

# Do Nurse-Led Skill Training Interventions Affect Informal Caregivers' Out-of-Pocket Expenditures?

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**Purpose of the Study:** This paper is a report of a study of the Assistance, Support, and Self-health Initiated through Skill Training (ASSIST) randomized control trial. The aim of this paper is to understand whether participating in ASSIST significantly changed the out-of-pocket (OOP) costs for family caregivers of Alzheimer's disease (AD) or Parkinson's disease (PD) patients. **Design and Methods:** Secondary analysis of randomized control trial data, calculating average treatment effects of the intervention on OOP costs. Enrollment in the ASSIST trial occurred between 2002 and 2007 at 2 sites: Durham, North Carolina, and Birmingham, Alabama. We profile OOP costs for caregivers who participated in the ASSIST study and use 2-part expenditure models to examine the average treatment effect of the intervention on caregiver OOP expenditures. **Results:** ASSIST-trained AD and PD caregivers reported monthly OOP expenditures that averaged \$500–\$600. The intervention increased the likelihood of caregivers spending any money OOP by 26 percentage points over usual care, but the intervention did not significantly increase overall OOP costs. **Implications:** The ASSIST intervention was effective and inexpensive to the caregiver

in direct monetary outlays; thus, there are minimal unintended consequences of the trial on caregiver financial well-being.

**Key Words:** Cost analysis, Intervention study, Nurses/midwives/nursing, Alzheimer's disease, Parkinson's disease, Average treatment effect

Informal care is the most common form of long-term care provided worldwide and offers a huge benefit to society by allowing disabled elderly to remain in their preferred setting—the home—and by substituting for costly formal long-term care (Bolin, Lindgren, & Lundborg, 2007; Charles & Sevak, 2005; Van Houtven & Norton, 2008). Caregiver interventions in the United States and in Europe (primarily the United Kingdom) have grown dramatically in the past decade and have exhibited modest improvements in health outcomes for caregivers and delayed nursing home admissions for care recipients (see Thompson et al., 2007 for a review). Largely focusing on caregivers of dementia patients, the most effective interventions have been theory-based and multicomponent

in content. Outcome assessments of these caregiver interventions have focused overwhelmingly on changes in caregivers' psychological and physical health (Brodaty, Green, & Koschera, 2003; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Pinquart & Sorensen, 2003).

The purpose of the paper is twofold: First, we aim to profile out-of-pocket (OOP) expenditures for a sample of caregivers who participated in Project Assistance, Support, and Self-health Initiated through Skill Training (ASSIST): a recently completed randomized trial of a multicomponent intervention consisting of direct care, self-care, and resource utilization skill training for caregivers of older adults with Alzheimer's disease (AD) or Parkinson's disease (PD). By OOP expenditures, we mean money spent by the caregiver on either the caregiver or the care recipient due to the caregiving role, such as on doctor's visits, respite care, or support groups. Because so few studies document the amount of OOP expenditures incurred by caregivers, the descriptive information on its own is valuable. Second, we aim to use treatment models to examine the effects of the intervention on caregiver OOP expenditures.

## Background

Despite increased understanding about the impact of caregiver interventions on caregivers' health outcomes, little is known about the economic impact of caregiver interventions on the caregiver. We know that caregiving often results in reduced work hours, labor force exits (Heitmuller & Inglis, 2007), or wage penalties (Van Houtven, Coe, & Skira, 2010), and in the few studies that document it, informal caregivers report substantial OOP costs (Fast, Williamson, & Keating, 1999; Grunfeld et al., 2004; Hayman et al., 2001; Moore, Zhu, & Clipp, 2001), perhaps upwards of \$500 a month (Longo, Fitch, Deber, & Williams, 2006; Port et al., 2005). It is not clear, however, whether or how caregiver OOP costs are altered, if at all, by caregiver interventions. Most interventions are designed to alleviate burden and depressive affect, improve caregivers' home care skills, or delay institutionalization of care recipients (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Gonyea, O'Connor, & Boyle, 2006). Thus, rarely do costs come under consideration other than as nursing home costs avoided (Mittelman et al., 1996; Mittelman, Haley, Clay, & Roth, 2006) or as a part of a cost (Wray et al., 2010) or cost-effectiveness

analysis (CEA; Nichols et al., 2008). CEA of caregiver interventions typically take a societal perspective (Jansen et al., 2005; Martikainen, Valtonen, & Pirttila, 2004; Nichols et al., 2008; Patel, Knapp, Evans, Perez, & Kalra, 2004) rather than the individual caregiver perspective, thus do not distinguish between research, care recipient, and caregiver costs.

Understanding whether caregiver interventions affect OOP costs of caregivers is important to consider separate from CEA, as there may be unintended OOP changes from an intervention that are rarely considered. It is not clear a priori, whether OOP costs would be expected to increase or decrease. Interventions may make a caregiver spend less on services for the care recipient if the caregiver learns to provide care more effectively herself or more if she becomes skilled at identifying and securing needed paid services. In fact, part of ASSIST training included modules on self-care and how to better find community and resource support (Davis, Gilliss, Deshefy-Longhi, Chestnutt, & Molloy, 2011), so the net effect on OOP expenditures is unclear. Similarly, a caregiver may spend less on herself if she needs less medical assistance (e.g., to treat depression) or more if the intervention leads to better caregiver recognition of his own needs and the needs of the care recipient in terms of medical care of supportive services. For example, the caregiver may learn to recognize adverse medication events better or uncontrolled chronic conditions (e.g., blood pressure of him or herself or the care recipient) and seek more medical care. These unintended consequences may lead to welfare or health gains to caregivers and/or care recipients, or welfare or health losses, depending on the case; but if unintended consequences exist and are ignored, then the health gains in the primary outcome may be over- or understating the net benefit of an intervention (this or any intervention).

Even if the ASSIST intervention does not change OOP costs, understanding the magnitude of OOP costs that the intervention AD and PD caregivers experienced is important because study subjects represent a typical set of care-dyads for AD and PD—These individuals are on fixed incomes due to their advanced age, have a high preponderance of joint household caregiving arrangements, and face intensive and long-term caregiving demands. As such, high OOP costs may affect their own care seeking behavior because we know that copayments and insurance status can be barriers to health care (Wong, Andersen, Sherbourne, Hays, & Shapiro,

2001) or the health care seeking behavior that they facilitate for the care recipient. Thus, OOP expenditures may have potentially important spillover effects such as a caregiver choosing to forgo utilization that could have led to health gains for the caregiver or care recipient.

## Design and Methods

### *The Intervention Study*

The aim of the ASSIST study was to reduce caregiver depressive symptoms and increase mastery among coresident family caregivers of AD and PD patients. ASSIST group caregivers randomized to treatment received skill training over a 24-week period of in-home or telephone-based sessions delivered by a trained nurse interventionist (12 weeks of weekly contacts followed by six biweekly booster sessions). The skill training focused on three main elements of home care skills: direct care skills, such as managing the care recipient's symptoms, assisting with activities of daily living, and monitoring home and environmental safety; self-care skills for managing the caregivers' care stress, optimizing their health and well-being; and resource acquisition skills for finding and using social and community support, assistance, and respite when needed (for more details, please see Davis et al., 2011).

The wait-list comparison received social phone contacts delivered over the same 24-week time period from individuals who were trained in conducting socially supportive conversations by phone. The trial occurred over a 12-month period and included baseline, Time 2 (postintervention), and Time 3 (after 6 months without the intervention). Results of the trial have been reported elsewhere (Davis, Levy, Habermann, Chestnutt, & Molloy, in press). However, when compared with wait-list group caregivers, ASSIST-trained AD and PD caregivers reported clinically and statistically significant improvements in their care skill mastery ( $t = 2.34$ ,  $df = 152$ ,  $p = .02$ ) and reductions in their depressive symptoms ( $t = -2.48$ ,  $df = 152$ ,  $p = .01$ ; Davis et al., in press). The ASSIST study was funded by the National Institute for Nursing Research, National Institutes of Health and was approved by the University of Alabama and Duke University Internal Review Boards.

**Sample.**—This analysis focused on the 187 enrolled dyads. We look at postintervention costs 6 months after the intervention had been completed

(i.e., 12 months after baseline [called Time 3 or post]). In the postperiod, there is cost data for the 152 dyads who completed the participation protocol and the postintervention assessment battery. Noncompleters (35 dyads) contribute an observation at baseline but not at follow-up for the multivariable analysis because we had no postintervention cost data for them. Those with no cost data postintervention did not differ on demographic characteristics in significant ways from those with cost data.

**The OOP Expenditure Measures.**—Detailed monthly OOP expenditures for ASSIST training and wait-list comparison groups were monitored over the 12 months of study participation using the Caregiving Assistance Measure (CAM; Davis et al., 2011). Caregivers were asked whether they had used a given service for the care recipient in the past month including a doctor's appointment or emergency room visit; support group attendance; physical therapy; counseling services, paid sitter in the home; adult day care; meals on wheels; or unexpected hospitalization. For a subset of these services, caregivers were also asked whether in the past month they personally had a doctor's appointment, an emergency department visit, used physical therapy, counseling or respite services, household help, participated in a support group, and finally, whether they were unexpectedly hospitalized. Caregivers who responded "yes" for any of these items were asked "In the past month, how much did you spend OOP for this service?" There were 17 total categories of OOP expenditures. Five services were not specific to the caregiver or care recipient: household help, sitters, respite care, adult day care, and meals on wheels. Six services were asked separately as being for the family member and for the caregiver: doctor's visits, emergency room, physical therapy, support groups, hospitalizations, and counseling. Clearly, other OOP expenses may have existed that we did not capture in our questionnaire, so it is useful to think of these as care-related OOP expenditures. Further, it is important to keep in mind that OOP expenditures represent only a fraction of the total cost to caregivers, such as foregone earnings or other expenditures not captured in our survey instrument (such as transportation costs and the like).

For the analysis, we aggregated past month expenditures across categories in each time period to calculate total expenditures spent on the care

recipient, total expenditures spent on the caregiver, and overall total OOP expenditures.

## Methods

For this paper, we focus on CAM data in the preintervention period, which was measured at baseline, and 6 months after the intervention had been completed (i.e., 12 months after baseline or post). Because a significant portion of the individuals had zero OOP expenditures, we use a two-part expenditure model (Duan, Manning, Morris, & Newhouse, 1984). First, we model the likelihood of having any costs using a linear probability model (LPM) with random effects to control for repeat observations on study subjects. We prefer the LPM to a probit or logit model because of difficulty interpreting interaction terms in maximum likelihood models (Ai & Norton, 2003). Because there are zero out of range prediction, LPM is a valid approach. Second, for individuals who had positive expenditures, we estimate a generalized estimating equations (GEE) model with semirobust standard errors (We assume the dependent variable follows the gamma distribution and checked that our results are robust to different distributional assumptions). Because OOP costs are highly skewed and do not therefore meet normality conditions (skewness = 3.0 in postperiods; kurtosis = 12.5), we used a log link. (Our results in the second part are robust to using a generalized least squares regression with random error components, estimating standard errors using a bootstrapping approach to account for possible violations of distributional assumptions [Barber & Thompson, 2000; Mott, Thorpe, Thorpe, Kreling, & Gadkari, 2010] and robust to using a logged ordinary least squares regression model of expenditures. We prefer the GEE model with a log link because of ease of interpretation and because it offers the advantage of a focus on the arithmetic, not geometric, mean). Because there may have been differences in OOP expenditures by diagnostic groups in the intervention, in preliminary analysis, we also examined whether there were differential effects by a care recipient's diagnosis, for example, AD or PD. Not finding any evidence of differential effects, diagnosis is not included in the models. Finally, because costs were accrued over a 1-year period, we do not make adjustments for inflation.

The basic LPM model to be estimated is as follows:

$$\text{pr}(\text{OOP}_{i,t}) = \alpha + \beta_1 \text{post}_{i,t} + \beta_2 \text{treatment}_i + \beta_3 \text{post}_{i,t} \times \text{treatment}_i + e_{i,t}. \quad (1)$$

OOP indicates the OOP costs at  $t = 1$ , the preperiod, and  $t = 2$ , the postperiod.  $i = 1, 2, 3$  indicates the different costs expended by the caregiver, which we model separately. The caregiver could indicate he or she spent money on the caregiver ( $i = 1$ ) or on the care recipient ( $i = 2$ ), whereas  $i = 3$  is simply the aggregation of all costs.

The sign and significance of  $\beta_3$  in Equation (1), the coefficient on the interaction term  $\text{Post} \times \text{Treatment}$ , is the test of whether the intervention caused the likelihood of having any OOP costs to increase or decrease, and is the primary explanatory variable of interest in the first part of the model. It gives us the average treatment effect on the discrete decision to use any OOP expenditures. The sign and significance on  $\text{treatment}_i$ ,  $\beta_2$ , indicates whether costs were higher or lower as a result of being in the intervention group compared with the usual care group. We also control for differences in costs pre- and postusing the dummy variable  $\text{post}_{i,t}$ . A positive (negative) and significant sign on  $\beta_1$  means that costs were higher (lower) in the postperiod.  $e_{i,t}$  is a randomly distributed error.

For individuals with positive expenditures, we calculate a GEE model with a log link and semirobust standard errors.

$$\text{OOP}_{i,t} = \delta + \alpha_1 \text{post}_{i,t} + \alpha_2 \text{treatment}_i + \alpha_3 \text{post}_{i,t} \times \text{treatment}_i + \sigma_{i,t}. \quad (2)$$

The variable definitions are the same as in Equation (1). The coefficient on  $\alpha_3$  gives the average treatment effect for the second part of the model, that is, for the level of expenditures conditional on having any expenditures OOP. In sensitivity analysis, we examined whether there were differential effects by caregiver relationship (e.g., spousal dyads vs. adult children-parent dyads) or by disease type of the care recipient. Because we found no differential effects, we present results from the parsimonious Model 2 above.

Because we employ a two-part model (Equation 1 and Equation 2), in order to look at the unconditional expectation of OOP expenditures, we multiply the two parts together using the following calculation:

$$\overline{\text{OOP}}_i = \text{Pr}(\text{OOP}_i > 0) \times E(\text{OOP} | \text{OOP}_i > 0), \quad (3)$$

where  $\overline{\text{OOP}}_i$  represents the unconditional expectation of OOP expenditures. To calculate the full



average treatment effect (ATE) of the intervention on OOP costs, we then consider the following difference in difference estimate using Equation (3) (Imbens & Angrist, 1994).

$$(\overline{\text{OOP}}_{i, \text{treatment}=1, \text{post}=1} - \overline{\text{OOP}}_{i, \text{treatment}=1, \text{post}=0}) - (\overline{\text{OOP}}_{i, \text{treatment}=0, \text{post}=1} - \overline{\text{OOP}}_{i, \text{treatment}=0, \text{post}=0}). \quad (4)$$

## Results

### Descriptive

We provide detail on the caregivers and care recipients in the sample in Table 1. Caregivers were around 65 years old, primarily women, with about 14 years of education completed. There were differences in characteristics by the care recipient's disease type, with caregivers of PD being more likely to be White, married, and in a spousal relationship to the care recipient (Table 1). Regarding care recipient characteristics, AD care recipients had moderate cognitive loss, as evidenced by a mean Mini-Mental State Examination (MMSE) score of 11 on the 30-point MMSE measure (Folstein, Folstein, & McHugh, 1975), and PD care recipients had bilateral disease involvement as evidenced by a mean score of 3 on a 5-point PD screening measure (Hoehn & Yahr, 1967).

Parkinson's care recipients were younger, more likely to be men (73.6% vs. 55% for AD), to have a higher educational status and to be working (6.94% vs. 1.32% of AD patients). The caregivers and care recipients in the AD group were much more diverse by race and care-dyad relationship. More than 30% of AD caregivers and care recipients were African American and 31% of caregivers were adult children compared with only 11% in the Parkinson's group. AD caregivers were also much more likely to have household income in the category of less than \$19,999 compared with Parkinson's caregivers, and yet they were also more likely than Parkinson's caregivers to be in the highest income category of \$60,000 or more (11.25% vs. 2.5% of Parkinson's caregivers; Table 1).

Caregivers used a diverse range of services for themselves and for the care recipient. In the preintervention period, for example, about half of all caregivers spent money on doctor's visits either for themselves or their care recipient in the past month. In addition, almost half paid for household help (cleaning, cooking, repairs) or sitters for the care recipient in the past month, whereas a quarter of caregivers had paid for respite care in the past month (Table 2).

Looking across the subcategories of costs, the highest cost categories across the full sample of caregivers were for household help or paid sitters (Table 2). Consistent with the course of disease for Alzheimer's and Parkinson's, over time, the mean amount spent on sitters for the care recipient in the home increased from \$109 at baseline to \$302 at Time 3. Expenditures for household help, by contrast, declined by about \$40 on average from baseline to Time 3.

Importantly, in each time period, a portion of the sample incurred zero OOP expenditures: 12% of caregivers in Time 1 and 29% in Time 3. In many of the expenditure categories, there was a higher likelihood of spending money (e.g., for physical therapy or emergency room visits), but it may be that simply enrolling in the intervention study (regardless of treatment arm) replaced the demand for support groups and/or counseling services. In each of these categories, there was a reduction in the proportion of caregivers using them by nearly half (e.g., 20% of caregivers at baseline used support groups, whereas 10% did in Time 3; Table 3). Despite this increase with zero expenditures, aggregating up expenditures from the past month, and looking at the three time periods, mean total monthly OOP costs grew slightly over time (Table 2). In Period 1, total caregiver expenditures were \$509 compared with \$601 in Time 3. This increase can be attributed to money spent on services for the care recipient, as money spent on services for the caregiver declined over the same time period by about half (from a mean of \$52–\$25).

### Multivariate

*First Part: Conditional Treatment Effect.*—The LPM showed that the treatment group had an increased likelihood of having any expenditures for expenditures spent on the caregiver herself and on total expenditures spent OOP (Table 3). The  $\beta_3$  coefficient in Model 1 tells us that the treatment caused a 0.26% point increase in the likelihood of spending money OOP on the caregiver in the past month on average and a 0.23% point increase in the chance of any spending in the past month on average (Model 3 in Table 3). There was no significant treatment effect on the likelihood of spending more on the care recipient (Model 2 in Table 3).

*Second Part: Conditional Treatment Effect.*—The results from the GEE model indicates that among those who had any spending, the intervention did

Table 1. Baseline Characteristics of Caregivers and Care Recipients, by Disease Type ( $n = 187$ )

Variable description	Care recipient has Alzheimer's disease (%)	Care recipient has Parkinson's Disease (%)
Caregiver		
Age, years ( <i>SD</i> )	64.2 (12.7)	66.7 (10.4)
Female	83.3	78.8
Race/ethnicity		
White	68.6	90.6
Black	29.4	8.2
Other	2.0	1.2
Marital status		
Married	75.5	90.6
Widowed	6.9	0
Divorced/single	17.6	9.4
Education	13.9 (2.3)	14.5 (3.1)
Works	25.5	27.1
Household income		
Less than 19,999	32.4	12.9
20,000–29,999	18.6	16.5
30,000–39,999	15.7	21.2
40,000–49,999	11.7	9.4
50,000–59,999	3.9	8.2
60,000 or more	10.8	25.9
Missing	6.9	5.9
Relationship to care recipient		
Spouse	56.9	85.9
Adult child	30.4	11.8
Other	12.7	2.3
Care recipient		
Age	78.21 (7.60)	71.9 (8.6)
Male	52.0	72.9
Race/ethnicity		
White	68.6	88.2
Black	30.4	9.4
Other	1.0	2.4
Married	59.8	85.9
Education	12.14 (3.37)	14.2 (3.6)
Works	2.0	25.8
Health insurance status <sup>a</sup>		
Medicare	88.2	89.4
Private insurance	24.5	44.7
Other insurance	7.8	10.6
Medicaid	6.9	3.5
Uninsured	0	2.4

Notes:  $N = 187$ ;  $n = 102$  caregivers of Alzheimer's disease patients;  $n = 85$  caregivers of Parkinson's patients. There were minimal differences in baseline characteristics by treatment and control groups; thus, we present descriptive statistics across the diagnosis groups.

<sup>a</sup>Insurance categories do not add up to 100% because a person could list multiple insurance types. Other insurance could be government, such as military insurance or Veteran's Affairs coverage, or retiree insurance or other private plans.

not significantly increase or decrease OOP costs across any subcategory (Table 4). The interaction term ( $\alpha_3$ ) was not significant for OOP costs spent on the caregiver (Model 4), on the care recipient (Model 5), or on both (Model 6); thus, there were no treatment effects on the amount of OOP expenditures, conditional on having

positive expenditures. Whereas the treatment effects for expenditures spent on the caregiver were negative (marginal effect [m.e.] = \$-57), positive for expenditures spent on the care recipient (m.e. = \$192), and positive for overall expenditures (\$57), none of these marginal effects are statistically significant (Table 4).

**Table 2. Prevalence and Amount of Caregiver OOP Costs in Time 1 (preintervention) and Time 3 (postintervention); Recall Period Is the Past Month**

Service/item asked about in the survey	Baseline	Postintervention
	(%/\$ mean)	(%/\$ mean)
Any paid household help (cleaning, cooking, repairs . . . ) <sup>a</sup>	44.4	55.1
Amount spent <sup>b</sup>	200.0	161.9
Any paid for someone to sit with your family member	44.4	50.0
Amount spent	109.1	301.5
Any paid for someone to stay with your family member so you can have some personal time out (respite)	23.0	30.6
Amount spent	26.8	32.6
Any paid visits to a senior day care center for your family member	11.2	13.0
Amount spent	26.6	35.8
Any paid meals on wheels	5.9	10.2
Amount spent	0.8	4.3
	% CR (CG)	% CR (CG)
Any paid for doctor's visits for your family member (for you)?	71.7 (55.6)	68.2 (44.6)
Amount spent	19.1 (26.5)	22.6 (17.7)
Any paid for support group attendance for your family member (for you)	20.1 (27.3)	10.2 (16.4)
Amount spent	0.2 (0.2)	0.03 (0.3)
Any physical therapy	13.5 (5.3)	24.3 (5.4)
Amount spent	2.2 (4.4)	5.6 (2.0)
Any paid visits to the emergency room for your family member (for you)	5.9 (1.1)	12.8 (4.1)
Amount spent	0.6 (0.8)	2.0 (1.9)
Any paid visits with a counselor for your family member (for you)	5.9 (1.1)	3.4 (8.1)
Amount spent	0 (2.7)	1 (2.1)
Any paid hospitalizations for your family member (for you)	3.8 (19.1)	11.0 (0)
Amount spent	2.0 (0)	7.2 (0)
Proportion with zero OOP expenditures	11.8	28.9
Average expenditures on care recipient (\$)	457	576
Average expenditures on caregiver (\$)	52	25
Average total caregiver expenditures (\$)	509	601

*Notes:* Number of observations = 187 in baseline; 152 in postintervention period (12 months after baseline). CR = Care recipient and CG = caregiver. We asked caregivers about 17 different categories of spending as shown. The care recipient could have received nonpaid respite or any other category, but this table reflects only services and items that were paid for by the caregiver. OOP = out-of-pocket.

<sup>a</sup>The wording for the discrete categories was as follows: "In the past month, did you use this service?" And above it the research assistant would say, for example, "Household help (cleaning, cooking, repairs . . . )."

<sup>b</sup>The amount of expenditure was assessed for each item as "In the past month, how much did you spend OOP for this service?"

**Overall Average Treatment Effect.**—We calculated the overall average treatment effect using Equations 3 and 4 above. The average treatment effect for OOP expenditures spent on caregivers was \$224, for care recipients was \$120, and overall was \$208, but these effects are not statistically significant when combining both parts of the two-part model. Thus, although the intervention increased the likelihood of a caregiver spending money on herself or himself, as well as the likelihood of spending any money OOP, the intervention had no effect on the overall level of expenditures (both among individuals who spent a positive amount OOP and among the full sample).

## Conclusion

Conclusions from our study are limited to coresident family caregivers of AD or PD in the United States. We look at only one aspect of costs faced by caregivers—OOP costs spent on the caregiver and care recipient. One cannot extrapolate from our study that caregiver interventions are cost-neutral in general because we only look at one aspect of costs faced by caregivers, OOP costs. If one were to include indirect costs to family caregivers, such as the value of one's time spent caregiving pre- and postintervention or changes in productivity experienced by employers, we may have drawn different

**Table 3. The Effect of the Intervention on the Likelihood of Having Any OOP Costs (total expenditures, expenditures caregivers, care recipients, and total) at 12 Months**

Variable description	Model 1	Model 2	Model 3
	OOP costs	OOP costs	OOP costs
	For caregiver	For care recipients	For both (total)
	Coeff/(Bootstrapped SE)		
Post $\times$ Treatment ( $\beta_3$ )	0.263*** (0.088)	0.114 (0.091)	0.229*** (0.057)
Postperiod ( $\beta_1$ )	-0.394 (0.062)	-0.209 (0.064)	-0.286 (0.057)
Treatment group ( $\beta_2$ )	-0.061 (0.070)	-0.044 (0.062)	-0.079 (0.056)
Constant	0.571*** (0.050)	0.846*** (0.044)	0.923*** (0.040)
Number of observations	339	339	339

*Note:* \* = significance at the 10% level; \*\* = 5% level; \*\*\* = 1% level. Results are from a linear probability model with random effects to control for repeat observations on individuals. OOP = out-of-pocket.

conclusions. This type of study must be left to future work, in which detailed measures are made of changes in objective burden (time spent) from an intervention as well as changes in work or income from an intervention.

It is rare to include OOP costs in caregiver interventions, so exploring the treatment effects on OOP costs is a valuable feature of the ASSIST trial evaluation. OOP costs for caregivers were significant both among usual care subjects and intervention subjects, averaging between \$500 and \$600 per month for our sample of U.S. caregivers participating in a skills training intervention. This amount matched costs from the one other caregiver study that profiled OOP costs in Canada (Longo et al., 2006).

Importantly, the average monthly OOP costs for ASSIST caregivers represented 18–24% of their reported average monthly household income

(mean household income was \$30,000 for adult children caregivers on average and \$40,000 for spousal caregivers). Whereas OOP costs were not significantly different by relationship type, it is helpful to consider that household income was significantly lower on average, for adult child caregivers, meaning that OOP costs were a larger proportion of total household income. We think it is important to frame this spending against household income because in many of the households, care-dyads live together. Thus, caregivers could be reporting spending, that is, from a household budget and not their individual budget. Considering that a typical 65- to 74-year-old American household spent 11% of their annual expenditures on health care, 13% on food, 18% on transportation, and 36% on housing (Purcell, 2007), paying nearly 18%–24% of one's household budget on OOP care-related expenditures for the

**Table 4. The Effect of the Intervention on Logged OOP Costs Among Those With Any Costs (expenditures on caregivers, care recipients, and total) at 12 Months**

Variable description	Model 4	Model 5	Model 6
	OOP costs	OOP costs	OOP costs
	For caregiver	For care recipient	For both (total)
	Marginal effect/(SE)	Marginal effect/(SE)	Marginal effect/(SE)
Post $\times$ Treatment ( $\alpha_3$ )	-54.32 (45.66)	192.25 (282.71)	57.42 (264.7)
Postperiod ( $\alpha_1$ )	27.61 (67.51)	150.08 (171.47)	207.19 (207.53)
Treatment group ( $\alpha_2$ )	-12.13 (34.11)	-111.58 (188.08)	-61.88 (175.38)
Number of observations	144	256	273

*Note:* \* = significance at the 10% level; \*\* = 5% level; \*\*\* = 1% level. Results are based on a generalized estimating equations model with a log link and robust standard errors, and we report the marginal effects (dy/dx) instead of the coefficients for ease of interpretation. Thus, being in the treatment group leads to a nonsignificant -\$54.32 reduction in caregiver expenditures on caregivers compared with controls on average (Model 1, interpretation of Post  $\times$  Treatment marginal effect). OOP = out-of-pocket.



caregiver or care recipient is large. And for the caregivers in the lowest household income category, households with \$19,999 a year, or the modal group of AD caregivers (Table 1), OOP costs represented upwards of 36% of monthly household income.

We collected monthly expenditures at two different study time points; thus, it is not certain that caregivers spent this amount in each month of a full year, so comparing to annual household income is admittedly an extrapolation. However, given that an episode of caregiving for AD had at baseline been going on for 4.5 years on average for AD caregivers and 8.8 years for PD caregivers, see Davis and colleagues (2011), it is likely that OOP expenditures observed were not limited to a couple of months of spending.

If anything, our definition of OOP spending may be an underestimate of expenditures by caregivers. Recall that we limited the questions to be primarily about care-related spending (Table 2), with the exception of meals on wheels expenditures and household help (cleaning, cooking, repairs . . . ). Thus, if we had broadened the definition of OOP costs to include indirect costs of caregiving (transportation), or expenditures on prescription or over the counter drugs for either member of the care-dyad, or collected expenditure data that the care recipient spent independent of the caregiver, in the cases of shared households, OOP costs would have likely been much higher, taking up an even higher proportion of monthly household income. Overall, our OOP estimates from caregiving, although asked in more detail than any other caregiver trial has reported, are likely to be undercounts of the direct expenditures of caregivers, given our limited number of categories.

One possible factor suggesting instead that our OOP costs observed were overestimates of a caregiver's spending, however, is if the caregiver was reimbursed for the services paid for, either by the care recipient or from a third party. It could be that, for example, among adult children, a parent reimbursed him or her for purchasing the services. The wording of the question should help to minimize this concern, however, as each caregiver was asked: "How much did you spend OOP for this service?" In future studies, it may be beneficial to distinguish between OOP spending that is reimbursed or not, to count number of household members in order to understand how many persons one's household income has to support, to understand whether household finances are completely

joint or not, and to distinguish between OOP spending on cleaning services in the home versus "cooking services" or other "household" help. Our wording of the household help question included cleaning, cooking, and repairs but might also have included unskilled home health aide services, and it could be the case that any cleaning services were long-standing and not arising from the caregiving role or due to the care recipient's disability.

The intervention's primary aim was to relieve caregiver burden and depressive symptoms and to improve skills for caregivers of family members with AD or PD. Clearly, the objective was not to reduce OOP expenditures. Nevertheless, it is useful for policy purposes to understand whether a supportive tailored caregiver intervention has spillover effects on OOP costs (Van Houtven, Voils, & Weinberger, 2010). For example, if caregivers undertook more self-care (e.g., physical therapy or sitters so they could go exercise) as a result of the intervention, we may see increases in OOP costs. On the other hand, if the reductions in caregiver subjective burden caused by the intervention reduced the strain caregivers felt and the need to hire outside help in the home, we might see a reduction in OOP costs.

In our two-part expenditures models, which distinguished between the likelihood of spending any money OOP and then the level of expenditures, we find that the treatment increased the likelihood of caregivers spending any money OOP. Examining again the detailed categories of costs (Table 2), this result can be attributable to increased spending by the caregiver on the caregiver (e.g., a higher proportion spent money on counseling and emergency visits in the postperiod rather than increased OOP expenditures on the care recipient). Despite this increase in the likelihood, however, there was no treatment effect on the level of expenditures conditional on having any expenditures (second part) nor on the overall expenditures (ATE effect). Therefore, we find no evidence that the intervention increased OOP costs overall. Furthermore, the contribution of OOP expenditures to any subsequent cost analyses of the ASSIST intervention will not significantly alter the incremental cost-effectiveness ratio.

Our analysis shows that participating in the intervention was cost-neutral overall in the domain of OOP expenditures. A priori it was unclear whether an intervention that targeted increasing caregiver self-care and resource seeking skills

would lead to unintended OOP expenditures for caregivers. Furthermore, whereas most caregiver trials have been found to be ineffective or have modest effects on important caregiver outcomes (Thompson et al., 2007; Wolff et al., 2010), our study illustrates that the ASSIST intervention was effective at increasing care preparation and reducing depressive symptoms for the caregiver, although being cost neutral for the caregiver in direct monetary outlays. Whether the high OOP spending observed in this study had the unintended effect of preventing caregivers from accessing health care for themselves or for the care recipient due to cost concerns was not within the scope of this paper. Yet spillover effects such as these, from the intervention or from caregiving in general, are worth future consideration, both in trying to categorize what the main spillover effects are likely to be (e.g., cost of caregiver depression treatment drugs) and how best to test for their existence. Finally, in addition to spillover effects, it is very true that OOP costs are an important but an incomplete picture of the total economic costs that caregivers face over time. Caregivers incur direct and indirect costs from their caregiving role. Caregivers could be using their time in other productive ways, such as pursuing hobbies, volunteering, or working for pay. Thus, there are other economic costs to caregivers beyond the scope of this paper that need to be considered to form a complete picture of the total economic costs of caregiving.

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## References

- Ai, C., & Norton, E. (2003). Interaction terms in logit and probit models. *Economics Letters*, 80, 123–129. doi:10.1016/S0165-1765(03)00032-6
- Barber, J., & Thompson, S. (2000). Analysis of cost data in randomized trials: An application of the non-parametric bootstrap. *Statistics in Medicine*, 19, 3219–3236. doi:10.1002/1097-0258(20001215)19:23<3219::AID-SIM623>3.0.CO;2-P
- Bolin, K., Lindgren, B., & Lundborg, P. (2007). Informal and formal care among single-living elderly in Europe. *Health Economics*, 17, 393–409. doi:10.1002/hec.1275
- Brodsky, H., Green, A., & Koschera, A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51, 657–664. doi:10.1034/j.1600-0579.2003.00210.x
- Charles, K. K., & Sevak, P. (2005). Can family caregiving substitute for nursing home care? *Journal of Health Economics*, 24, 1174–1190. doi:10.1016/j.jhealeco.2005.05.001
- Davis, L. L., Gilliss, C. L., Deshefy-Longhi, T., Chestnutt, D. H., & Molloy, M. (2011). The nature and scope of stressful spousal caregiving relationships. *Journal of Family Nursing*, 17, 224–240. doi:10.1177/1074840711405666
- Davis, L. L., Levy, J., Habermann, B., Chestnutt, D., & Molloy, M. (in press). A randomized trial of ASSIST for Alzheimer's and Parkinson's disease caregivers. *Family & Community Health*.
- Duan, N., Manning, W. G., Morris, C. N., & Newhouse, J. P. (1984). Choosing between the sample-selection and multi-part model. *Journal of Business and Economic Statistics*, 2, 283–289.
- Fast, J. E., Williamson, D. L., & Keating, N. C. (1999). The hidden costs of informal elder care. *Journal of Family and Economic Issues*, 20, 301–326. doi:10.1023/A:1022909510229
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state" A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189–198.
- Gitlin, L. N., Corcoran, M., Winter, L., Boyce, A., & Hauck, W. W. (2001). A randomized, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist*, 41, 4–14. doi:10.1093/geront/41.1.4
- Gonyea, J. G., O'Connor, M. K., & Boyle, P. A. (2006). Project CARE: A randomized controlled trial of a behavioral intervention group for Alzheimer's disease caregivers. *The Gerontologist*, 46, 827–832. doi:10.1093/geront/46.6.827
- Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C., et al. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, 170, 1795–1801. doi:10.1503/cmaj.1031205
- Hayman, J. A., Langa, K. M., Kabeto, M. U., Katz, S. J., DeMonner, S. M., Chernew, M. E., et al. (2001). Estimating the cost of informal caregiving for elderly patients with cancer. *Journal of Clinical Oncology*, 19, 3219–3225.
- Heitmuller, A., & Inglis, K. (2007). The earnings of informal carers: Wage differentials and opportunity costs. *Journal of Health Economics*, 26, 821–841. doi:10.1016/j.jhealeco.2006.12.009
- Hoehn, M. M., & Yahr, M. D. (1967). Parkinsonism: Onset, progression and mortality. *Neurology*, 17, 427–442.
- Imbens, G., & Angrist, J. (1994). Identification and estimation of local average treatment effects. *Econometrica*, 62, 467–475.
- Jansen, A. P., van Hout, H. P., van Marwijk, H. W., Nijpels, G., de Bruijne, M. C., Bosmans, J. E., et al. (2005). (Cost)-effectiveness of case-management by district nurses among primary informal caregivers of older adults with dementia symptoms and the older adults who receive informal care: Design of a randomized controlled trial [ISRCTN83135728]. *BMC Public Health*, 5, 133. doi:10.1186/1471-2458-5-133
- Longo, C. J., Fitch, M., Deber, R. B., & Williams, A. P. (2006). Financial and family burden associated with cancer treatment in Ontario, Canada. *Supportive Care in Cancer*, 14, 1077–1085. doi:10.1007/s00520-006-0088-8
- Martikainen, J., Valtonen, H., & Pirttila, T. (2004). Potential cost-effectiveness of a family-based program in mild Alzheimer's disease patients. *European Journal of Health Economics*, 5, 136–142. doi:10.1007/s10198-003-0214-1
- Mittelman, M. S., Ferris, S. H., Shulman, E., Steinberg, G., & Levin, B. (1996). A family intervention to delay nursing home placement of patients with Alzheimer disease: A randomized controlled trial. *Journal of the American Medical Association*, 276, 1725–1731. doi:10.1001/jama.1996.03540210033030
- Mittelman, M. S., Haley, W. E., Clay, O. J., & Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*, 67, 1592–1599. doi:10.1212/01.wnl.0000242727.81172.91
- Moore, M. J., Zhu, C. W., & Clipp, E. C. (2001). Informal costs of dementia care: Estimates from the National Longitudinal Caregiver Study. *Journal of Gerontology: Social Sciences*, 56, S219–S228. doi:10.1093/geronb/56.4.S219
- Mott, D. A., Thorpe, J. M., Thorpe, C. T., Kreling, D. H., & Gadkari, A. S. (2010). Effects of Medicare Part D on drug affordability and use: Are seniors with prior high out-of-pocket drug spending affected more? *Research in Social and Administrative Pharmacy*, 6, 90–99. doi:10.1016/j.sapharm.2010.02.004
- Nichols, L. O., Chang, C., Lummus, A., Burns, R., Martindale-Adams, J., Graney, M. J., et al. (2008). The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. *Journal of the American Geriatrics Society*, 56, 413–420. doi:10.1111/j.1532-5415.2007.01569.x
- Patel, A., Knapp, M., Evans, A., Perez, I., & Kalra, L. (2004). Training care givers of stroke patients: Economic evaluation. *British Medical Journal*, 328, 1102. doi:10.1136/bmj.328.7448.1102

- Pinquart, M., & Sorensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *Journal of Gerontology: Psychological Sciences*, 58, P112–P128. doi:10.1093/geronb/58.2.P112
- Port, C. L., Zimmerman, S., Williams, C. S., Dobbs, D., Preisser, J. S., & Williams, S. W. (2005). Families filling the gap: Comparing family involvement for assisted living and nursing home residents with dementia. *The Gerontologist*, 45(Suppl. 1), 87–95. doi:10.1093/geront/45.suppl\_1.87
- Purcell, P. (2007). *Consumer spending by older Americans, 1985 to 2005* (Report No. RL34185). Washington, DC: Congressional Research Service. Retrieved from <http://benefitslink.com/articles/guests/RL34185.pdf>
- Thompson, C. A., Spilsbury, K., Hall, J., Birks, Y., Barnes, C., & Adamson, J. (2007). Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics*, 7, 18. doi:10.1186/1471-2318-7-18
- Van Houtven, C., Coe, N., & Skira, M. (2010). *Effect of informal care on work and wages*. Unpublished manuscript, Center for Retirement Research, Boston College, Chestnut Hill, MA.
- Van Houtven, C., & Norton, E. (2008). Informal care and Medicare expenditures: Testing for heterogeneous treatment effects. *Journal of Health Economics*, 27, 134–156. doi:10.1016/j.jhealeco.2007.03.002
- Van Houtven, C., Voils, C., & Weinberger, M. (2010). *A conceptual framework for informal caregiver interventions*. Unpublished manuscript, General Internal Medicine, Duke University, Durham, NC.
- Wolff, J. L., Giovannetti, E. R., Boyd, C. M., Reider, L., Palmer, S., Scharfstein, D., et al. (2010). Effects of guided care on family caregivers. *The Gerontologist*, 50, 459–470. doi:10.1093/geront/gnp124
- Wong, M. D., Andersen, R., Sherbourne, C. D., Hays, R. D., & Shapiro, M. F. (2001). Effects of cost sharing on care seeking and health status: Results from the Medical Outcomes Study. *American Journal of Public Health*, 91, 1889–1894. doi:10.2105/AJPH.91.11.1889
- Wray, L. O., Shulan, M. D., Toseland, R. W., Freeman, K. E., Vasquez, B. E., & Gao, J. (2010). The effect of telephone support groups on costs of care for veterans with dementia. *The Gerontologist*, 50, 623–631. doi:10.1093/geront/gnq040