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# Depression among Alzheimer's caregivers: Identifying risk factors

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## Abstract

**Purpose:** The purpose of this study was to reveal risk factors contributing to the development of depression among caregivers of Alzheimer's disease patients.

**Methods:** In a cross-sectional study, all caregivers of consecutive Alzheimer's disease patients were asked to participate in the study. Patient and caregiver depression was evaluated by using the Yesavage Geriatric Depression Scale (GDS). Information regarding patients' functional status, driving status, and type of behavioral abnormalities was obtained from caregivers. Patients' functional status was evaluated by using the Katz Activity of Daily Living (ADL) scale. The Folstein Mini-Mental Status Examination (MMSE) was used to evaluate cognition. Risk factors for Alzheimer's caregiver depression were assessed by means of logistic regression analysis.

**Results:** A total of 92 patients and caregivers were evaluated. Fifteen were excluded due to incomplete data. A total of 77 pairs were included in this analysis. The age of caregivers ranged from 28 to 88 years. Mean (standard deviation [SD]) age was 63.1 (SD = 16.3) years old. Husbands and wives (caregivers) accounted for 49.4 percent; daughters or sons (or daughters- or sons-in-law) accounted for 42.9 percent. There were 29 caregivers (38 percent) found to be depressed. By using multivariate analysis, the following factors have been identified as risk factors for depression in Alzheimer's caregivers: depression in the dementia patient; ADL functional scores of 12 or greater; and the presence of hallucinations.

**Conclusion:** Three risk factors were found to have a strong association with Alzheimer's caregiver depression. Early recognition of such risk factors may help to identify Alzheimer's caregivers with depression.

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## Introduction

It has been estimated that, for every American stricken with dementia, three close family members will be affected by the burden of caregiving.<sup>1,2</sup> Caring for the patient with dementia has been described as one of the most demanding situations encountered.<sup>3,4</sup> Caregivers of dementia patients will experience various emotional problems during the course of the illness.<sup>4</sup>

One emotional disorder, which is frequently overlooked and not treated, is depression in caregivers.<sup>5</sup> Identified risk factors for caregiver depression include social isolation, reduced control over their lives, fear of inadequacy, inappropriate guilt, loss of a previously joyous relationship and lack of positive reinforcement.<sup>1,6,7</sup> Moreover, caregivers themselves may suffer from medical, social, or financial

burdens. This places additional strain on individuals providing care for the dementia patient.<sup>5,10</sup>

Dementia patients often display serious behavioral problems, placing tremendous burdens upon caregivers.<sup>5,8-11</sup> Such reported behavioral complications include personality changes (*i.e.*, apathy, irritability, agitation, and disinhibition), delusions, hallucinations, and aberrant motor behavior.<sup>5,12,13</sup> In the landmark study by Rabins *et al.*, the six most commonly reported behavioral symptoms of dementia patients included: physical violence (75 percent), memory disturbance (68 percent), incontinence (62 percent), catastrophic reactions (56 percent), hitting (50 percent), making accusations (50 percent), and suspiciousness (48 percent). Such abnormal behavior may result in caregiver depression. The frequency of depression is estimated to be 14 percent to 81 percent in persons providing direct care for Alzheimer's patients.<sup>8,9,14-16</sup>

Low cognitive status was found to be an important risk factor for caregiver depression. In one study, an MMSE<sup>17</sup> score below 17 was associated with depression in caregivers.<sup>5</sup> In the same study, depression in the dementia patient was not found to be a risk factor for caregiver depression.<sup>5</sup> In another study, age of patient, duration of dementia, poor functional status, and agitation were found to be independent risk factors for depression among formal (paid) caregivers.<sup>18</sup>

This is a new area of research with little published. Therefore, the study was undertaken in an effort to reveal specific factors contributing to the development of depression among Alzheimer's caregivers.

## Methods

In a cross-sectional study, all caregivers of consecutive Alzheimer's disease patients were asked to participate in the study. Participants provided verbal informed consent. The surveys were conducted at two primary care offices, which are sites of the Memory Disorders Institute, a service of Meridian Institute for Aging. A Rutgers University student, who attended office hours twice a week, performed the data collection. The study period was from July 15 to August 17, 1999. Patients selected for the study fulfilled the NINCDS-ADRDA<sup>19</sup> possible criteria for Alzheimer's disease. Each patient's primary care physician made the diagnosis.

A self-designed form was utilized to record information, which included a caregiver depression scale (performed during the interview). Information regarding the patient's functional status, driving status, and type of behavioral abnormalities was gathered from caregivers. The same day, the patient's cognitive status was assessed and a depression evaluation was performed.

The Yesavage GDS (short form) was chosen as the tool for detection of depressive symptoms among the caregivers.<sup>20-22</sup> The same scale has been used as a screening tool

for depression in the Memory Disorders Institute. Depression was defined as GDS score greater than or equal to 5.<sup>21</sup> If the score was less than 5, the subject was considered not depressed.<sup>21</sup>

The Folstein MMSE was used to detect severity of dementia among patients who participated in the study. MMSE is a dementia tool, well accepted for clinical use.<sup>17,23</sup> Dementia is defined as an MMSE score below 24.<sup>24,25</sup> For study purposes, patients with MMSE score greater than or equal to 20 were considered to have satisfactory cognitive ability.<sup>26</sup> Cognitive level was defined as impaired if MMSE score was less than 20.<sup>26</sup> A score of 20 in the MMSE was designated as the comparative scoring level, since caregiver burden was found to be better correlated at this result.<sup>26</sup>

There are two main functional scales used in the clinical geriatric setting.<sup>27-31</sup> For study purposes, the functional status of the patient was determined by interviewing the caregiver and using the Katz ADL scale.<sup>27,29,30</sup> ADL is a functional assessment used to evaluate elders' ability to perform basic life activities at home.

There are six domains in the ADL<sup>27</sup> scale: bathing, dressing, toileting, transfer, continence, and feeding. There were three different scores for each functional domain. If the selected function was normal, one point was accredited. If the function was impaired, two points were accredited, and if the patient was not able to perform a certain function, three points were accredited. Total score ranged between 6 (normal function) to a maximum score of 18 (*i.e.*, unable to perform any of the six ADL functions). For a subject with an ADL score greater than or equal to 12, the subject was defined as having a significant functional impairment. For such patients, a high level of home assistance is needed.<sup>30</sup> Patients and caregivers were also evaluated for their driving status.

Risk factors for caregivers' depression status (as a dichotomous outcome) were assessed by means of logistic regression analysis. Univariate analysis was performed on all of the factors. Odds ratio (OR) and the 95 percent confidence interval (CI) were calculated. Factors found to be significant in the univariate analysis were included in a multivariate logistic regression model. All tests were two-sided. A p value of less than or equal to 0.05 was considered to indicate statistical significance.

## Results

A total of 92 pairs of subjects (Alzheimer's disease patients with their caregivers) were evaluated. There were 15 (16 percent) pairs excluded from the study due to lack of a depression (GDS) score. Four caregivers (4 percent) had language barriers, six pairs (6.5 percent) had incomplete data, three pairs (3.2 percent) were in crisis (emergency visit) and the questionnaire was not

**Table 1. Patient and caregiver characteristics**

Characteristics	Patients (n = 77)	Caregivers (n = 77)
<b>Age (years)</b>		
Mean (SD)	80.4 (6.8)	63.1 (16.3)
Median	81	67
Range	55 to 93	28 to 88
≥ 65	76 (99%)	41 (53%)
<b>Gender</b>		
Female	54 (70%)	50 (65%)
Male	23 (30%)	27 (35%)

introduced, plus two (2 percent) caregivers refused to participate. Only data from 77 pairs of subjects (84 percent) were included in the analysis. Patient and caregiver characteristics are summarized in Table 1.

A total of 77 patients were included in this analysis. Twenty-three (30 percent) of them were male, and 54 (70 percent) were female. The age ranged from 55 to 93 years with a mean (SD) age of 80.4 (6.8) years. The median was 81 years old. Seventy-six patients (99 percent) were 65 years of age or older.

There were 77 caregivers included in the analysis. Twenty-seven (35 percent) were male and 50 (65 percent) were female. The age ranged from 28 to 88 years with a mean (SD) age of 63.1 (16.3) years. The median age was 67 years. Forty-one (53 percent) of them were older than or equal to 65 years.

Relationships of caregivers to patients are shown in Table 2. Husbands or wives accounted for 49.4 percent; while daughter or son and daughter-in-law or son-in-law relationships accounted for 42.9 percent. Daughters had the highest percentage among those who took care of the patients in this analysis.

Alzheimer's patient evaluations revealed that 40 patients (52 percent) had low cognitive scores (MMSE < 20). Depression (GDS score ≥ 5) was diagnosed in 32 patients (42 percent). Advanced functional impairment (ADL score ≥ 12) was found in 32 patients (42 percent). See also Table 4.

Information regarding patients' driving status was retrieved from the patient and caregiver. Twenty-three (30 percent) of the study patients were still driving. The

data revealed that seven patients (18 percent) with low cognitive status (MMSE < 20) were still driving.

Data regarding behavioral status of patients was gathered from caregiver information. Fifty-one patients (66 percent) had general agitation. Nineteen patients (25 percent) exhibited verbal aggressiveness. Twenty patients (26 percent) showed paranoia. Nineteen patients (25 percent) experienced hallucinations (see Table 3). As compared with other characteristics, general agitation is the most prevalent behavior problem found in this patient population.

Caregiver depression was evaluated, using the same depression scale (GDS) as used for Alzheimer's patients. There were 29 caregivers (38 percent) found to be depressed. (See also Table 4.) The proportion was similar to the prevalence in the study patients. Eighty-one percent of the caregivers were able to drive.

To assess which caregiver or patient characteristics were associated with caregiver depression status, all of the suspected factors were evaluated using the univariate logistic regression analysis (Table 5). Among these factors, the patient's depression status, cognitive status, functional level, and hallucination status showed a statistically significant association with caregivers' depression status. For those who cared for patients with depression, the odds of being depressed were 3.1 times higher than those who took care of nondepressed patients ( $p = 0.02$ ). The odds of being depressed among those who cared for patients with poor cognitive level was 5.2 times higher than those who cared for normal cognitive level patients ( $p = 0.002$ ). The general agitation and paranoia status of the patients also increased the

Relation	N	Percent
Husband	19	24.7
Wife	19	24.7
Daughter	22	28.6
Son	7	9.1
Daughter-in-law	3	3.9
Son-in-law	1	1.3
Granddaughter	1	1.3
Sister	1	1.3
Friend	1	1.3
Hired	2	2.6
Social worker	1	1.3

caregivers' chance of being depressed. However, the association did not reach statistical significance and might be a result of the low statistical power (0.39 and 0.58, respectively).

Risk factors found to be statistically significant in the univariate analysis were included in a multivariate

analysis to assess predictors of caregivers' depression status. When patients' cognitive level was included in the model, all of the other factors turned out to be insignificant. Cognitive level was highly associated with the patients' depression status (OR = 4.2;  $p = 0.004$ ). In the final model, patient's depression status, functional level, and hallucination status remained significant in the multivariate analysis, predicting caregivers' depression status. The adjusted odds ratios for each variable from the multivariate model are shown in Table 5. For caregivers who cared for patients with depression, the odds of being depressed were 2.9 times higher than those who cared for normal patients, after adjusted for patient's functional level and hallucination status. The odds of being depressed for caregivers responsible for patients with significant impairment of function were 3.1 times higher than those responsible for patients with a good ADL score. The caregivers had a higher chance of being depressed when responsible for patients with hallucinations (OR = 4.0).

## Discussion

In the early stages of dementia, first-degree relatives as caregivers do not have a reported higher rate of depression compared to controls.<sup>32,33</sup> As the disease progresses, the spousal rate of depressive symptoms has been reported to increase to 30 percent compared to controls, with only a 1 percent reported rate of depression.<sup>32</sup>

Various studies have described health and social consequences for relatives of elders with dementia.<sup>34-36</sup> The many

Characteristics	Patients (n = 77)	Caregivers (n = 77)
<b>Behavioral level</b>		
<b>General agitation</b>		
Positive	51 (66 percent)	Not applicable
<b>Paranoia</b>		
Positive	20 (26 percent)	Not applicable
<b>Hallucination</b>		
Positive	19 (25 percent)	Not applicable
<b>Verbal aggressiveness</b>		
Positive	19 (25 percent)	13 (17 percent, of 75)

**Table 4. Patient and caregiver evaluation scores**

Characteristics	Patients (n = 77)	Caregivers (n = 77)
<b>Depression</b>		
GDS score		
≥ 5 if depressed	32 (42 percent)	29 (38 percent)
<b>Cognitive ability</b>		
MMSE score		
< 20 if poor cognitive level	40 (52 percent)	Not applicable
<b>Functional level</b>		
ADL		
≥ 12 if poor function	32 (42 percent)	Not applicable
Driving status		
Yes	23 (30 percent)	62 (81 percent)

functional incapacities associated with increasing severity of dementia places the caregiver at increased risk for depression, anxiety, social isolation, and stress-related physical symptoms.<sup>36-38</sup> In this awkward situation, many caregivers find it difficult to express their own depressive symptoms. Others feel that their situation is an inevitable, nontreatable consequence of caring for their loved one with dementia.

The study by Baumgarten<sup>1</sup> used the Center for Epidemiological Studies Depression Scale (CES-D) to determine the prevalence of depression among caregivers of dementia patients. Baumgarten noted that, as compared to noncaregivers, caregivers of dementia patients suffered from depression in significantly higher numbers.<sup>1</sup>

To our knowledge, this is the first study to use the self-reported depression tool, GDS, to measure the frequency of depression in the elder caregiver of the dementia patient. A prior review of the literature did not report the use of the GDS tool.<sup>1</sup> The GDS has been validated, standardized, and has a high inter-rater and intra-rater reliability, making it a very useful tool for the clinician to administer in the office setting. Other well known depression tools used in prior studies have included: the Hopkins Symptoms Checklist (SCL-90); CES-D; Zung Self-Rated Depression Scale (SDS); self-rated mental health instrument; Short Psychiatric Evaluation Schedule (SPES); Midtown Manhattan Psychiatric Impairment Scale; Structured Clinical Interview for *DSM-III R* (SCID); Hamilton Depression Rating Scale (HDRS); Beck Depression Inventory (BDI); and the Brief Symptom Index for depression and anxiety (BSI).<sup>1</sup> Those tools are rarely used in the clinical setting of geriatrics and internal medicine.

Our study evaluated demented patients and their caregivers in a primary care geriatric clinic. The geriatric program is very representative of the “real world” patients seen by primary care physicians in the everyday practice of medicine. Thus, our data appear to be very generalizable to other outpatient settings dealing with dementia. In prior studies, a subjective feeling of psychological stress was mainly utilized, rather than standardized tools, as were used in our study.<sup>33</sup>

The following variables have been identified to be statistically significant risk factors for depression in the caregiver from the univariate analysis:

1. Depression in the dementia patient;
2. MMSE score of less than 20;
3. ADL functional scores of 12 or greater; and
4. Presence of hallucinations.

Using a multivariate analysis, the following were independent risk factors for the presence of depression in the caregiver of the dementia patient:

1. Depression in the dementia patient (GDS score of 5 or greater);
2. ADL score of 12 or greater; and
3. Presence of hallucinations.

**Table 5. Univariate and multivariate risk factors of caregivers' depression status**

Variable	Univariable		Multivariable	
	Odds ratio (95 percent CI)	p value	Adjusted odds ratio (95 percent CI)	p value
<b>Caregiver</b>				
Age (years) ≥ 65	1.42 (0.56, 3.58)	0.46	—	
Gender ( <i>male</i> )	1.55 (0.60, 4.04)	0.37	—	
Driving status <i>Yes</i>	0.45 (0.14, 1.40)	0.17	—	
<b>Patient</b>				
Age (years) ≥ 65	304 (9.8 x 10 <sup>-10</sup> , 9.4 x 10 <sup>13</sup> )*	0.67	—	
Gender ( <i>male</i> )	0.63 (0.23, 1.79)	0.39	—	
GDS score ≥ 5 <i>if depressed</i>	3.12 (1.20, 8.13)	0.02	2.85 (1.02, 7.97)	0.046
MMSE score < 20 <i>if poor cognitive level</i>	5.24 (1.87, 14.70)	0.002	—	
ADL ≥ 12 <i>if poor function</i>	3.12 (1.20, 8.13)	0.02	3.11 (1.11, 8.73)	0.032
Driving status <i>Yes</i>	0.84 (0.30, 2.31)	0.73	—	
General agitation <i>Positive</i>	2.06 (0.74, 5.76)	0.17	—	
Paranoia <i>Positive</i>	2.65 (0.93, 7.52)	0.07	—	
Hallucination <i>Positive</i>	4.13 (1.39, 12.30)	0.01	3.95 (1.23, 12.60)	0.021
Verbal aggressiveness <i>Positive</i>	0.96 (0.33, 2.79)	0.93	—	
* Due to only one patient being under the age of 65 years.				

Age and gender of the caregiver were not found to be risk factors for depression in the caregiver. In our study, behavioral problems, such as paranoia and verbal aggressiveness, were also not found to be risk factors for depression in the caregiver.

Several limitations of this study are noted. This was a cross-sectional study over a very short time period rather than a longitudinal study. Also, the caregivers' depression may have influenced their judgement on whether the patients' behaviors were bothersome or disruptive.

The study is based mainly on the Yesavage Geriatric Depression Scale. The GDS is used mainly as a screening

tool. The reliability and validity of this scale has been verified.<sup>21-23</sup> It is a simple tool, and does not require a professional person to administer it. In our study, we used a college student to administer the test. More sophisticated neuropsychological tests, such as the Hamilton depression scale or the Beck depression inventories, were not used. Those tests require a health care professional to administer, such as physician, nurse, and social worker.

Although several limitations of this study are noted, the study utilized the most acceptable and widely used screening tools in the practice of geriatric medicine. We were able to identify significant risk factors for depression in

the caregiver. The three statistically significant risk factors for caregiver depression are patients who were depressed, patients with impaired functional status, and patients who experienced hallucinations.

We urge all health care professionals caring for patients with dementia to consider the mental health needs of the caregiver as part of the dementia patient's overall care plan. Practical implementation of caregiver assistance can have positive outcomes on the welfare of the patients and their caregivers.<sup>39</sup>

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