (58.9)	<0.001
Comorbidity score, median (IQR) [§]	2 (0–4)	3 (0–6)	2 (0–5)	0 (0–4.5)	0.01
Social Support score (range 0–100), mean $\pm$ SD ^{††}	67.8 $\pm$ 27.0	67.4 $\pm$ 28.3	62.9 $\pm$ 29.3	64.3 $\pm$ 28.5	0.68
Caregiver Mastery Score (range 0–100), mean $\pm$ SD ^{††}	62.1 $\pm$ 26.5	55.9 $\pm$ 26.3	59.8 $\pm$ 25.6	56.2 $\pm$ 25.0	0.46
Satisfaction with patient's health care (range 0–100), mean $\pm$ SD ^{††}	59.4 $\pm$ 21.6	64.2 $\pm$ 16.7	64.6 $\pm$ 19.5	64.8 $\pm$ 17.9	0.59
Access to care and subspecialist (seen at least once in previous 6 months, n (%))					
Primary Care physician	21 (87.5)	52 (76.5)	112 (79.4)	129 (79.1)	0.73
Geriatrician	2 (8.3)	5 (7.4)	8 (5.7)	13 (8.0)	0.88
Neurologist	8 (33.3)	24 (35.3)	40 (28.4)	53 (32.5)	0.75

IQR – Interquartile Range

[†] Blessed-Roth Dementia scale score; range, 0–17. Higher scores indicate more severe dementia.

[‡] Charlson comorbidity index; range, 1–21. Higher scores indicate more severe comorbidity.

[§] Comorbidity score was calculated as an unweighted count of comorbid conditions. Higher scores indicate more severe comorbidity.

^{††} Scales scored 0 to 100, where high scores indicate greater social support, greater caregiver mastery, and greater satisfaction.

Figure. Adjusted Mean Care Processes for Four Quality of Care Dimensions

LEGEND: REF = reference group, INT = Intervention, UC = Usual Care. Analytic sample is 396. Adjusted values at baseline and follow-up across the four caregiver education categories were estimated using fully adjusted models which included: patient age, sex, education, comorbidity, race/ethnicity, dementia severity; caregiver age, sex, race/ethnicity, social support, mastery, satisfaction with care; whether patient and caregiver live in same residence; whether the patient visited a primary care physician, geriatrician, or neurologist in the prior 6 months; study site; and baseline process score. P-values are for pairwise comparisons of intervention effects for each caregiver education category compared with the less than high school category (=reference group; REF). Intervention effects were estimated by subtracting the difference between adjusted baseline and follow up scores for the usual care participants from those of the intervention participants for the fully adjusted model. Standard errors for each Intervention Effect (IE) was estimated using bootstrapping. Intervention effects are significant for all four care dimensions across all caregiver education categories (i.e. the IE is different from zero).

Table 1

Baseline Characteristics of Patients and Caregivers *

Characteristic	Usual Care (N = 165) N (%) or Mean $\pm$ SD	Intervention (N = 231) N (%) or Mean $\pm$ SD
Patients		
Female, n (%)	91 (55.2)	126 (54.6)
Age, mean $\pm$ SD, years	80.2 $\pm$ 6.9	80.1 $\pm$ 6.5
Married or living with someone, n (%)	96 (58.2)	137 (59.6)
Non-white race/ethnicity, n (%)	24 (14.5)	30 (13.1)
Educational attainment, n (%)		
Did not graduate high school	32 (19.4)	41 (17.8)
High school graduate or GED	57 (34.6)	77 (33.3)
Some college or 2-year degree	34 (20.6)	43 (18.6)
College graduate	42 (25.5)	70 (30.3)
Duration of dementia diagnosis, mean $\pm$ SD, years	2.9 $\pm$ 2.6	2.5 $\pm$ 2.8
Duration of dementia symptoms, mean $\pm$ SD, years	4.6 $\pm$ 3.2	4.1 $\pm$ 3.5
Dementia severity score (range 0–17), mean $\pm$ SD [†]	6.3 $\pm$ 4.2	5.6 $\pm$ 3.4
Reported behavior problem in past year, n (%)	84 (50.9)	109 (47.2)
Charlson comorbidity index (range 0 – 21), mean $\pm$ SD [‡]	2.6 $\pm$ 1.8	2.7 $\pm$ 1.8
Caregivers		
Female, n (%)	116 (70.3)	159 (68.8)
Age, mean $\pm$ SD, years	65.2 $\pm$ 13.1	65.8 $\pm$ 13.2
Married or living with someone, n (%)	136 (82.9)	194 (84.0)
Non-white race/ethnicity, n (%)	24 (14.5)	26 (11.3)
Educational attainment, n (%)		
Did not graduate high school	8 (4.9)	16 (6.9)
High school graduate or GED	32 (19.4)	36 (15.6)
Some college or 2-year degree	59 (35.8)	82 (35.5)
College graduate	66 (40.0)	97 (42.0)
Income		
Median household income for residential census tract (IQR), \$US	66,066 (55,202 – 76,536)	61,389 (49,266 – 79,703)
Relationship to person with dementia, n (%)		
Spouse	90 (54.9)	128 (55.4)
Son/son-in-law or daughter/daughter-in-law	63 (38.4)	90 (38.9)
Other	11 (6.7)	13 (5.6)
Lives with person with dementia, n (%)	115 (69.7)	163 (70.6)
Comorbidity score, median (IQ range) [§]	2 (0–5)	2 (0–5)

Characteristic	Usual Care (N = 165) N (%) or Mean $\pm$ SD	Intervention (N = 231) N (%) or Mean $\pm$ SD
Social Support score (range 0–100), mean $\pm$ SD ^{††}	63.5 $\pm$ 28.5	64.9 $\pm$ 28.7
Caregiver Mastery Score (range 0–100), mean $\pm$ SD ^{††}	59.2 $\pm$ 23.6	57.3 $\pm$ 26.5
Satisfaction with patient's health care (range 0–100), mean $\pm$ SD ^{††}	66.0 $\pm$ 18.3	62.9 $\pm$ 18.7
Access to care and subspecialist (seen at least once in previous 6 months, n (%))		
Primary Care physician	127 (77.0)	187 (81.0)
Geriatrician	11 (6.7)	17 (7.4)
Neurologist	42 (25.5)	83 (35.9)

IQR – Interquartile Range

* Wilcoxon 2-sample rank-sum test was used for Charlson comorbidity index and caregiver index and caregiver comorbidity score; 2-sample t-test was used for all other continuous variables. The intervention and usual care groups did not differ by patient and caregiver sociodemographic or clinical characteristics ($p > 0.05$ for all comparisons).

[†] Blessed-Roth Dementia scale score; range, 0–17. Higher scores indicate more severe dementia.

[‡] Charlson comorbidity index; range, 1–21. Higher scores indicate more severe comorbidity.

[§] Comorbidity score was calculated as an unweighted count of comorbid conditions. Higher scores indicate more severe comorbidity.

^{††} Scales scored 0 to 100, where high scores indicate greater social support, greater caregiver mastery, and greater satisfaction.

Table 2

Baseline Quality of Care Dimensions by Caregiver Education Categories (n = 396)

	Mean care processes that occurred per patient (SD)				P-value
	Did not graduate from high school (N = 24)	High school graduate (N = 68)	Some college or 2 year degree (N = 141)	College degree or graduate school (N = 163)	
Assessment	40.6 (24.5)	37.3 (19.9)	37.6 (24.0)	36.4 (21.3)	0.86
Treatment	23.2 (29.8)	30.0 (28.8)	32.2 (28.6)	38.5 (32.9)	0.03
Education/Support	35.4 (24.3)	48.0 (26.4)	52.2 (28.7)	56.3 (28.7)	0.004
Safety	16.7 (24.1)	18.6 (21.1)	20.8 (24.7)	22.5 (25.4)	0.57

Table A3

Follow up quality of care dimensions (N=396)

	Assessment		Treatment		Education/Support		Safety	
	(95%CI)	P-value	(95%CI)	P-value	(95%CI)	P-value	(95%CI)	P-value
Intervention vs usual care	51.7 (32.1, 71.3)	<0.001	40.1 (28.4, 51.8)	<0.001	21.4 (10.8, 32.1)	0.001	66.1 (42.3, 90.0)	<0.001
Caregiver Educational attainment (ref = less than high school)								
Less than high school (ref)	-	-	-	-	-	-	-	-
High school grad	-3.9 (-18.9, 11.1)	0.59	5.7 (-14.7, 26.1)	0.56	-5.5 (-30.2, 19.3)	0.65	-6.1 (-31.1, 18.8)	0.38
Some college	5.2 (-6.5, 16.8)	0.36	9.1 (-3.9, 22.2)	0.16	2.5 (-19.3, 24.3)	0.61	-7.3 (-24.5, 9.9)	0.61
College degree/grad school	8.6 (-3.1, 23.4)	0.23	14.1 (-2.4, 30.5)	0.09	0.1 (-24.1, 24.3)	0.99	4.8 (25.5, 15.9)	0.63
Intervention × caregiver education attainment interaction	-	0.22	-	0.01	-	0.47	-	0.05
Other covariates:								
Patient age	-0.4 (-0.9, 0.0)	0.05	0.1 (-0.5, 0.6)	0.76	-0.4 (-0.9, 0.1)	0.11	-0.4 (-1.0, 0.3)	0.27
Patient female	-3.4 (-10.0, 3.2)	0.29	0.5 (-7.7, 8.7)	0.90	-1.6 (-11.6, 8.4)	0.74	-5.4 (-15.9, 5.1)	0.29
Patient high school degree or higher	6.8 (0.2, 13.5)	0.05	2.4 (-6.0, 10.8)	0.55	4.5 (-6.3, 15.3)	0.39	7.6 (-4.3, 19.5)	0.20
Patient minority	2.1 (-6.8, 10.9)	0.63	19.2 (7.5, 30.9)	0.003	2.1 (-14.4, 18.5)	0.80	9.5 (0.0, 18.9)	0.05
Charlson comorbidity score	0.9 (-1.0, 2.9)	0.33	1.2 (-1.3, 3.6)	0.33	0.9 (-0.7, 2.5)	0.25	1.4 (-0.5, 3.3)	0.14
Dementia severity score	-0.9 (-1.8, 0.0)	0.04	-0.1 (-0.9, 0.8)	0.85	0.1 (-0.8, 1.1)	0.82	-1.1 (-2.0, 0.1)	0.03
Caregiver age	-0.1 (-0.4, 0.2)	0.42	-0.1 (-0.3, 0.2)	0.65	0.0 (-0.3, 0.3)	0.96	0.4 (-6.3, 7.1)	0.90
Caregiver female	2.3 (-3.5, 8.2)	0.41	-5.1 (-11.7, 1.4)	0.12	-0.5 (-10.9, 9.8)	0.91	-5.5 (-19.3, 8.3)	0.41
Caregiver minority	3.0 (-8.1, 14.1)	0.58	-12.8 (-28.3, 2.7)	0.10	-0.7 (-18.6, 17.2)	0.94	8.0 (-0.5, 16.4)	0.06
Caregiver lives with patient	8.8 (1.0, 16.6)	0.03	-0.8 (-11.5, 10.0)	0.88	13.2 (3.3, 23.2)	0.01	0.0 (0.1, 0.1)	0.85
Social support	0.0 (-0.1, 0.1)	0.96	0.1 (-0.1, 0.2)	0.22	0.0 (-0.1, 0.1)	0.89	-0.1 (-0.3, 0.0)	0.14
Caregiver mastery score	-0.1 (-0.1, 0.0)	0.09	-0.1 (-0.3, 0.0)	0.08	-0.2 (-0.3, 0.0)	0.02	0.1 (-0.1, 0.3)	0.14
Satisfaction with healthcare	0.1 (-0.1, 0.2)	0.39	0.0 (-0.2, 0.1)	0.67	0.0 (-0.2, 0.2)	0.89	0.1 (-0.1, 0.3)	0.22
Visit to geriatrician	-13.5 (-25.2, -1.7)	0.03	-1.0 (-13.1, 11.1)	0.87	-4.1 (-16.9, 8.7)	0.51	-17.2 (-35.3, 0.9)	0.06
Visit to neurologist	-4.3 (-8.7, 0.1)	0.05	-1.5 (-7.7, 4.7)	0.62	0.7 (-4.6, 6.0)	0.79	2.8 (-3.7, 9.4)	0.38
Visit to PCP	2.0 (-4.0, 8.1)	0.47	0.9 (-9.2, 10.9)	0.85	-2.1 (-8.4, 4.1)	0.48	3.7 (-4.3, 11.7)	0.34
Baseline adherence	41.3 (25.3, 57.3)	<0.001	28.0 (16.4, 39.7)	<0.001	17.4 (5.0, 29.8)	0.009	0.24 (13.5, 35.2)	<0.001

Reference group for education is less than high school. Models also adjusted for patient age, sex, education, comorbidity, race/ethnicity, dementia severity; caregiver age, sex, race/ethnicity, social support, mastery, satisfaction with care, whether patient and caregiver live in same residence, visits to PCP, geriatrician, neurologist, study site; baseline process score.