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Spousal wellbeing and patient utilization

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1 **Abstract:**

2 **Background/Objectives:** Disabled older adults are a high-cost population often relying on  
3 spouses for caregiving. We aim to measure the association of spousal depression, general health,  
4 fatigue and sleep with patient future healthcare expenditures and Emergency Department (ED)  
5 utilization.

6 **Design:** Prospective cohort study.

7 **Setting/Participants:** 3,101 home-dwelling spousal dyads where one individual (“patient”) is age  
8  $\geq 65$  with  $\geq 1$  disabilities in activities of daily living or instrumental activities of daily living and  
9 enrolled in Medicare Part B within the Health and Retirement Study.

10 **Exposure:** Caregiver sleep (Jenkins Sleep Scale), depressive symptoms (Center for  
11 Epidemiological Studies Depression-8 Scale), and self-reported general health measures.

12 **Measurements:** Primary outcome was patient Medicare expenditures. Secondary outcome was  
13 patient ED utilization. Follow-up was 6 months.

14 **Results:** Caregiver depressive symptoms score and 6 of 17 caregiver wellbeing measures were  
15 prospectively associated with higher patient expenditures after minimal adjustment ( $p < 0.05$ ).  
16 Higher patient expenditures remained significantly associated with presence of caregiver fatigue  
17 (cost increase, \$1,937 [95% CI, \$770-\$3,105]) and caregiver sadness (cost increase, \$1,323 [95%  
18 CI, \$228-\$2,419]) after full adjustment. Four of 17 caregiver wellbeing measures, including  
19 severe fatigue, were significantly associated with patient ED utilization after minimal adjustment  
20 ( $p < 0.05$ ). Greater odds of patient ED utilization remained significantly associated with caregiver  
21 fatigue (odds ratio, 1.24 [95% CI, 1.01-1.52]) and caregiver fair/poor health status (odds ratio,  
22 1.23 [95% CI, 1.04-1.45]) after full adjustment. Caregiver total sleep score was not associated  
23 with patient outcomes.

24 **Conclusions:** Poor caregiver wellbeing, particularly severe fatigue, is independently and  
25 prospectively associated with higher patient Medicare expenditures and ED utilization.

26

**27 Background:**

28       As the population of adults age 65 years and older in the United States is predicted to rise  
29 from 14.9% in 2015 to 22.1% in 2050,<sup>1</sup> supporting community-dwelling aging adults is critical.<sup>2</sup>  
30 One key component of this support is the presence of informal caregivers, who support an  
31 estimated 14.7 million Americans,<sup>3</sup> and are growing in number over the last decade.<sup>4</sup> Given the  
32 common and critical role of the caregiver, a growing body of literature has explored the health  
33 impact of caregiving—both positive and negative—on the caregiver. While caregiving itself may  
34 have health benefits,<sup>5,6</sup> caregiver wellbeing may deteriorate if caregiver strain or burnout  
35 develops.<sup>7,8</sup> Several pathways have been proposed that link patient illness and exposure to high-  
36 intensity medical care at the end of life to poor caregiver health and increased caregiver  
37 healthcare utilization.<sup>9-11</sup> In addition, the extent of patient suffering has been identified as an  
38 additional risk factor for caregiver strain.<sup>12</sup>

39       While patient illness and utilization are risk factors for poor caregiver wellbeing, the  
40 reverse may also be true: that poor caregiver wellbeing could contribute to higher patient  
41 healthcare utilization in a causal fashion through several possible mechanisms. Caregiving  
42 demands may contribute to more physical and mental impairment in the caregiver,<sup>9</sup> resulting in  
43 the inability to keep up with caregiving demands, which may worsen the patient's health  
44 requiring medical attention and leading to additional healthcare expenditures. In addition,  
45 caregivers with poor wellbeing such as severe fatigue may be more prone to burnout and thus  
46 decreased capacity to provide care,<sup>12-15</sup> leading to reliance on the health system and Emergency  
47 Department in particular as a source of respite, commonly described by clinicians as the “Pop  
48 drop”. Complicating these hypothesized pathways is the potential for reverse causality. Either  
49 high patient treatment intensity<sup>16</sup> or the emotional impact of worsening illness<sup>8,9</sup> may result in  
50 both poor caregiver wellbeing and higher patient utilization, thus confounding the association.  
51 Therefore, longitudinal measurements of caregiver wellbeing and spousal patient utilization are  
52 necessary to elucidate the association.

53       Even in the absence of a causal association, there is a great need to identify factors  
54 associated with higher future patient utilization, especially potentially burdensome utilization  
55 such as Emergency Department visits. Patient factors that are not captured by traditional claims-  
56 based risk models have been showed to predict hospital readmissions<sup>17</sup> as well as utilization and  
57 mortality better than claims-based approaches.<sup>18</sup> For older adults with functional impairment, it

58 is possible that caregiver factors such as wellbeing predict utilization as well. If this is true,  
59 screening for poor caregiver wellbeing and offering targeted supports has the potential to reduce  
60 future patient utilization as well as improve caregiver health and outcomes.

61 The Health and Retirement Study (HRS) provides a unique opportunity to study these  
62 phenomena as both individuals in spousal pairs are enrolled in this longitudinal cohort study.<sup>19</sup> In  
63 this analysis, we tested the association of caregiver symptoms of wellbeing with patient  
64 utilization using data on these spousal caregiver and care recipient (“patient”) dyads. To help  
65 account for the possibility that patients’ healthcare utilization might drive caregiver distress, we  
66 determined patient healthcare utilization *following* the caregiver assessment, adjusting for the  
67 patients’ previous six months of utilization.

68

### 69 **Methods:**

70 This study used Medicare-linked data from the HRS between 2000 and 2012. The HRS is  
71 a nationally-representative longitudinal panel study in the U.S. designed to assess wellbeing and  
72 disability in respondents age 51 and older through biennial surveys. HRS also enrolls the spouses  
73 of all respondents, which allows for spousal dyads to be examined. Proxy respondents were  
74 interviewed where sampled participants are unable to complete the survey. HRS has baseline  
75 response rates of 70% to 82% with re-interview rates of 90%.<sup>20</sup> HRS respondents were asked for  
76 permission to release their Medicare claims, which are then linked to their survey responses.

### 77 *Study population:*

78 This study included 8,785 HRS observations of respondents from 2000-2012 who were  
79 home dwelling, ADL or IADL disabled, residing with a spouse and alive 6 months after  
80 interview. ADLs were defined as bathing, dressing, eating, toileting, walking, or transferring in  
81 and out of bed and IADLs were defined as grocery shopping, cooking, making telephone calls,  
82 managing money or taking medications. Of these, 463 (5.3%) were excluded as they did not  
83 consent to Medicare linkage or had failed linkage and 2,362 (26.9%) were excluded as they did  
84 not have continuous Medicare Fee-for-Service coverage the 6 months before and after surveying,  
85 which resulted in 5,960 observations.

### 86 *Study variables:*

87 The primary dependent variable was patient Medicare expenditures during the 6 months  
88 following the spousal caregiver HRS survey. We adjusted expenditures to 2012 US dollars using

89 the medical Consumer Price Index.<sup>21</sup> The secondary outcome was patient ED utilization, defined  
90 as the count of ED visits.

91 Prior work has demonstrated that wellbeing measures that capture depressive symptoms,  
92 sleep symptoms, and self-reported health status have all been associated with caregiver strain in  
93 this population.<sup>22-24</sup> Given that there is no composite scale of caregiver wellbeing in the HRS,  
94 these wellbeing measures were instead used. Primary independent variables were therefore the  
95 eight-item (yes/no) Center for Epidemiological Studies Depression Scale (CES-D-8);<sup>25</sup> four  
96 items of the Jenkins Sleep Scale,<sup>26</sup> with responses classified as 0 “rarely or never,” 1  
97 “sometimes,” or 2 “most of the time”; a single-item severe fatigue item (yes/no); and the  
98 validated single-item general self-rated health item,<sup>27</sup> which was dichotomized into fair/poor vs.  
99 good/very good/excellent. Within the HRS, the CES-D-8 items were not surveyed in the case of  
100 a proxy respondent. These measures have all been validated in an older adult population.<sup>25,27,28</sup>

101 The CES-D-8 and Jenkins sleep scale have been demonstrated to contain multiple  
102 dimensions in prior psychometric analysis in our cohort of caregivers.<sup>29</sup> Therefore, we tested the  
103 effect of the total CES-D-8 score, total Jenkins sleep scale score as well as individual measures  
104 comprising these scales on the 2 patient outcomes.

105 All models adjusted for either patient total Medicare expenditures or ED visits in the 6  
106 months prior to the patient HRS survey depending on whether the outcome variable was  
107 expenditures or ED visits, respectively. All models also adjusted for caregiver age, sex, and  
108 proxy-respondent status. Other covariates included caregiver race (white, black or other), net  
109 worth, education level, and presence of children residing within 10 miles to help account for  
110 support for the caregiver. We also included the number of ADL/IADL impairments and the  
111 presence of cognitive impairment for both patient and caregiver as determined by the Langa-  
112 Weir method which includes cognitive measures assessed within the HRS.<sup>30</sup> Final models  
113 additionally included whether or not the spouse assisted with the patients’ impaired ADL(s).

#### 114 *Statistical analysis:*

115 Descriptive statistics, adjusting for survey weights and design, were used to compare the  
116 observations of spouses and patients in identified dyads. Separate models were constructed to  
117 assess the effect of each caregiver wellbeing measure on total healthcare expenditures and  
118 numbers of ED visits in the following six months. Because both expenditures and ED visits have  
119 a high concentration of observations with a value of zero and a skewed distribution, two-part

120 models were used.<sup>31-33</sup> The first part was a multilevel mixed effects logistic regression for any  
121 expenditures vs. no expenditures and any ED use vs. no ED use, accounting for multiple  
122 observations for individuals. The second part of each model was a mixed effects generalized  
123 linear regression model with a gamma distribution and log link to assess the effect of caregiver  
124 wellbeing characteristics on greater expenditures or greater ED use for those with non-zero  
125 values. Therefore, two separate statistics describe both expenditures and ED utilization.

126 The first minimally adjusted models adjusted for patients' prior 6 month expenditures or  
127 ED visits, proxy status, caregiver age and sex. Prior 6 month expenditures or ED visits were  
128 included to isolate the association between caregiver wellbeing and future expenditures given the  
129 potentially bidirectional relationship.<sup>9</sup> For those caregiver characteristics with significant  
130 ( $p < 0.05$ ) associations, fully adjusted models were built that included all demographic,  
131 socioeconomic, functional and cognitive covariates of the patient and caregiver. Given that  
132 multiple caregiver wellbeing characteristics were tested, the Bonferroni method was used to  
133 adjust p-values used to determine statistical significance. This altered the threshold for statistical  
134 significance from  $p < 0.05$  to  $p < 0.01$ . This is considered a more conservative approach to adjust  
135 for multiple comparisons.<sup>34</sup>

136 In order to elucidate whether the association between spousal wellbeing and patient  
137 utilization was driven by cohabitation vs. caregiving, one final analysis step was performed. For  
138 all fully-adjusted models that remained statistically significant to a threshold of  $p < 0.01$ ,  
139 interaction effects were assessed between the wellbeing characteristic and whether or not the  
140 spouse assisted the patient with impaired ADLs. All analysis was done using Stata 14.0  
141 software.<sup>35</sup>

142

### 143 **Results:**

144 There were 3,101 patient-caregiver dyads with 5,960 observations (mean number of  
145 observations 1.83, median 1, range 1-7). Given the longitudinal nature of the HRS, some dyads  
146 were observed multiple times. Table 1 shows that the patient and spouse in each dyad were  
147 similar in age, race and education, although patients were more likely to be male and have higher  
148 degrees of functional and cognitive impairment.

149 The mean adjusted healthcare expenditures for the cohort of functionally-disabled home-  
150 dwelling patients for the 6 months following assessment were \$8,751 (standard deviation \$226).

151 There were 311 observations (5.2%) that had zero expenditures in the 6 months following HRS  
152 assessment and 4,539 observations that had no ED visits over this time (76.2%). Mean number  
153 of ED visits the 6 months following HRS assessment was 0.39.

154 Caregiver wellbeing measures did not predict whether patients had any healthcare  
155 expenditures (See Table 1a in appendix). However, among patients who did incur Medicare  
156 costs (94.8% of observations), caregiver total CES-D score and 6 of 17 individual caregiver were  
157 significantly associated with higher patient healthcare costs after adjusting for prior expenditures,  
158 age, sex, and proxy status ( $p < 0.05$ ) (Table 2). Specifically, caregiver reports of feeling depressed,  
159 sad, and severe fatigue were associated with higher patient utilization costs; conversely,  
160 caregiver reports of feeling happy and rested were associated with lower patient costs. The total  
161 Jenkin's sleep scale, and the other individual caregiver measures (caregiver reports that  
162 everything takes effort, restlessness, loneliness, enjoying life, difficulty getting going, fair/poor  
163 health, trouble falling asleep, waking at night, and waking up early) were not associated with  
164 healthcare expenditures. In fully adjusted models, only caregiver sadness (coefficient, 0.13 [95%  
165 CI, 0.03-0.23];  $P = 0.01$ ) and caregiver severe fatigue (coefficient, 0.20 [95% CI, 0.08-0.32];  
166  $P = 0.001$ ) remained significantly associated with higher patient expenditures. These results  
167 remained statistically significant after adjusting for multiple comparisons. The interaction for  
168 spousal fatigue and whether the spouse assisted with ADLs/IADLs was significant at  $p = 0.02$ . As  
169 Figure 1 demonstrates, the patients of spouses who assisted with ADLs/IADLs and were fatigued  
170 had \$3,262 higher expenditures over the following 6 months than the patients of spouses who  
171 assisted with ADLs/IADLs but were not fatigued (Standard Error \$1,952-\$4,572). There was no  
172 significant difference for non-caregiving spouses reporting fatigue vs. no fatigue. The  
173 interaction term for spousal sadness and caregiving was not significant ( $p = 0.17$ ). Regardless of  
174 ADL/IADL assistance, patients with sad spouses had greater adjusted expenditures of \$1,323  
175 (95% CI, \$228-\$2,419) over the following 6 months.

176 In models predicting the presence/absence of patient ED utilization (binary outcome)  
177 (Table 3), spousal report of depression, sadness, fair/poor health and severe fatigue were  
178 significantly ( $P < 0.05$ ) associated with higher odds of the patient having an ED visit in the next 6  
179 months when adjusting for sex, age, proxy status, and ED utilization over the prior 6 months.  
180 Caregiver total CES-D score and report of trouble waking up at night were non-significantly  
181 associated with odds of the patient having an ED visit. Measures for caregiver reports that



182 everything takes effort, restlessness, happiness, loneliness, enjoying life, difficulty getting going  
183 as well as the total Jenkins sleep scale were not associated with odds of ED utilization. In fully  
184 adjusted models, caregiver fair/poor health was associated with significantly higher odds of  
185 having an ED visit (odds ratio, 1.23 [95% CI, 1.04-1.45];  $P=0.01$ ) as was caregiver severe  
186 fatigue (odds ratio, 1.24 [95% CI, 1.01-1.52];  $P=0.04$ ), although only caregiver fair/poor health  
187 was statistically significant when alpha was adjusted for multiple comparisons. An added  
188 interaction term for caregiver fair/poor health and whether or not the spouse provided ADL  
189 assistance was not significant ( $p=0.25$ )

190 In minimally adjusted models predicting the number of ED visits (continuous outcome)  
191 for the 23.8% of patients with non-zero ED use, caregiver total CES-D score and 6 of 17  
192 individual caregiver wellbeing measures were associated with number of ED visits (Appendix  
193 Table 2A). In particular, caregiver total CES-D score and reports of sadness, difficulty getting  
194 going, fair/poor health status, and severe fatigue were associated with increased number of ED  
195 visits. Conversely, decreased number of ED visits was significantly associated with caregiver  
196 reports of feeling happy and rested and non-significantly associated with caregiver report of  
197 enjoying life. After full adjustment, only caregiver report of difficulty getting going was  
198 associated with more ED visits (coefficient, 0.07 [95% CI, 0.00-0.13];  $P=0.04$ ) and this result  
199 was not statistically significant after adjusting for multiple comparisons.

200

## 201 **Discussion:**

202 The recent National Academies report highlights the dire need for increased attention and  
203 support for caregivers in the United States.<sup>36</sup> Our findings are novel in linking caregiver  
204 wellbeing to patient utilization. Even with a conservative analysis approach that adjusted for  
205 prior health care use as well as caregiver and patient characteristics, caregiver sadness and severe  
206 fatigue were significantly associated with higher expenditures in functionally disabled patients.  
207 In addition, these disabled spouses of caregivers who have fair/poor health and severe fatigue  
208 were significantly more likely to visit the ED. These findings suggest that identifying spousal  
209 caregivers with suboptimal wellbeing may help to identify *patients* with impending higher  
210 healthcare costs and ED use. This work raises the potential that screening for caregivers with  
211 poor wellbeing could not only benefit caregivers but help target interventions to reduce patient  
212 utilization as well.

213 We found that caregiver's total CES-D score and several individual caregiver wellbeing  
214 measures were prospectively and significantly associated with patient health care costs and  
215 number of ED visits over the next 6 months with the effects in the expected directions after  
216 adjusting for caregiver age, sex, and proxy status. Our results also suggest that caregiver and  
217 patient factors explain some, but not all, of the association between these caregiver wellbeing  
218 measures and patient health care utilization. In particular, caregiver fatigue was consistently  
219 associated with patient health care costs and ED utilization, though some associations were no  
220 longer statistically significant, after accounting for all caregiver and patient characteristics. Our  
221 analysis of caregiver fatigue showed that the association of fatigue and patient utilization was  
222 specifically associated with higher patient healthcare costs when the spouse was assisting with  
223 impaired ADL/IADLs (one of many forms of caregiving), indicating that it is caregiving and not  
224 cohabitation driving this pattern. Taken together, our data suggest that caregiver wellbeing is  
225 associated with patient outcomes, and that caregiver and patient factors may attenuate these  
226 associations. Our findings suggest a scientific need to better understand the pathways between  
227 caregiver wellbeing and patient outcomes and to determine how caregiver and patient factors  
228 influence these pathways.

229 The nature and direction of the relationship between patient medical care and caregiver  
230 characteristics is challenging to disentangle due to likely bidirectional relationships between  
231 caregiver wellbeing and patient utilization. Previous research has established that patient severity  
232 of illness and intensity of medical treatment are both risk factors for caregiver burnout.<sup>9</sup>  
233 However, as we suggest in our conceptual model, it is possible that caregiver characteristics  
234 could also drive patient utilization. In our study, we used the patients' prior 6 months of  
235 expenditures and adjusted for their levels of cognitive and functional disability to account for the  
236 key patient characteristics that might drive caregiver distress. By adjusting for these important  
237 patient characteristics and incorporating prior expenditures, our findings contribute evidence that  
238 caregiver distress may potentially lead to higher patient expenditures and health care utilization.  
239 These results also suggest that caregiver distress could serve as a marker for patients likely to  
240 have higher utilization in the future.

241 This study has several limitations. Two of our models had null results (for predicting  
242 likelihood of healthcare expenditures and for predicting higher numbers of ED visits), but we are  
243 likely underpowered to assess these effects. However, given the distribution of expenditures and

244 ED visits, relying on two-part models was the best statistical approach and allowed for better  
245 estimations of higher healthcare expenditures and likelihood of ED visits. This study is unable to  
246 establish a causal relationship between caregiver wellbeing and patient utilization because our  
247 data are observational and the relationship is likely bidirectional. We attempted to isolate the  
248 directionality of the association by adjusting for prior costs, recognizing that this likely results in  
249 a conservative bias to our estimates, given the probable correlation of caregiver wellbeing and  
250 prior costs as well. Although the HRS captures several valuable measures of caregiver wellbeing  
251 domains that we use in this study, caregiver strain is not specifically assessed. Future work  
252 should specifically explore the association of strain with utilization. In addition, while we adjust  
253 for degree of caregiver assistance with ADL/IADLs and presence of children, a more nuanced  
254 picture of the role of the caregiver such as emotional support, medication administration and  
255 healthcare decision support would be useful to understand moderating factors for the association  
256 of caregiver symptoms and patient utilization.

257 The HRS presents a unique opportunity to explore the issue of how caregiver factors  
258 influence patient healthcare utilization and expenditures that has not been measured before.  
259 However, because the HRS enrolls spouses but no other individuals (e.g., children) providing  
260 caregiving for older adults, our results are not generalizable to other caregivers and may  
261 underestimate the total impact of caregiver wellbeing on patient healthcare use. The role of  
262 caregivers is critical to understand given the growing recognition that factors external to the  
263 health system often drive healthcare utilization. While our goal is not to reduce disabled  
264 patients' health care costs, excessive ED use likely signals care that is not optimal for patients  
265 and their families and is a potential marker of caregiver distress and unmet needs. The  
266 attenuation of some of the effects of caregiver distress on patient health care costs and ED  
267 utilization by adjusting for caregiver and patient factors such as availability of child help and net  
268 assets suggests that these effects are potentially modifiable and that these patient/caregiver  
269 factors or subgroups are potential targets for interventions. Since functionally disabled older  
270 adults represent a high-cost population, our findings suggest caregivers are critical targets to  
271 improve care received by older adults with functional disabilities.

272

273

274

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277 Dr. Ankuda had full access to all the data in the study and takes responsibility for the integrity of  
278 the data and the accuracy of the data analysis.

279 Concept and Design: Ankuda, Kabeto, Langa, Levine, Maust, McCammon

280 Acquisition, analysis, or interpretation of data: Ankuda, Kabeto, Levine, McCammon

281 Drafting of the Manuscript: Ankuda, Levine, Maust

282 Critical Revision of the manuscript for important intellectual content: Ankuda, Kabeto, Langa,  
283 Levine, Maust, McCammon

284 Statistical Analysis: Ankuda, Kabeto, Levine, McCammon

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**Title: Figure 1. Mean adjusted patient healthcare expenditures by spousal wellbeing characteristic and caregiver role.**

Legend: [Gray]= Spouse reports fatigue/sadness, [Black/white stripe]= Spouse does not report fatigue/sadness

Supplementary Table S1. The association of caregiver wellbeing characteristics with odds of having patient healthcare expenditures.

Supplementary Table S2. The association of caregiver wellbeing characteristics with higher ED utilization.

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Table 1. Characteristics of observations of spousal dyads (N=5,960)

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	Patient	Spousal caregiver
Age, mean (SD)	76.21 (0.18)	74.17 (0.24)
Sex:		

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## Spousal wellbeing and patient utilization

Men, %	57.3%	42.6%
Women, %	42.7%	57.4%
Race:		
White, %	90.9%	90.2%
Black, %	7.1%	6.8%
Other, %	2.0%	3.0%
Education:		
Less than high school, %	29.6%	24.8%
High school, %	49.6%	53.7%
>High school, %	20.8%	21.5%
Mean household net assets, mean (SD)	\$488,824 (33,325)	
Independent in ADL/IADLs (%)	0	66.19%
Mean number ADL/IADL impairments (SD)	2.75 (0.06)	0.86 (0.05)
Cognitive function:		
Normal, %	57.1%	73.1%
CIND, %	26.7%	20.7%
Dementia, %	16.2%	6.2%
Child resides within 10 miles, %	62.1%	
<i>Healthcare use:</i>		
Expenditures next 6 months, mean (SD) <sup>1</sup>	\$8,751 (\$226)	
No expenditures next 6 months, %	5.2%	
ED visits next 6 months, mean (SD)	0.39	
No ED visits next 6 months, %	76.2%	
<i>Spouse wellbeing characteristics:</i>		
Depressed, %		16.1%
Everything takes effort, %		28.3%
Restless, %		32.1%
Happy, %		87.3%
Lonely, %		13.2%
Enjoys life, %		92.1%
Sad, %		19.7%
Difficulty getting going, %		25.0%

## Spousal wellbeing and patient utilization

Fair/poor health, %	32.1%
Difficulty falling asleep, %	14.2%

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Table 2. The association of caregiver wellbeing characteristics with higher patient healthcare expenditures.<sup>1</sup>

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Difficulty with waking up at night, %	30.6%
Difficulty with early waking, %	13.8%
Feel rested, %	58.9%

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Source: Health and Retirement Study, 2000-2012. Abbreviations: SD= standard deviation, ADL= activities of daily living, IADL= instrumental activities of daily living, CIND= cognitive impairment no dementia, ED= Emergency Department, CES-D-8= Center for Epidemiologic Studies- Depression Scale. <sup>1</sup>Expenditures are in adjusted 2012 USD.

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	Minimally adjusted <sup>2</sup>		Fully adjusted <sup>3</sup>	
	coefficient	p-value	coefficient	p-value
<i>CES-D-8 items:</i>				
Total CES-D-8 scale	0.02 (0.00-0.05)	0.03	0.01 (-0.01-0.04)	0.26
Depressed	0.12 (0.01-0.23)	0.04	0.07 (-0.04-0.19)	0.23
Everything takes effort	-0.03 (-0.12-0.06)	0.52		
Restless	0.06 (-0.03-0.15)	0.18		
Happy	-0.14 (-0.26- -0.02)	0.02	-0.10 (-0.23 to 0.02)	0.11
Lonely	0.04 (-0.08-0.16)	0.49		
Enjoys life	-0.01 (-0.15-0.13)	0.88		
Sad	0.19 (0.09-0.29)	<0.001	0.13 (0.03- 0.23)	0.01
Difficulty getting going	0.03 (-0.06-0.12)	0.51		
<i>Self-reported general health:</i>				
Fair/poor health	0.04 (-0.05-0.13)	0.39		
<i>Severe fatigue:</i>				
Severe fatigue	0.26 (0.15-0.38)	<0.001	0.20 (0.08-0.32)	0.001
<i>Jenkin's sleep scale:</i>				
Total Jenkin's sleep scale:	-0.00 (-0.03-0.03)	0.98		
Trouble falling asleep	-0.02 (-0.09-0.06)	0.67		
Trouble with waking at night	-0.04 (-0.11-0.02)	0.18		
Trouble waking up early	-0.01 (-0.08-0.06)	0.83		
Rested	-0.07 (-0.13- -0.01)	0.03	-0.05 (-0.11-0.02)	0.14

Data source: Health and Retirement Study, 2000-2012. CES-D-8= Center for Epidemiologic Studies 8-item Depression Scale. <sup>1</sup>Among those with non-zero expenditures. The coefficients are the unstandardized logit-scale regression coefficients. See appendix for first part of two-part model examining the association of caregiver characteristics and odds of non-zero expenditures. <sup>2</sup>Minimally adjusted models include proxy status, caregiver age and sex as covariates. <sup>3</sup>Fully adjusted models additionally adjust for race, net assets, functional limitations of caregiver and patient, cognitive function of caregiver and patient, whether a child resides within 10 miles, whether the spouse reports assisting with activities of daily living/instrumental activities of daily living.

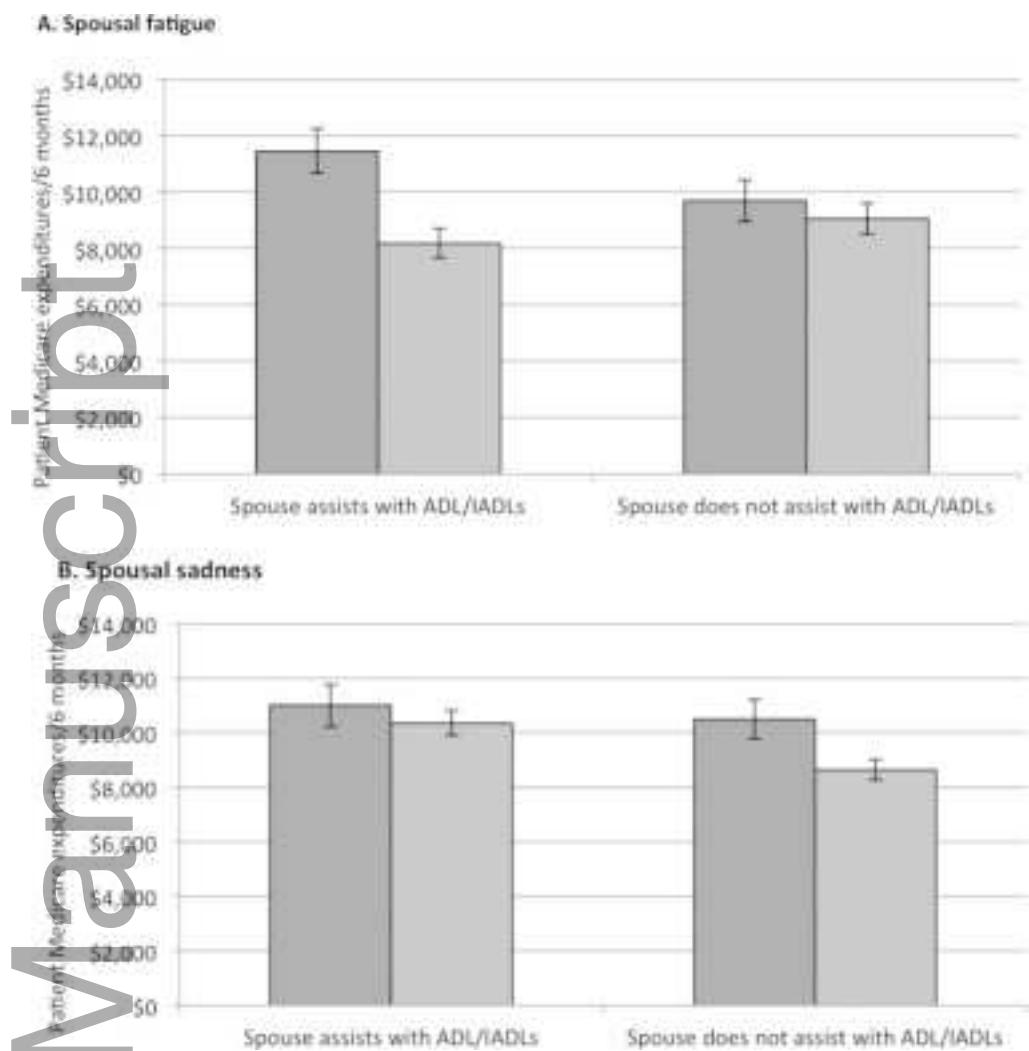
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Table 3. The association of caregiver wellbeing characteristics odds of Emergency Department use in the next 6 months.<sup>1</sup>

	Minimally adjusted: <sup>2</sup>		Fully adjusted: <sup>3</sup>	
	OR	p-value	OR	p-value
<i>CES-D-8 items:</i>				
Total CES-D-8 scale:	1.03 (1.00-1.07)	0.08		
Depressed	1.25 (1.05-1.49)	0.01	1.16 (0.96-1.40)	0.12
Everything takes effort	1.02 (0.88-1.19)	0.77		
Restless	1.01 (0.87-1.17)	0.89		
Happy	0.92 (0.75-1.11)	0.39		
Lonely	1.09 (0.90-1.32)	0.37		
Enjoys life	0.94 (0.74-1.20)	0.63		
Sad	1.26 (1.07-1.48)	0.006	1.16 (0.97-1.38)	0.10
Difficulty getting going	1.06 (0.91-1.24)	0.46		
<i>Self-reported general health:</i>				
Fair/poor health	1.24 (1.07-1.43)	0.004	1.23 (1.04-1.45)	0.01
<i>Severe fatigue:</i>				
Severe fatigue	1.30 (1.07-1.57)	0.007	1.24 (1.01-1.52)	0.04
<i>Jenkin's sleep scale:</i>				
Total Jenkin's sleep scale:	0.98 (0.94-1.02)	0.31		
Trouble falling asleep	0.99 (0.88-1.11)	0.81		
Trouble waking at night	0.91 (0.82-1.01)	0.07		
Trouble waking up early	0.98 (0.87-1.09)	0.67		
Rested	0.99 (0.89-1.09)	0.82		

Data source: Health and Retirement Study, 2000-2012. CES-D-8= Center for Epidemiologic Studies Depression Scale, 8 item. <sup>1</sup>The first of a two-part model: see Appendix Table 2A for the association between caregiver wellbeing and greater emergency department use for those with non-zero utilization. <sup>2</sup>Minimally adjusted models include proxy status, caregiver age and sex as covariates. <sup>3</sup>Fully adjusted models additionally adjust for race, net assets, functional limitations of caregiver and patient, cognitive function of caregiver and patient, whether a child resides within 10 miles, whether the spouse reports assisting with activities of daily living/instrumental activities of daily living.

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