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## One Extra Month of Depression: The Effects of Caregiving on Depression Outcomes in the IMPACT Trial

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### Abstract

**Background**—Depression occurs in 5–10% of older adults and there are nearly 6 million informal caregivers aged 65 or older. Prior research has focused on vulnerability to psychological distress in caregivers. Research has not addressed the caregiving burden of depressed elderly patients or how that burden affects depression treatment outcomes.

**Aims**—To describe the caregiving burden in a large, representative cohort of depressed elderly patients and compare depression treatment outcomes between caregivers and non-caregivers.

**Methods**—Univariate and multiple regression analyses were performed comparing 24-month depression outcomes (measured as depression free days) in those providing care at any time over the 24-month trial to those who never reported a caregiving burden.

**Results**—At 3, 6, 12, 18, and 24 months, nearly 10% of cohabitating elderly depressed patients provided care for basic activities such as bathing or dressing while nearly 20% reported providing care for other activities such as making phone calls or taking medication. Over 24 months, after adjusting for marital status, intervention status, and number of medical comorbidities, those reporting any caregiving burden had over 30 more days with depression compared to those with no caregiving burden. The IMPACT collaborative care model did not modify the effect of caregiving on depression outcomes.

**Conclusion**—Caregiving is common in depressed older adults and appears to affect response to depression treatment. In the future, interventions for depressed older adults should consider and specifically address caregiving activities in addition to specific depression treatment.

### Keywords

Depression; Elderly; Caregiving; IMPACT

### Introduction

A recent national survey estimated there are 44.4 million informal adult caregivers in the US. About 5.8 million of those caregivers (13%) were over 65 years of age. (NAFC and AARP, 2004) Research has shown that caregivers of family members with dementia experience higher rates of psychological and physical problems than non-caregivers. (Schulz et al., 1995, Schulz and Martire, 2004) In general, those who care for the disabled elderly develop depressive symptoms at twice the rate of non-caregivers. (Alexopoulos, 2005) and are significantly more likely than non-caregivers to meet criteria for an affective or anxiety disorder. (Cochrane et al., 1997) An analysis of the longitudinal Health and Retirement Study found that caregiving

was a predictor of a higher number of depressive symptoms in men and women. (Choi and Bohman, 2007) Stress associated with caregiving may also affect physical health. The Caregiver Health Effects Study found that, after adjusting for sociodemographic and physical health factors, stressed caregivers had a 63% higher mortality risk compared to those who did not have caregiver stress over a four year follow-up period. (Schulz and Beach, 1999)

Depression occurs in 5–10% of older adults seen in primary care settings. (Oxman et al., 1990, Lyness et al., 1999, Schulberg et al., 1999) This common illness leads to poor functioning, lower quality of life, increased health service utilization, poor medical outcomes, and premature death. (Penninx et al., 2001, Callahan et al., 1994, Unutzer et al., 2000, Penninx et al., 1999). Several studies have shown that collaborative care interventions in primary care are effective models to improve the outcomes of older depressed patients. (Unutzer et al., 2002, Bruce et al., 2004) Nonetheless, there are still major areas we must understand to continue to improve the care of older patients with depression. One such area is the extent to which older depressed patients have additional stress due to caregiving responsibilities and whether that caregiving burden requires an intervention above and beyond that focused on depression. We were not able to find studies addressing either the extent of caregiving burden in older depressed adults or how such a burden affected depression treatment outcomes.

This study describes caregiver burden in the large cohort of depressed elderly patients from the IMPACT (Improving Mood, Promoting Access to Collaborative Treatment for late-life depression) trial. In addition, it will test the hypothesis that a caregiving burden reduces the effectiveness of a collaborative care program for depression.

## Patients and Methods

### Overview

The IMPACT trial studied a cohort of 1,801 elderly depressed patients from 18 primary care clinics in eight diverse health care organizations in the US. The clinics were affiliated with diverse health care organizations that included VA clinics, University affiliated primary care practices, health maintenance organizations (HMO's), and private group practices. Study participants represented 2–3% of the elderly population served by the clinics in the trial. Inclusion criteria for the study included age  $\geq 60$  years, current diagnosis of major depression and / or dysthymia based on the Structured Clinical Interview for the DSM-IV (SCID), and plans to receive medical care in the same clinic over the year following recruitment. Patients were excluded if they had current alcohol abuse, a history of bipolar disorder or schizophrenia, ongoing treatment by a psychiatrist, severe cognitive impairment, or a high acute risk for suicide. (Unutzer et al., 2001) The Institutional Review Boards from each participating organization and the study coordinating center approved the study procedures and all patients signed informed consents. None of the authors have any financial conflicts of interest that would bias this work.

### Intervention

The collaborative IMPACT intervention was provided by a team including the patient's primary care doctor, a depression care manager (DCM), and a supervising psychiatrist. Patients in the usual care group and their physicians were notified that the patient met research diagnostic criteria for major depression and / or dysthymia and were free to use any type of medical or specialty mental health care.

## Survey Data

All participants were assessed independently, prior to random assignment at baseline, and at 3, 6, 12, 18, and 24 months after study enrollment. Details of the independent assessment procedures have been reported elsewhere. (Unutzer et al., 2001)

## Caregiving Data Measure

Caregiving for 'basic needs' and 'other activities' was assessed at each interview for the 1,152 participants who reported living with someone at the time of the baseline interview. Each subject was asked if someone in the home required care and if he or she provided any of that care over the last month (see Table 1 for questions). Subjects reporting any amount of caregiving over the past month either at baseline or any of the 5 follow-up assessments were considered 'caregivers' for this study. 'Basic needs' caregivers provided help with dressing, eating, or bathing. 'Other activities' caregivers provided help with hot meals, shopping for groceries, making telephone calls, getting to the doctor, or taking medications.

## Outcome Measures

The primary study outcome was severity of depression measured by the 20 depression items from the Hopkins Symptom Checklist (HSCL-20). (Derogatis et al., 1973). A 50% decrease from baseline of the HSCL-20 score represents a treatment response while a score  $< 0.5$  represents a complete remission of depressive symptoms. For this analysis, the HSCL-20 was used to calculate the number of depression free days (DFDs) over the 2-year study period. This calculation is based on an approach developed by Lave (Lave et al., 1998) and modified for use with the HSCL-20 by Simon. (Simon et al., 2002) With this method, patients with an HSCL-20 score  $< 0.5$  are assumed to have one completely depression free day (DFD) and patients with an SCL score  $\geq 1.7$  (the mean baseline HSCL-20 score of study participants) are assumed to have zero DFD's. Scores between 0.5 and 1.69 are weighed proportionately (i.e. a score of 1.1 is considered one half of a DFD as it is half way between 0.5 and 1.7). The calculation of total DFDs for any given period uses the DFD estimate based on the HSCL-20 scores from two adjacent assessment points multiplied by the number of days during this period.

## Statistical Analysis

We conducted univariate analyses using linear regression models to compare the 24-month depression-free days of caregivers to non-caregivers. Baseline variables significantly associated with caregiving at the  $p < .05$  level were entered jointly into multiple linear regression models along with the care-giving variable and randomization status. Missing values in this data set had been previously imputed using an extended hot deck multiple imputation technique that modifies the predictive mean matching method to impute item-level missing data. (Tang et al., 2005, Little and Raghunathan, 1999) This method involved developing 5 imputed data sets. Rates of item level missing data were less than 2% for all variables discussed in this article. All the statistics were first computed within each data set and then were combined according to the formula suggested by Rubin. (Rubin, 1987) All the analyses were performed using SAS 9.1 (SAS Institute Inc., Cary, NC). We performed logistic regression models and linear regression models under the PROC MIANALYZE procedure to examine the unadjusted as well as adjusted association between care-giving and 24-month depression-free days on the 5 multiply imputed data sets. The testing statistic followed a t distribution for both continuous and binary variables.

## Results

Table 2 presents the prevalence of 'basic needs' and 'other activities' caregiving at baseline and each follow-up interview. At each follow-up, about 10% of subjects reported providing

basic needs caregiving while 20% reported providing care in the home care for other activities. We compared demographic measures, number of medical comorbidities, and baseline depression scores for those who reported any caregiving burden over the 24-month trial to those who never reported such a burden (Table 3). Married subjects were more likely to provide care for other activities than those not married. Elderly depressed patients reporting any type of caregiving burden (for basic needs or other activities) over the course of the trial had higher average baseline HSCL-20 scores than their counterparts that had no such burden. Table 4 presents unadjusted 24-month DFD outcomes comparing caregivers to non-caregivers. Subjects reporting any type of caregiving burden over the 24 months of the IMPACT trial had, on average, over 30 more days with depression compared to those reporting no caregiver burden.

### Regression Results

A multiple regression analysis was performed for each of the four independent variables listed in Table 4. The dependent variable was number of depression free days over 24 months. Each analysis controlled for intervention status, marital status, and number of chronic illnesses reported. For each analysis, an interaction between caregiving burden and intervention was tested but was not found to be significant. Table 5 presents the coefficient estimates for each independent caregiving variable. The regression analysis results are similar to those of the unadjusted analysis presented in Table 4. Namely, after adjusting for intervention, marital status, and number of medical comorbidities, patients reporting a caregiving burden have, on average, over 30 fewer depression free days than those with no caregiving burden.

### Discussion

Current caregiving research has focused on the prevalence and risk factors for psychiatric and physical distress in those providing care for others with illnesses such as dementia, stroke, heart disease, and HIV. The psychological problems are described as being caused by the caregiving burden and intervention programs have shown some success at limiting that distress. (Burns et al., 2003, Douglas et al., 2005). We did not find research addressing the extent of caregiving burden in older depressed adults or how that caregiving affects depression treatment outcomes.

The IMPACT trial followed a representative sample of 1,801 elderly depressed patients over two years. Using data from this trial, we found that almost one out of every ten elderly patients with depression reported providing care for basic activities such as dressing, eating or bathing, and one out of every five elderly patients with depression reported providing care for activities such as food preparation, making phone calls, or taking medicine. After adjusting for intervention status, medical comorbidities, and marital status, elderly depressed subjects with any type of caregiving burden at any time over the two years of the trial experienced, on average, over one more month of depression compared to those subjects with no caregiving burden. No interaction was found between caregiving stress and whether a subject was receiving the IMPACT intervention. This indicates that the relative effect of caregiving on depression over two years was similar in depressed subjects treated in usual care and in those treated in the IMPACT intervention program.

Caregiving is a common occurrence in older patients with depression and this study adds to caregiving research by suggesting that depressed patients with caregiving burdens have higher initial severity of depression and less response to treatment compared to older depressed patients without caregiving burdens. Depressed patients with comorbid psychiatric or medical problems have also been shown to have more chronicity and less responsiveness to treatment. (Iosifescu et al., 2004, Johnson et al., 2005, Kessing, 2003, Lin et al., 1998, Wilhelm et al., 1999) Of course, caregiving is not a disease. It is often a necessary part of life that older patients accept and carry out with dignity. However, caregiving in older adults, especially those

suffering from depression, must be taken into account when considering interventions for depression treatment. Future research should attempt to understand the mechanisms of the relationship of caregiving to increased depression severity and intervention studies should attempt to systematically address caregiving to help reduce the additional depression burden experienced by caregivers.

Our study has several limitations. First, we do not have detailed information about the nature of caregiving provided. We also do not have detailed information about the balance of providing care and receiving care because many older adults are not simply caregivers or care recipients but may be both. The survey did not ask participants who reported living alone about caregiving but it is quite possible that such individuals also perform caregiving duties. As such, we cannot generalize from our findings to those living alone.

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**Table 1**

## Caregiving Questions in IMPACT Trial

<b>Basic Needs Caregiving Questions</b>	<b>Response</b>
<b>1. Does anyone in your household require help with basic personal needs such as dressing, eating, or bathing?</b>	1. Yes 2. No 3. Do not know 4. Refuse
<b>2. How often in the last <u>month</u> did you provide help with basic personal needs?</b>	1. Every day 2. Several times a week 3. About once a week 4. Less than once a week 5. Not at all 6. Do not know 7. Refuse
<b>Other Activity Caregiving Questions</b>	<b>Response</b>
<b>1. Does anyone in your household require help with other activities, such as preparing hot meals, shopping for groceries, making telephone calls, getting to the doctor, or taking medications?</b>	1. Yes 2. No 3. Do not know 4. Refuse
<b>2. How often in the last month did you provide help with such activities?</b>	1. Every day 2. Several times a week 3. About once a week 4. Less than once a week 5. Not at all 6. Do not know 7. Refuse

**Table 2**

Caregiving Prevalence at Each Follow-Up Interview

	<b>Baseline</b>	<b>3 Months</b>	<b>6 Months</b>	<b>12 Months</b>	<b>18 Months</b>	<b>24 Months</b>
Basic Needs (BN)	83 (7%)	98(9%)	105(9%)	98(9%)	106(10%)	99(10%)
Other Activity (OA)	152(13%)	217(19%)	208(19%)	199(18%)	193(18%)	183(18%)



Table 3 Demographic Comparisons between Caregivers and Non-caregivers: 24 Month Caregiving Data

		Ever Provides Caregiving for Basic Needs? <sup>1</sup>		p	Ever provides Caregiving for Other Activities? <sup>1</sup>		p
		Yes	No		Yes	No	
Age	Mean (SE)	70.71 (.49)	70.68 (.23)	.949	70.53 (.38)	70.78 (.28)	.633
Female	Yes	166	668	.512	289	548	.172
	No	113	407		200	321	
White	Yes	222	803	.132	370	657	.927
	No	58	273		119	213	
HS Graduate	Yes	226	854	.597	394	688	.601
	No	53	222		95	182	
Married	Yes	180	634	.143	330	483	<.001
	No	100	441		159	386	
Baseline HSCL=20 score	Mean (SE)	1.35 (.05)	1.22 (.03)	.022	1.31 (0.03)	1.20 (0.03)	.012
Number of Chronic Conditions	Mean (SE)	3.76 (.12)	3.75 (.06)	.929	3.78 (0.10)	3.74 (0.07)	.762

<sup>1</sup> Answering "yes" at any interview point over the 24 months of the trial

**Table 4**  
24 Month Depression Free Days and 24 Month Caregiving Burden

		N	Yes	N	No	p-value
0–24 month: Ever Provided Basic Needs (BN) Caregiving	DFD	279	297.3 (13.4)	1075	331.0 (7.2)	0.034
0–24 month: Ever Provided Other Activity (OA) Caregiving	DFD	489	301.1 (11.2)	870	336.9 (7.9)	0.014
0–24 month: Ever Provided <b>Either</b> BN or OA Caregiving	DFD	539	301.9 (10.5)	819	338.6 (8.2)	0.010
0–24 month: Ever Provided <b>Both</b> BN or OA Caregiving	DFD	229	294.6 (15.5)	1130	329.9 (7.1)	0.043

**24 Month DFD Regression Results**  
 24 month caregiving status adjusted for treatment intervention, marital status, and number of comorbid illnesses.

**Table 5**

Independent Variable	$\beta$ estimate	SE	95%CI	t-statistic	p-value
1) EverCCBN24 <sup>1</sup>	-33.0	13.6	(-61.3, -4.9)	-2.41	.0233
2) EverCGOA24 <sup>2</sup>	-36.3	12.4	(-62.4, -10.2)	-2.91	0.0089
3) EverCGOR24 <sup>3</sup>	-35.7	11.9	(-60.5, -10.8)	-2.99	0.0070
4) EverCGAND24 <sup>4</sup>	-37.2	15.5	(-69.3, -5.1)	-2.41	0.0251

- <sup>1</sup> Ever provided basic needs caregiving over the 24 month trial
- <sup>2</sup> Ever provided other activities caregiving over the 24 month trial
- <sup>3</sup> Ever provided *either* basic needs or other activities caregiving over the 24 month trial
- <sup>4</sup> Ever provided *both* basic needs and other activities caregiving over the 24 month trial