

**Early Impact of the Maine Caregiver Companion
Program on Caregivers' Burden, Depression, and Affect**

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EXECUTIVE SUMMARY

Introduction

The Caregiver Companion Program (CCP) is an innovative approach to improving the quality of life of caregivers of persons with Alzheimer's disease receiving Home and Community Based Services, by providing consumer-directed Companion services to the Caregiver. Trained Companions provide individualized support and education, tailored to the caregiver's needs, through a combination of in-home visits, telephone calls, and other activities.

This report describes the results of a pilot program to provide CCP services in rural Maine that was designed to reduce the burden and depression of caregivers for persons with Alzheimer's disease (the clients). The program was well received by family caregivers and by those providing the service. Feedback from national evaluators suggested that this program appeared to be unique in the country. Because of these two factors, the Project was encouraged to do a formal evaluation of the demonstration to determine the effect of the caregiver intervention on caregiver burden, stress, and depression.

The report has two objectives:

- 1) To profile caregivers involved in the CCP in terms of their socio-economic and demographic characteristics, their level of burden and depression, and their relationship with the person with Alzheimer's disease
- 2) To measure the impact of the CCP on the caregivers' burden and depression

Study design and methods

The Caregiver Companion Service has been provided by Elder Independence of Maine (EIM) as part of the ADDGS grant since 2000. EIM has the state contract to provide care management and coordination to individuals eligible for state and federally funded home care programs.

The specific menu of services provided by the Companions is developed by the Companion, and the caregiver, based on his or her situation, strengths, and needs, within the resources available. The services to be provided are mutually agreed on by the Companion and the caregiver.

This evaluation relates to activities provided through the CCP in six rural counties in Maine to caregivers of clients of EIM. The CCP services were provided between October, 2003, and September, 2004. We compared changes in measures of caregiver burden and depression between a group of randomly selected caregivers receiving the CCP services and a similar group of randomly selected caregivers not receiving CCP services at baseline and at 3, 6, and 9 months after the CCP began. The main outcomes were changes from the baseline period to 3 months after the CCP services began in the caregivers' a) burden (objective burden, subjective stress burden, subjective demand burden) and b) depression (depressive affect, somatic symptom, and overall depression). We also measured the percent of clients who were admitted to nursing facilities within 15 months after the CCP began.

Results

Description of the caregivers at baseline: All the participating caregivers were caring for people with Alzheimer's disease (the "clients") who were eligible to receive home and community based services (HCBS). Some of the clients were receiving these HCBS at the beginning of the study, some clients were on a waiting list to receive HCBS and began to receive the services during the time period we studied, and some clients did not receive HCBS during the time period we studied. We reflected these differences in how we classified the clients for the evaluation.

Ninety five caregivers participated in the evaluation; 42 received the CCP services and 53 did not. The caregivers had scores indicating high levels of stress, burden, and depression at the start of the program and many of them were not in good health or were among the "oldest old." Over half the caregivers had been caring for the client for 5 years or more. Three-fourths of the caregivers had to deal with the client's incontinence during the past week and two-thirds had to manage clinging or following behavior. Two thirds of clients received home and community based services (HCBS) at baseline in addition to care provided by

the caregiver. The remaining third were assessed as eligible to receive services but were placed on a waiting list due to lack of funding.

Outcome evaluation: Due to attrition for the 6- and 9-month interviews, we focused the evaluation of the impact on the caregivers using the 3-month outcomes. Of the 95 caregivers at baseline, we had 3-month follow up interview information for 63 caregivers: 28 with CCP services and 35 of the caregivers in the comparison group. The caregivers were similar at baseline to each other in terms of burden, stress, and depression.

The program had a mixed impact on the caregivers. After 3 months, the only measure with a statistically significant difference was objective burden – the average score in the group with the Companion declined more than the average for the comparison group. None of the other measures showed any statistically significant differences in the changes between the groups with and without Companion services at 3 months.

The caregivers who benefited most from the CCP were caring for clients receiving home-and-community-based services. They had significantly better improvement in objective burden at 3 months compared to the caregivers who did not receive CCP and the client received HCBS ($p < .05$). The caregivers who received CCP services who cared for people who received HCBS also had the biggest improvement in the three measures of depression, but the differences between this group and the others were not statistically significant.

In addition to studying changes in caregivers' burden and depression at 3 months, we analyzed changes at 6- and 9- months after the baseline interview. Because of the small numbers of caregivers remaining in the study, however, we focused on the three-month results. In addition, we tracked the client's admissions to nursing homes within 15 months after the baseline interview. At 15 months, 24.5% of the clients in the group without CCP services had entered a nursing facility compared to 16.7% of the clients with CCP services. These differences were not statistically significantly different, however.

Discussion

The CCP is an extremely innovative program that is well-suited to rural areas that lack a broad and deep mix of support services for caregivers of people with Alzheimer's disease. The introduction of the pilot program described here was greeted enthusiastically by the caregivers and the Companions. The CCP would seem to be ideally suited to the rural Maine areas in which it was piloted and to the caregivers who received the Companion services. However, the results of this evaluation are disappointing. While it is true that after three months the CCP showed a statistically significant impact on the caregivers' measure of objective burden, there was no significant difference between caregivers with and without CCP services in the other measures of stress, burden, or depression.

What can we learn from the results? The small numbers in the sample, which was compounded by the attrition of clients from the study over time, may have contributed to the lack of statistical significance observed. The design was further complicated because during the time of the study, individuals came off a waiting list for HCBS services and started to receive them. Therefore, other factors may have impacted the measures of caregiver stress, burden and depression.

Two of the results have implications for future work. First, as noted above, the caregivers with Companion Services of clients who received home-and-community-based services and Companion Services had an improvement in objective burden, but the other caregivers did not. The CCP services alone were not enough to reduce the burden and depression of people caring for clients with Alzheimer's who were eligible for HCBS, but were waiting for services due to lack of funding. This is not surprising, given the demands placed on the caregivers by the clients' needs, functional limitations, and behavior, and by the advanced age of many of the clients and their caregivers. This result suggests that whether or not the caregiver received HCBS should be a variable that is included in future evaluations. Second, the clients of caregivers receiving CCP services were less likely to be admitted to a nursing facility during the study period and up to 6 months afterwards. It suggests that future evaluations of programs like this could include measures of use of long-term care services and the associated costs of such services. The CCP may have financial benefits to MaineCare in addition to any psychosocial benefits the caregivers may receive.

REPORT

Introduction

Alzheimer's disease, the most common form of dementia among older people, affects between 4 and 4.5 million people in the United States.¹ One in ten individuals over 65 and nearly half of those over 85 has the disease.² In addition to the impact it has on those with Alzheimer's, including impaired memory and communication, the disease imposes heavy demands on their caregivers.³ Almost 8 million American caregivers, one quarter of whom live in rural areas, provide unpaid care to an adult age 50 or older with Alzheimer's disease, dementia or other mental confusion. The National Alliance for Caregiving and the AARP estimate there are 33.9 million American caregivers providing unpaid care to an adult age 50 or older.⁴ Nearly one quarter (23%) of caregivers helping someone over the age of 50 reports the person they care for is suffering from Alzheimer's, dementia or other mental confusion.³

The exhaustion, financial demands, disrupted activities, and ongoing burden associated with caring for a person with Alzheimer's disease can lead to significant mental health issues for the care giver, including depression and anxiety.^{5,6} Caregivers with an increased level of depressive symptoms are more likely to place patients in a nursing facility.⁷

An estimated one-fourth of the persons age 65 and older at risk of developing dementia live in rural areas; rural families may be more likely to keep their elder with dementia in the community than families in urban areas.⁸ In addition to the challenges faced by all caregivers, rural caregivers may experience additional burdens due to isolation and lack of mental health services.

The Caregiver Companion Program (CCP) is an innovative approach to improving the quality of life of caregivers of persons with Alzheimer's disease by providing consumer-directed services. In the CCP model, trained Companions provide individualized support and education to the caregiver through a combination of in-home visits, telephone calls, and other activities. Within the resources available, the types of services provided, their scheduling, and their duration are tailored to the needs and preferences of the caregiver. The specific menu of services to be provided by the Companions is developed through discussion between the

Companion, based on his or her skills and expertise, and the caregiver, based on his or her situation, strengths, and needs. The services to be provided are mutually agreed on by the Companion and the caregiver.

Study objectives

This report describes the results of a pilot program to provide CCP services in rural Maine that was designed to alleviate the burden and depression of caregivers for persons with Alzheimer's disease (the clients). The program was well received by family caregivers and by those providing the service. Feedback from national evaluators suggested that this program appeared to be unique in the country. Because of these two factors, the Project was encouraged to do a formal evaluation of the demonstration to determine the effect of the caregiver intervention on caregiver burden, stress, and depression.

The report has two objectives:

- 1) To profile caregivers involved in the evaluation in terms of their socio-economic and demographic characteristics, their level of burden and depression, and their relationship with the person with Alzheimer's disease and
- 2) To measure the impact of the CCP on the caregivers' burden and depression.

Study design and methods

The Caregiver Companion Service has been provided by Elder Independence of Maine (EIM) as part of the ADDGS grant since 2000. EIM has the state contract to provide care management and coordination to individuals eligible for the state and federally funded home care programs.

The specific menu of services provided by the Companions is developed by the Companion, based on his or her skills and expertise, and the caregiver, based on his or her situation, strengths, and needs, within the resources available. The services to be provided are mutually agreed on by the Companion and the Caregiver.

This evaluation relates to activities provided through the CCP in six rural counties in Maine to caregivers of clients of Elder Independence of Maine (EIM). The CCP services were provided between October, 2003, and September, 2004. We compared changes in measures of caregiver burden and depression between a group of randomly selected caregivers receiving the CCP services and a similar group of randomly selected caregivers not receiving CCP services at baseline and at 3, 6, and 9 months after the CCP began.

The main outcomes were changes from the baseline period to 3 months after the CCP services began in the caregivers' a) burden (objective burden, subjective stress burden, subjective demand burden) and b) depression (depressive affect, somatic symptom, and overall depression). We also measured the percent of clients who were admitted to nursing facilities within 15 months after the CCP began.

There was a complication in the research design because, after the study commenced, a waiting list developed for clients who needed HCBS. Consequently, some caregivers received CCP services with no services available for the client with dementia. We reflected these differences in how we classified the clients for the evaluation.

Three scales were used to measure caregiver burden⁹: *Objective burden* (“the perceived infringement or disruption of tangible aspects of a caregiver’s life”); *Subjective stress burden* (“the emotional impact of caregiving responsibilities on the caregiver”); and *Subjective demand burden* (“the extent to which the caregiver perceives care responsibilities to be overly demanding”). Scores of 23 or more for objective burden, 13 or more for subjective stress, and 15 or more for subjective demand indicate a high risk of stress.

Three scales were used to measure depression¹⁰: *Depressive affect* (how often feelings of depression, loneliness, crying, feeling sad, or having the blues were experienced over the past week); *Somatic symptoms* (appetite and eating, concentration, energy, sleep, motivation)¹¹; and *Overall depression* (the sum of the responses for the responses to the questions for depressive affect and somatic symptoms). Scores from 16 - 26 predict a high probability of mild depression and scores of 27 and higher predict a high probability of severe depression.¹²

Results

Types of services provided by the Companions: First, we describe the caregivers who received the Caregiver Companion Program (CCP) services. The Companions provided a wide range of services to the caregivers during the first year of program implementation (Figure 1). They provided information to the caregivers, helped motivate and advocate for them, and provided emotional and practical assistance with daily activities and accessing services. The specific services provided were developed and agreed on by the Companion and the caregiver.

Figure 1. Services provided by Companions

Listen	Listen to caregiver concerns and caregiving stories on the phone or in person
Educate	Educate the caregiver on caregiving tasks (such as how to manage wandering), disease process, community resources (such as the Alzheimer’s Association), and signs and symptoms of caregiver stress and the need to take care of oneself while caregiving
Participate	Participate with caregivers in local caregiver support groups
Coordination	Educate and work with the Elder Independence of Maine (EIM) care management team in accessing respite service benefits under various programs for the caregivers
Research	Participate in research to understand the caregiving role and how state and/or federally funded services inhibit or enhance that role
Intervene	Help the caregiver manage stress through activities such as gardening, going for a walk, taking the caregiver for coffee or lunch, or cooking with the caregiver
Advocate	Advocate for the caregiving family in getting a formal Alzheimer’s diagnosis. Assist in working with families who have multiple caregiving challenges; use data collected and stories to help inform advocacy efforts

Description of the caregivers at baseline: Ninety five caregivers participated in the evaluation, 42 received the CCP services and 53 did not. Of the caregivers, 78% were female; 64% were married or had a domestic partner; the average age was 61 and the ages ranged from 29 to 85 (Table 1). Almost half worked part-time or were “retired” but working part-time, and 26% worked full-time. Slightly more than a third had an annual income of less than \$20,000 and about a fifth earned \$40,000 or more. (One-third did not report their income.) Sixty percent reported that their health was very good or good and 40% that it was fair, poor, or very poor. None was a professional caregiver.

Table 1. Characteristics of caregivers in the Alzheimer's Caregiver Companion (CGC) Study at intake

Characteristics	At Intake (n=95) Percent or number	With Companion(n=42) Percent or number	Without Companion(n=53) Percent or number
All persons	100.0%	100.0%	100.0%
Gender **			
Female	77.9%	90.5%	67.9%
Male	22.1%	9.5%	32.1%
Marital status			
Married/domestic partner	64.2%	71.4%	58.5%
Single	14.7%	11.9%	17.0%
Widow/widower	11.6%	7.1%	15.1%
Other or unknown	9.5%	9.5%	9.4%
Age (in years)			
Average	61.0	61.3	60.7
Minimum	29.1	29.1	40.9
Maximum	84.9	84.4	84.9
Standard deviation	12.2	11.6	12.7
Race (report all that apply)			
Asian	1.1%	0.0%	1.9%
White	98.9%	100.0%	98.1%
Ethnicity			
Hispanic or Latino	3.2%	2.4%	3.8%
Not Hispanic or Latino		97.6%	96.2%
Languages (report all that apply)			
English	100.0%	100.0%	100.0%
Spanish	0.0%	0.0%	0.0%
Other	4.2%	4.8%	3.8%
Educational attainment			
Eighth grade or less	7.4%	7.1%	7.5%
Some high school	10.5%	9.5%	11.3%
High school graduate	31.6%	31.0%	32.1%
Some college	24.2%	35.7%	15.1%
Associates degree	9.5%	7.1%	11.3%
Bachelor's degree	9.5%	2.4%	15.1%
Graduate degree	7.4%	7.1%	7.5%
Employment status			
Works full-time	26.3%	23.8%	28.3%
Works part-time	15.8%	23.8%	9.4%
Retired part-time	31.6%	31.0%	32.1%
Fully retired	14.7%	14.3%	15.1%
Homemaker	2.1%	0.0%	3.8%
Unemployed	9.5%	7.1%	11.3%
Caregiver's total annual income			
Under \$8,000	12.6%	7.1%	17.0%
\$8,000 - \$11,999	9.5%	7.1%	11.3%
\$12,000 - \$14,999	7.4%	7.1%	7.5%
\$15,000 - \$19,999	7.4%	11.9%	3.8%
\$20,000 - \$29,999	10.5%	7.1%	13.2%
\$30,000 - \$39,999	5.3%	9.5%	1.9%
\$40,000 and over	18.9%	14.3%	22.6%
Not Reported	28.4%	35.7%	22.6%
Self-rated health *			
Very good	16.8%	14.3%	18.9%
Good	42.1%	31.0%	50.9%
Fair	32.6%	47.6%	20.8%
Poor	7.4%	4.8%	9.4%
Very poor	1.1%	2.4%	0.0%

The caregivers were more likely to say they were competent as caregivers than that they able to manage their own stress or to get emotional support (Table 2). The caregivers' average scores indicated a high risk of objective burden, subjective stress, and subjective demand, and a risk of depression that was almost at the level indicating a high risk of severe depression (Table 3). More than half of the caregivers said they frequently or always had restless sleep, 26% said that they felt everything was an effort frequently or always, and 20% said that they frequently or always felt depressed, lonely, and sad (not in the table).

* Significant at the 0.1 level ** Significant at the 0.01 level

Table 2. Attitudes of caregivers in the Alzheimer's Caregiver Companion (CGC) Study at intake

Caregiver attitudes	At Intake (n=94) ¹ Percent	With Companion(n=42) Percent	Without Companion (n=52) ¹ Percent
All persons	100.0%	100.0%	100.0%
I believe that I know a great deal about my relative's condition.			
Never	2.1%	0.0%	4.5%
Rarely	4.3%	6.0%	2.3%
Sometimes	16.0%	10.0%	22.7%
Quite frequently	23.4%	20.0%	27.3%
Nearly always	54.3%	48.0%	61.4%
I know where and how to request help from others when I need it.			
Never	4.3%	4.0%	4.5%
Rarely	9.6%	10.0%	9.1%
Sometimes	25.5%	24.0%	27.3%
Quite frequently	18.1%	12.0%	25.0%
Nearly always	42.6%	34.0%	52.3%
I feel confident that I know how to manage a difficult situation.			
Never	2.1%	2.0%	2.3%
Rarely	2.1%	4.0%	0.0%
Sometimes	22.3%	20.0%	25.0%
Quite frequently	31.9%	24.0%	40.9%
Nearly always	41.5%	34.0%	50.0%
I believe that, all in all, I am a capable caregiver.			
Never	2.1%	2.0%	2.3%
Rarely	2.1%	4.0%	0.0%
Sometimes	11.7%	6.0%	18.2%
Quite frequently	29.8%	24.0%	36.4%
Nearly always	54.3%	48.0%	61.4%
I have been able to develop ways to manage the stresses of caregiving.			

Caregiver attitudes	At Intake (n=94) ¹	With Companion(n=42)	Without Companion (n=52) ¹
	Percent	Percent	Percent
Never	5.3%	4.0%	6.8%
Rarely	5.3%	6.0%	4.5%
Sometimes	29.8%	34.0%	25.0%
Quite frequently	28.7%	14.0%	45.5%
Nearly always	30.9%	26.0%	36.4%
I feel I get the emotional support I need.			
Never	8.5%	12.0%	4.5%
Rarely	11.7%	12.0%	11.4%
Sometimes	34.0%	28.0%	40.9%
Quite frequently	20.2%	12.0%	29.5%
Nearly always	25.5%	20.0%	31.8%

¹ Responses are missing for one caregiver.

Table 3. Caregiver burden and depression scores at baseline

	Mean scores			p value for 2-tailed t-test ¹
	All caregivers (n=95)	Has Companion (n=42)	No Companion (n=53)	
Burden and stress				
Objective burden	26.37	27.10	25.79	0.097
Subjective stress	13.97	13.74	14.15	0.410
Subjective demand	16.11	16.25	16.00	0.682
Depression				
Depression	24.97	25.90	24.23	0.293
Depressive affect	11.84	12.26	11.51	0.411
Somatic symptoms	13.13	13.64	12.72	0.272

¹ This measures the statistical significance of the difference of the means between caregivers with and without Companion services.

Ideally, in a study like this, the intervention group (with CCP services) and the control group (without CCP services) will be identical to each other at baseline on all the characteristics that might influence the outcomes of the CCP. The more closely they resemble each other, the more we can be assured that any differences we observe between them after the intervention is due to the CCP services. To increase the chance that the two groups would be as similar to each other as possible, as noted above, caregivers were randomly assigned to either the intervention or the control group. To see how similar the groups were, we compared them on several characteristics (Table 1).

The two groups of caregivers were statistically similar to each other at $p < .05$ at baseline in all the variables in Tables 1, 2, and 3 except for gender (those with a Companion were more likely to be female) and self-rated health (those with a Companion were less likely to have very good or good health).

Description of the clients at baseline: Next, we describe the people with Alzheimer's disease (the clients) who were cared for by the caregivers receiving the CCP services. The average age of the clients was 83 and they ranged in age from 52.5 years to 99 years of age (Table 4). Sixty percent lived in a rural or farm community and 40% lived in a non-suburban small city or town. None lived in an urban area. All of the clients needed assistance with at least one ADL and at least one IADL. As we noted above, all the clients were eligible to receive home- and community-based services (HCBS) at the time the study began, though not all were receiving services. Two-thirds of the clients were receiving HCBS at baseline; some clients were on a waiting list to receive services and began to receive them during the course of the study, and some clients did not receive HCBS during the study.

At baseline two groups were similar at the $p < .05$ level of significance except that the clients in the group with CCP services were older on average and were more likely to receive home-and-community-based services than the group without CCP services.

Table 4. Characteristics of clients whose caregivers participated in the Alzheimer's Caregiver Companion (CGC) Study at intake

Characteristics	All clients (n=95)	With Companion (n=42)	Without Companion (n=53)
	Percent or Number	Percent or Number	Percent or Number
All persons			
Gender			
Female	71.6%	71.4%	71.7%
Male	28.4%	28.6%	28.3%
Marital status			
Married/domestic partner	36.8%	33.3%	39.6%
Single	2.1%	2.4%	1.9%
Widow/widower	55.8%	57.1%	54.7%
Other	3.2%	2.4%	3.8%
N/A	2.1%	4.8%	0.0%
Age			
Average**	83.0	85.4	80.9
Minimum	52.5	72.2	52.5
Maximum	98.6	94.5	98.6
Standard deviation	8.6	6.2	9.9
Race (report all that apply)			
Asian	1.1%	0.0%	1.9%
White	98.9%	100.0%	98.1%
Ethnicity			
Hispanic or Latino	4.2%	2.4%	5.7%
Not Hispanic or Latino	95.8%	97.6%	94.3%
Languages (report all that apply)			
English	98.9%	100.0%	98.1%
Spanish	0.0%	0.0%	0.0%
Other	7.4%	7.1%	7.5%
Residence			
Rural or farm community	60.0%	64.3%	56.6%
Non-suburban small city or town	40.0%	35.7%	43.4%
Living environment			
Nursing home	2.1%	0.0%	3.8%
Alone in house or apartment	17.9%	21.4%	15.1%
Lives w/ others in house or apartment	80.0%	78.6%	81.1%
Client's total annual income			
Under \$8,000	21.1%	21.4%	20.8%
\$8,000 - \$11,999	28.4%	21.4%	34.0%
\$12,000 - \$14,999	16.8%	21.4%	13.2%
\$15,000 - \$19,999	8.4%	9.5%	7.5%
\$20,000 - \$29,999	8.4%	4.8%	11.3%
\$30,000 and over	2.1%	2.4%	1.9%
Not Reported	14.7%	19.0%	11.3%

Table 4. - continued –

Characteristics	All clients Percent or Number	With Companion Percent or Number	Without Companion Percent or Number
Alzheimer's disease			
Medically diagnosed	41.1%	52.4%	32.1%
Probable but not diagnosed	45.3%	38.1%	50.9%
Memory problems suspected	13.7%	9.5%	17.0%
ADL count (out of a possible 6 ADLs)¹			
Average	4.1	4.3	3.8
Minimum	0	0	0
Maximum	6	6	6
Standard deviation	1.9	1.8	1.9
IADL count (out of a possible 10)²			
Average	9.6	9.5	9.6
Minimum	0	0	7
Maximum	10	10	10
Standard deviation	1.2	1.6	0.7
Client receives home & community-based services*			
Yes	65.3%	83.3%	64.2%
No	34.7%	16.7%	35.8%

¹ Number of Activities of Daily Living (ADLs) for which the person with Alzheimer's needed at least some assistance or could not perform the activity at all

² Number of Instrumental Activities of Daily Living (IADLs) for which the person with Alzheimer's needed at some assistance or could not perform the activity at all

* Significant at the 0.05 level ** Significant at the 0.01 level

Description of the caregiver/client pairs: Finally, we describe the pairs of caregivers and clients, to highlight aspects of their relationship that indicate the demands the caregivers face. At baseline 95% of the caregivers were family members of the clients, the remaining caregivers were friends; over half (55%) had been caring for the client for 5 years or more (Table 5). The caregivers lived an average of 4 minutes away from the client's home; the distances between the caregivers' and the clients' homes ranged from 0 to 90 minutes travel time. By far, the two most often performed services provided by the caregiver were case management and personal care provision (each provided by more than 70% of the caregivers). Caregivers spent the most time during the week on meal preparation, laundry and light housework (18 hours on average) and on providing help with activities of daily living such as eating, bathing, dressing, or toileting (12 hours). Three-fourths of the caregivers had to deal with the client's incontinence during the week and two-thirds had to manage clinging or following behavior.

The two groups were similar except that the clients in the group with CCP services were more likely to both be female; the clients without CCP services were more likely to have a male caregiver and a female client.

Table 5. Characteristics of the relationship between clients and their caregivers who participated in the Alzheimer's Caregiver Companion (CGC) Study, at intake

Characteristics	All Clients (n=95)	With Companion (n=42)	Without Companion (n=53)
	Percent or Number	Percent or Number	Percent or Number
All persons	100.0%	100.0%	100.0%
Relationship of caregiver and client (1 missing)			
Spouse	26.3%	26.2%	26.4%
Child	63.2%	64.3%	62.3%
Sibling	2.1%	0.0%	3.8%
Other relative	3.2%	2.4%	3.8%
Friend	5.3%	7.1%	3.8%
Combined genders of caregiver and client *			
Both female	51.6%	61.9%	43.4%
Both male	2.1%	0.0%	3.8%
Female caregiver w/ male client	26.3%	28.6%	24.5%
Male caregiver w/ female client	20.0%	9.5%	28.3%
How long has caregiver provided assistance?			
Less than 6 months	1.1%	0.0%	1.9%
6 to 12 months	9.5%	14.3%	5.7%
13 to 24 months	6.3%	2.4%	9.4%
24 to 59 months	27.4%	26.2%	28.3%
5 years or more	54.7%	57.1%	52.8%
Not reported	1.1%	0.0%	1.9%
How far does caregiver live from client?			
Average minutes	4.2	3.6	4.7
Minimum minutes	0	0	0
Most minutes	90	45	90
Standard deviation	12.0	9.7	13.6
Which services does the caregiver perform?			
Companion	4.2%	2.4%	5.7%
Paid supervision	16.8%	21.4%	13.2%
Chore services	8.4%	7.1%	9.4%
Homemaker	8.4%	9.5%	7.5%
Personal care	76.8%	85.7%	69.8%
Home health	44.2%	47.6%	41.5%
Adult day care	7.4%	14.3%	1.9%
Respite care	2.1%	2.4%	1.9%
Which services does the caregiver perform?			
Case management	80.0%	85.7%	75.5%
Transportation	13.7%	19.0%	9.4%
Support groups	4.2%	4.8%	3.8%

Characteristics	All Clients (n=95)	With Companion (n=42)	Without Companion (n=53)
	Percent or Number	Percent or Number	Percent or Number
Which services does the caregiver perform?			
Caregiver training	16.8%	26.2%	9.4%
Psychological counseling	6.3%	7.1%	5.7%
Group meals	17.9%	14.3%	20.8%
Other	13.7%	14.3%	13.2%

Characteristics	All Clients	With Companion	Without Companion
	Percent or Number	Percent or Number	Percent or Number

During the past week, how many hours did you help with meal preparation, laundry & light housework?			
Average	17.8	19.2	16.7
Minimum	0	0	0
Maximum	50	40	50
Standard deviation	11.9	11.4	12.4

During the past week, how many hours did you help with eating, bathing, dressing, or toileting?			
Average	12.3	14.5	10.5
Minimum	0	0	0
Maximum	66	50	66
Standard deviation	12.7	12.3	12.8

During the past week, how many hours did you help with legal matters, banking or money matters?			
Average	2.1	1.9	2.2
Minimum	0	0	0
Maximum	8	5	8
Standard deviation	1.5	1.3	1.7

During the past week, how many hours did you help with transportation to appointments and/or shopping?			
Average	4.4	5.0	3.9
Minimum	0	0.0	0.0
Maximum	17	17.0	12.0
Standard deviation	3.4	3.9	2.9

In past week, how many days did you have to deal with your relative having a bowel or bladder "accident"?			
No days	22.1%	14.3%	28.3%
1-2 days	22.1%	19.0%	24.5%
3-4 days	11.6%	9.5%	13.2%
5-or-more days	44.2%	57.1%	34.0%

In past week, how many days did you have to deal with your relative clinging to or following you around?			
No days	34.7%	45.2%	26.4%
1-2 days	14.7%	9.5%	18.9%

In past week, how many days did you have to deal with your relative clinging to or following you around?

3-4 days	10.5%	4.8%	15.1%
5-or-more days	40.0%	40.5%	39.6%

* Significant at the 0.1 level

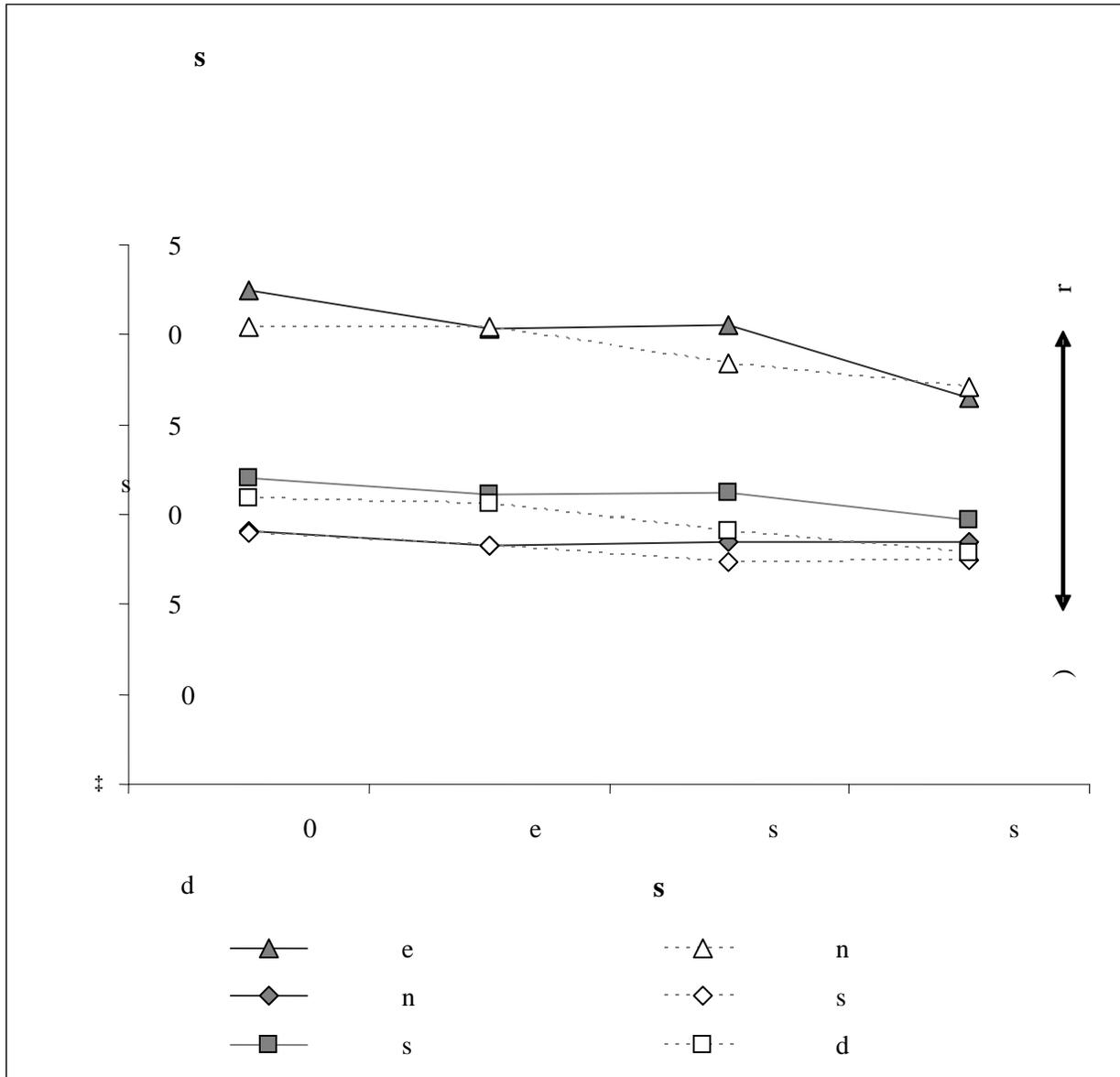
For 89 of the caregiver/client pairs we knew the age of each person. Among those whose ages were known, 33% of the caregivers were age 65 and older, and 16% were 75 and older. Almost all (97%) of the clients were 65 and older and 43% were 85 and older. In 33% of the caregiver/client pairs each person was 65 and older (not in the table).

Results of the outcome evaluation: The number of caregivers interviewed declined with each subsequent interview. Of the 95 caregivers receiving Companion services at baseline, we had 3-month follow up interview information for 63 caregivers: 28 with CCP services and 35 in the comparison group. The most common reason for termination from the study between the baseline and 3-month interview was that the person with Alzheimer’s died (8 of 19 terminations). (The most common reason between the 3-month and 6-month interview was that the person with Alzheimer’s entered a facility (12 of 17 terminations).) Due to the drop off in the number of caregivers participating at 6 months, we focused on the changes between baseline and three months in the statistical analysis of the outcome measures.

As noted above, the two groups of caregivers were similar at baseline to each other in terms of burden, stress, and depression.

The program had a mixed impact on the caregivers. The only measure with a statistically significant difference was the measure for objective burden – the average caregivers’ burden declined more after three months than the average for the comparison group (Figure 2). The average scores for the measures of caregiver burden improved in both groups over nine months; the average scores for depression did not show any clear cut pattern of change (Figure 3). However, none of these other measures showed any statistically significant differences in the changes between the groups with and without CCP services over time.

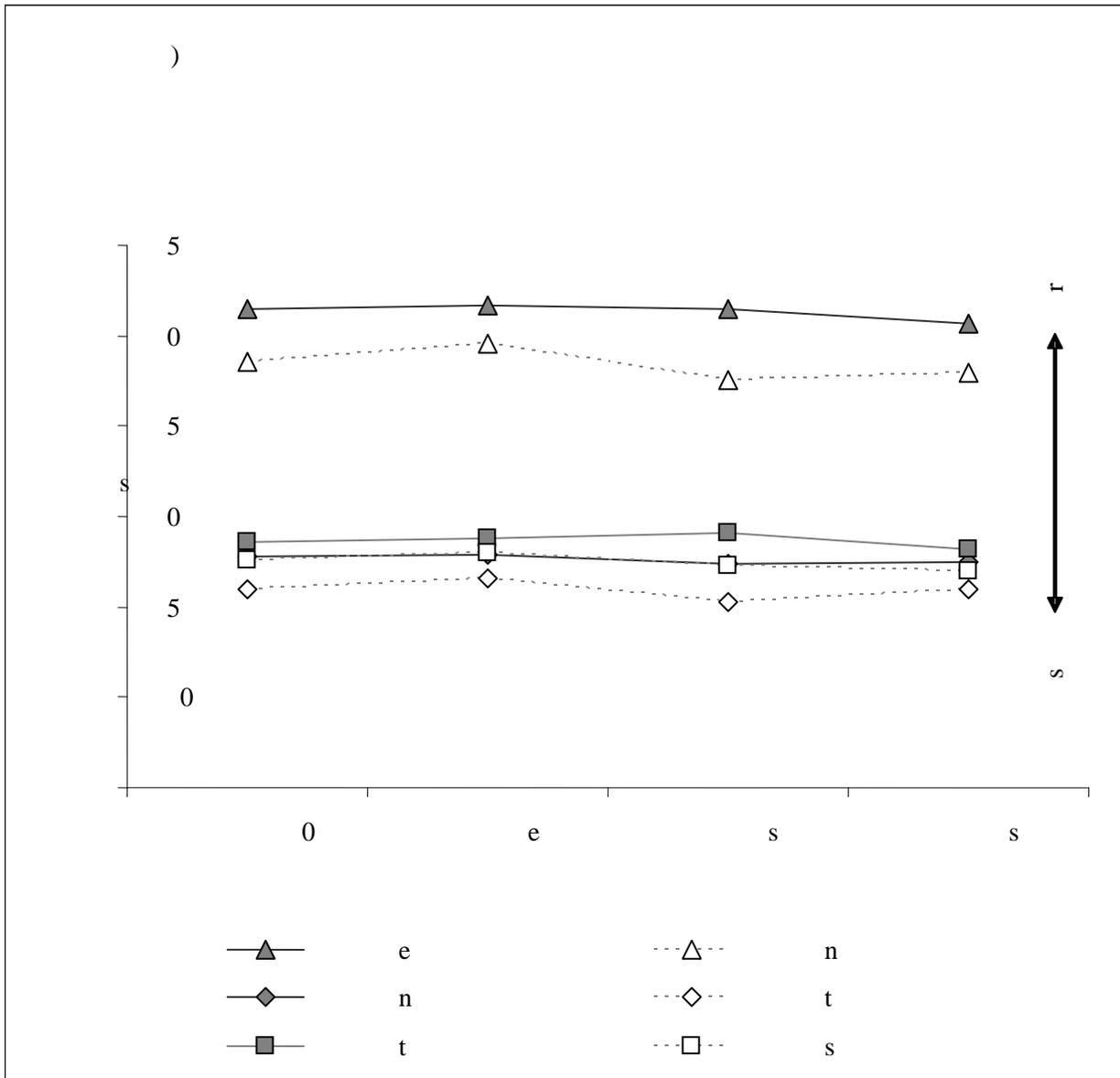
Figure 2



‡ Objective burden scores can range from 10 to 30. Subjective Stress and Subjective Demand scores can range from 4 to 20.

* Statistically significant difference (at $p < .05$) between the change for the caregivers with Companion services compared to the change for caregivers without Companion services.

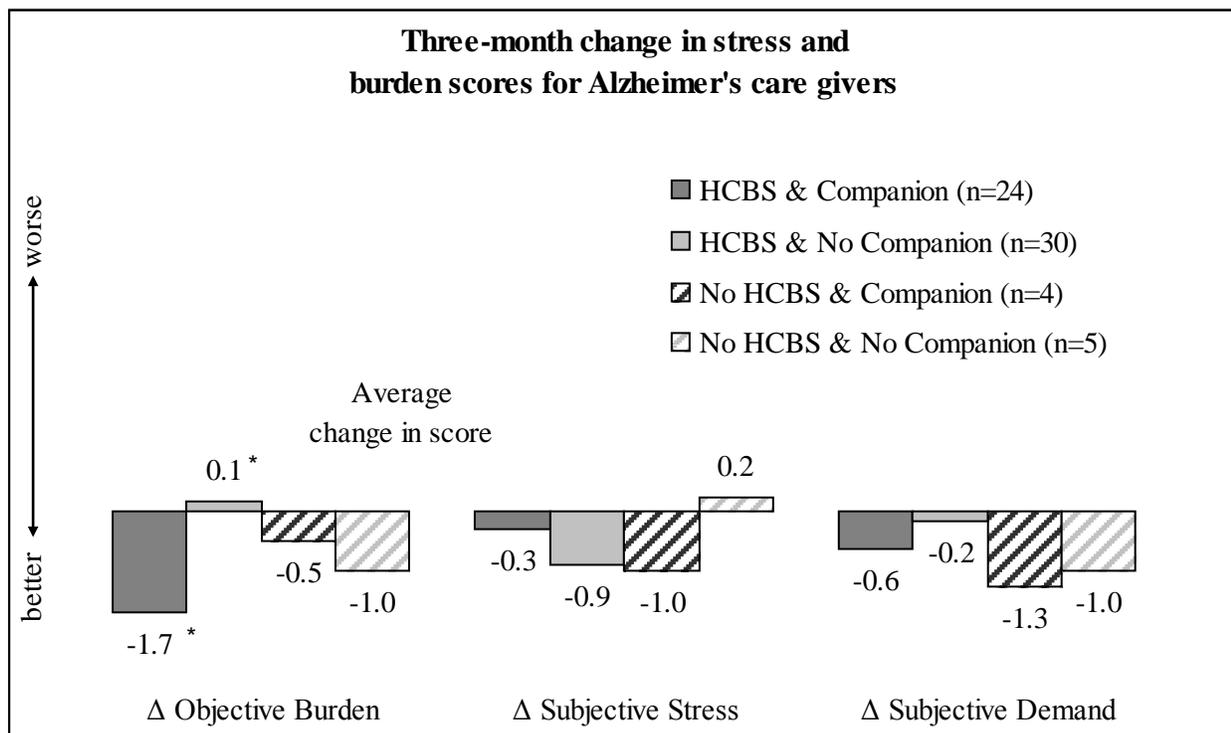
Figure 3



‡ Total depression scores can range from 10 to 50. Depressive Affect and Somatic Symptom scores can range from 5 to 25.

The caregivers who benefited most from the CCP were caring for clients who received home-and-community-based services (Figure 4). They had significantly better improvement in objective burden at 3 months compared to the caregivers who did not receive CCP and the client received HCBS ($p<.05$). There were no significant differences in improvement in objective burden in the other groups. The 24 caregivers who received CCP services who cared for people who received HCBS also had the biggest improvement in the three measures of depression, but the differences between this group and the others were not statistically significant.

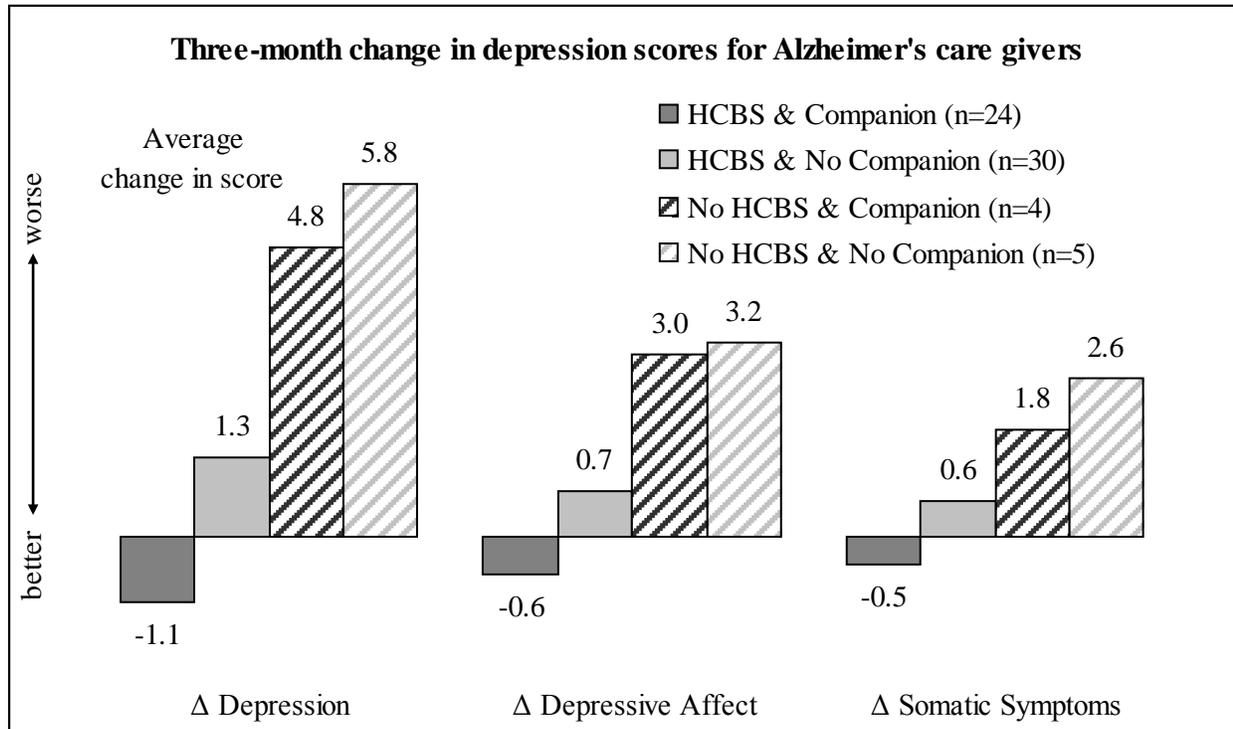
Figure 4



‡ Objective burden scores can range from 10 to 30. Subjective Stress and Subjective Demand scores can range from 4 to 20.

* Significant at the $p<.05$ level.

Figure 5



‡‡ Total depression scores can range from 10 to 50. Depressive affect and Somatic symptom scores can range from 5 to 25.

By the ninth month slightly more clients in the group without CCP services had entered a nursing facility compared to the clients with CCP services (18.9% vs. 16.7%) (Table 6). By 15 months, the difference was even greater: 24.5% of the clients without CCP services had entered a nursing facility compared to 16.7% of the clients with CCP services. These differences were not statistically significantly different, but they suggested directions for exploration in the future.

Table 6. Number of study participants with Alzheimer's Disease who entered a nursing facility during the study

Cumulative number of persons entering nursing facility, by quarter					
During quarter	Cumulative number		Percent of all participants		
	Companion	No Companion	Companion	No Companion	
1st		1	2	2.4%	3.8%
2nd		2	5	4.8%	9.4%
3rd		7	10	16.7%	18.9%
4th		7	12	16.7%	22.6%
5th		7	13	16.7%	24.5%
<i>Never</i>		35	41	83.3%	77.4%

Number of persons entering nursing facility, by quarter					
During quarter	Number		Percent of all participants		
	Companion	No Companion	Companion	No Companion	
1st		1	2	2.4%	3.8%
2nd		1	3	2.4%	5.7%
3rd		5	5	11.9%	9.4%
4th		0	2	0.0%	3.8%
5th		0	1	0.0%	1.9%
		1	2		
Sub-total	7	13	6.7%	4.5%	
<i>Never</i>		35	40	83.3%	75.5%
Total		42	53	100.0%	100.0%
Total		42	53	100.0%	100.0%

Summary and discussion

The CCP is an extremely innovative program that is well-suited to rural areas that lack support services for caregivers of people with Alzheimer’s disease. The caregivers involved in the CCP demonstration project had scores indicating high levels of stress, burden, and depression at the start of the program, and many of them were not in good health or were among the “oldest old.” The CCP was greeted enthusiastically by the caregivers and the Companions.

Research shows that interventions can improve caregiver’s quality of life, such as caregiver burden, mood, and perceived stress, and that caregivers with a high level of depressive symptoms can achieve clinically significant outcomes.¹³ Specific factors that may be of interest when targeting interventions that address

caregiver depressive symptoms can include caregiver health and dealing with problem behaviors. There is a strong consensus that enhanced information about the disease, the caregiver role, and resources available will benefit caregivers.¹³ Interventions that address caregiver's emotional response to caregiving are also beneficial.¹³

The CCP would seem to be ideally suited to the rural Maine areas in which it was piloted and to the caregivers who received the Companion services. However, the results of this evaluation are disappointing. While it is true that after three months the CCP showed a statistically significant impact on the caregivers' measure of objective burden, there was no significant difference between caregivers with and without CCP services in the other measures of stress, burden, or depression.

What can we learn from the results? The small numbers of caregivers in the sample and the attrition of clients from the study over time may have contributed to the lack of statistical significance observed. The study was probably underpowered to detect significant differences due to the intervention, the CCP, which produced very small effects. The number of caregivers included was limited by the number eligible for the study in the counties included in the demonstration project. In addition, after the study design was developed a waiting list developed for home and community based services, which resulted in an altered research design. In some instances, caregivers received CCP but the client with Alzheimer's disease received no HCBS. During the course of the study, many of these individuals came off the waiting list and began receiving services, making it impossible to determine if the CCP services affected caregiver stress, burden or depression, or if the onset of services caused a change. Also, it may be that we did not measure the right outcomes and that other measures of caregiver well-being would show improvements attributable to the CCP over time.

Two of the results have implications for future work. First, as noted above, the caregivers with Companion Services of clients who received home-and-community-based services had an improvement in objective burden, but the other caregivers did not. The CCP services alone were not enough to reduce the burden and depression of people caring for clients with Alzheimer's who are eligible for HCBS. This is not surprising,

given the demands placed on the caregivers by the clients' needs, functional limitations, and behavior, and by the advanced age of many of the clients and their caregivers. The caregivers spent an average of 18 hours a week on meal preparation, laundry, and light housework and an average of 12 hours a week on helping the client with activities of daily living. Three fourths had to deal with the client's incontinence during the week and half with clinging or following behavior. These levels of care were over and above the HCBS assistance that two thirds of the clients received. This result suggests that whether or not the caregiver received HCBS should be a variable that is included in future evaluations. Second, the clients of caregivers receiving CCP services were less likely to be admitted to a nursing facility during the study period and up to 6 months afterwards. It suggests that future evaluations of programs like this could include measures of use of long-term care services and the associated costs of such services. The CCP may have financial benefits to MaineCare in addition to any psychosocial benefits the caregivers may receive.

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Endnotes

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