# The Effect of Dementia Patient's Physical, Cognitive, and Emotional/ Behavioral Problems on Caregiver Well-Being: Findings From a Spanish-Speaking Sample From Colombia, South America

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The current study aims to (1) determine whether there is a relationship between the problems of patients with dementia and the psychosocial functioning of the caregiver, (2) determine whether these relationships exist independent of sociodemographic and caregiving-related variables, and (3) determine which type of problems of patients with dementia best predict the psychosocial functioning of the caregiver. In all, 73 family caregivers were recruited from Bogota, Colombia. The caregivers completed a checklist of problems presented by the person with dementia, Patient Health Questionnaire (PHQ-9), Zarit Burden Interview (ZBI), Interpersonal Support Evaluation List (ISEL-12), and Satisfaction with Life Scale (SWLS).

# Introduction

Dementia is a progressive disease causing changes in the brain that result in the loss of nerve cells, altering the ability to think, remember, interpret, and perform other mental functions.<sup>1</sup> Dementia is a major public health issue for the 21st century.<sup>2</sup> It currently affects more than 24 million people

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Number of cognitive and behavioral/emotional problems presented by the person with dementia was positively correlated with caregiver PHQ-9 and ZBI scores. Number of behavioral/emotional problems was negatively correlated with ISEL-12 scores. Cognitive and behavioral/emotional problems, but not physical, presented by the person with dementia were associated with higher levels of depression and burden of caregiver. Behavioral/emotional difficulties were associated with lower caregiver-perceived social support rating.

**Keywords:** dementia; caregivers; burden; depression; social support

worldwide, and the prevalence increases by 4.6 million people each year. It is estimated that every two decades, the yearly average of new cases will double to over 9 million people. Ultimately, by the year 2040, over 80 million people worldwide will be diagnosed with dementia.<sup>3</sup>

Caregiving for individuals with a chronic disease has been shown to negatively impact the caregiver's physical, social, and emotional well-being. Caregiving for individuals with dementia is particularly difficult, due to the physical, cognitive, and behavioral/ emotional problems presented by the person with dementia. The features of dementia have been linked to numerous negative outcomes in caregivers, including psychological disturbances<sup>4</sup> such as anger, burden, anxiety, depression, guilt, and worry<sup>5-7</sup> and physical health problems<sup>8</sup> such as a decrease in immune system functioning,<sup>9,10</sup> hypertension,<sup>11</sup> cardiovascular disease,<sup>12-14</sup> symptoms of fatigue,<sup>15</sup> and sleep problems.<sup>16</sup> Relationship changes,<sup>17</sup> social

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activity restrictions,<sup>18</sup> and feelings of isolation and inadequate social support<sup>19</sup> are also common. Finally, caring for a person with dementia is related to poor quality of life and financial problems.<sup>20-22</sup>

In studying the factors that determine the psychosocial functioning of caregivers, several perspectives have been used in the literature. Some studies have focused mainly on patient characteristics,<sup>23</sup> others have included caregiver characteristics as well,<sup>24</sup> and some have taken into account factors related to the caregiving situation.<sup>25</sup> Regarding patient characteristics, these have been shown to be one of the more important predictors in determining the placement and amount of time caregivers spend caring for the patient,<sup>26</sup> and variables such as cognitive impairment, behavioral/emotional problems, and functional impairment predict long-term care placement and nursing home admission.<sup>27,28</sup> Because cognitive and neurobehavioral problems are among the more important problems presented by persons with dementia, their relationship to and influence on physical health and emotional wellbeing of caregivers have received great attention during the past two decades.

Even though there is a large body of literature examining the impact of dementia symptoms on caregivers, most of the studies have focused on Anglo-Saxon caregivers.<sup>29</sup> There is a lack of research about the experiences of caregivers from other cultures, and given intercultural differences in values and approaches to caregiving, it is reasonable to expect the impact to be different in caregivers from South America. For instance, residential care options are limited in developing countries, as are day care for adults, support groups, and respite care. Many caregivers also have limited access to information and little knowledge about the resources that exist in their communities. Furthermore, even if these resources are available to potentially alleviate some of the caregiving burden, families usually feel responsible for providing care and may not access or use them.<sup>30,31</sup> For instance, in many Latin American countries, the placement of a family member in a nursing home is not an acceptable way of caring for elders. Families from these cultures that have placed or are considering placement of a patient may be dealing with issues of shame and guilt, especially if other members of the family or community express disapproval.<sup>27</sup>

The present study aims (1) to report the prevalence of physical, cognitive, and emotional/ behavioral problems in the patient with dementia and the resulting degree of distress in the family member caregiver, (2) to describe caregivers' psychosocial functioning (burden, depression, social support, general health, and satisfaction with life), (3) to determine whether there is a relationship between the problems of patients with dementia, as reported by the caregivers, and psychosocial functioning of the caregivers, (4) to determine whether these relationships exist independent of sociodemographic and caregiving-related variables, (5) to determine which type of problems of patients with dementia best predict the psychosocial functioning of caregivers, and (6) to examine potential mediators of these relationships.

## Methods

#### **Participants**

For the current study, caregivers were defined as family members actively providing day-to-day care for a person with dementia and who were familiar with the patient's medical and social status.<sup>32</sup> In all, 73 family caregivers were recruited from the Memory Clinic of the Central Police Hospital in Bogota, Colombia. The inclusion and exclusion criteria were: (1) be the primary caregiver of a patient with a diagnosis of dementia, (2) have been providing care to the patient for a minimum of 6 months, and (3) have no personal history of neurological and psychiatric disorders or learning disabilities.

Demographic information for the sample is provided in Table 1. The sample consisted of 13 men (17.8%) and 60 women (82.2%), with a total average age of 57.7 years (SD = 13.5) and an average educational level of 9.3 years (SD = 4.9). The Colombian government defines 6 levels of socioeconomic status (SES) based on income and the location of one's residence, where level 1 is low and level 6 is high SES. The mean SES for the sample was 3.08 (SD = 0.7), with 4.1% of the sample in SES level 1, 5.5%in level 2, 72.6% in level 3, 15.1% in level 4, 1.4% in level 5, and 1.4% in level 6. Of the caregivers, 56 (76.7%) were married. Caregivers had been providing care to their patients for an average of 40.2 months (SD = 25) and 128 hours per week (SD = 55) at the time of entry into the study. Of the caregivers, 40 were spouses/partners of the patients (54%), and 53 (72%) caregivers were unemployed at the time of the interview.

#### Measures

*Dementia Symptoms Questionnaire*. This is a 27-item checklist designed specifically for the current study.

Primary caregiver	
Age (years)	
Mean	57.7 ( $\pm 13.5$ )
Gender	
Male	13 (17.8%)
Female	60 (82.2%)
Marital status	
Single	12 (16.4%)
Married	56 (76.7%)
Divorced	1 (1.4%)
Separated	2 (2.7%)
Cohabiting	2 (2.7%)
Relationship to the patient	
Son/daughter	30 (41.4%)
Spouse/partner	40 (54.8%)
Other relative	3 (4.1%)
Employment	
Employed	19 (27.4%)
Unemployed	53 (72.6%)
Education (years)	
Mean	$9.3(\pm 4.9)$
Time caregiving (months)	
Mean	40.2 (±25.0)
Hours per week providing care	
Mean	$128.0 (\pm 55.0)$
Socioeconomic status	
Mean	$3.08(\pm 0.7)$
Level 1	4.1%
Level 2	5.5%
Level 3	72.6%
Level 4	15.1%
Level 5	1.4%
Level 6	1.4%

**Table 1.** Demographic Information of the Primary<br/>Caregivers (n = 73)

After a review of the literature on dementia, 27 of the most frequent problems reported in people with dementia were selected. Items were created based on each problem and categorized into physical (motor problems, convulsions, etc), cognitive (loss of memory, attention and concentration problems, etc), and emotional/behavioral difficulties (depression, anxiety, etc). Caregivers indicate whether the individual with dementia presented the problem in the past month (yes/no). If the problem is present, the caregiver must then indicate how much distress these difficulties cause. The degree of distress was rated on a 4-point Likert scale from 1 = no distress to 4 = severe distress.

The Zarit Burden Interview. The Zarit Burden Interview (ZBI) is the most widely referenced scale used

to assess caregiver burden.<sup>33</sup> The self-administered scale consists of 22 items asking how one feels about their current situation from "never" to "nearly always." The questions were devised using qualitative information on how people tend to feel when providing care to someone and evaluate specific topics that are usually affected in the caregiver's life (eg, stress level, emotional health, financial strain, relationships, embarrassment, overall burden). Each question is worth 0 to 4 points, with 88 total points possible. A higher score correlates with a higher level of burden: 0 to 20 points indicates little or no burden, 21 to 40 points reflects mild-to-moderate burden, 41 to 60 points indicates moderate-to-severe burden, and 60 to 88 points reflects severe levels of burden.<sup>34</sup> The current study uses a Spanish version of the ZBI, which has shown 0.91 consistency and 0.86 test-retest reliability.<sup>35</sup>

The Patient Health Questionnaire. The Patient Health Questionnaire (PHQ-9) is а selfadministered examination used to diagnose mental disorders. The PHQ-9 is the module of the PHQ that specifically evaluates depression. A study of the PHQ-9 concluded that it is a "useful clinical and research tool" and is a "reliable and valid measure of depression severity".<sup>36</sup> The evaluation consists of 9 items that reflect typical symptoms of depression, and directs the respondent to indicate a response from 0 to 3 ("not at all" to "nearly every day"), depending on how often they have been bothered by each problem over the past 2 weeks. The response scores are totaled, and the total score ranges from 0 to 27,<sup>37</sup> with higher scores reflecting higher levels of depression [includes ranges 0 to 4 None, 5 to 9 Mild depression, 10 to 14 Moderate depression, 15 to 19 Moderately severe depression, and 20 to 27 Severe depression]. There is an additional question at the end of the questionnaire that asks the respondent to indicate the level to which the identified problems have affected his/her ability to do work or care for home/others. The response ranges from "not difficult at all" to "extremely difficult," but is not included in the total score. The PHQ-9 is often used in epidemiological studies and clinical primary care settings and can be given in English or Spanish. The current study uses the Spanish version of the PHQ-9.<sup>37</sup>

Satisfaction With Life Scale. The Satisfaction With Life Scale (SWLS) is a global measure of life satisfaction.<sup>38</sup> The measure consists of self-reported

	Burden	Depression	Social Support	Satisfaction With Life	General Health
Patient physical problems Patient cognitive problems Patient emotional/behavioral problems	$0.06 \\ 0.52^{a} \\ 0.58^{a}$	$-0.04 \\ 0.34^{a} \\ 0.40^{a}$	-0.17 -0.22 $-0.29^{b}$	0.09 -0.10 -0.06	$0.05 \\ 0.01 \\ -0.10$

 Table 2.
 Relationship between Patient Problems and Caregiver Functioning

 $^{\rm a}_{\rm P} < .01.$ 

<sup>b</sup> P < .05.

agreements on a scale from 1 = strongly disagree to 7 = strongly agree for the following 5 items: (1) In most ways my life is close to my ideal; (2) The conditions of my life are excellent; (3) I am satisfied with my life; (4) So far I have gotten the important things I want in life; and (5) If I could live my life over, I would change almost nothing. The responses are summed and the SWLS total score ranges from 5 to 35, with higher scores indicating higher life satisfaction. The current study uses a Spanish version of the SWLS that has shown 0.82 reliability.<sup>39</sup>

Perceived Functional Social Support (ISEL). The Interpersonal Support Evaluation List-Short Version (ISEL-12) consists of a list of 12 statements concerning the perceived availability of potential social resources.<sup>40</sup> The items are counterbalanced for desirability. Half the items are positive statements about social relationships and half are negative statements. The ISEL-12 was shortened from the 40-item version ISEL<sup>40</sup> and designed to assess the perceived availability of 3 separate functions of social support, as well as providing an overall support measure. The items which comprise the ISEL-12 fall into three 4-item subscales. The "tangible" subscale is intended to measure perceived availability of material aid; the "appraisal" subscale, the perceived availability of someone to talk to about one's problems; and the "belonging" subscale, the perceived availability of people one can do things with. The ISEL has been used widely in health-related research. For the 40-version scale,  $\alpha$  and test-retest reliability are approximately 0.90. For the subscales, internal consistency and test-retest reliabilities range from 0.70 to 0.80, and they are moderately intercorrelated.<sup>40</sup> The present study uses the Spanish version of the ISEL-12.41

Short Health Survey (SF-36). The Short Health Survey (SF-36) is a 36-item survey designed to evaluate perceived general health, including physical functioning, mental health, and social ability.<sup>42</sup> For the

current study, we used only the first question of the SF-36, "How would you rate your general health on a scale from 1, indicating excellent, to 5, indicating poor?" to measure perceived general health. The current study uses the first question of the Spanish version of the SF-36 Health Survey.<sup>43</sup>

## Procedure

All potential participants were approached and told about the purpose of the study. All consented to participate in accordance with the research protocol approved by the ethics committee of the Central Police Hospital (Bogota, Colombia). Subsequently, all caregivers completed the Dementia Symptoms Questionnaire to determine the physical, cognitive, and behavioral/emotional problems presented by the person with dementia and corresponding levels of resulting distress. Then, caregivers' depression levels were assessed via the PHQ-9, burden levels using the ZBI, social support via the ISEL-12, and quality of life using the SWLS.

## Results

## Functioning of Patients with Dementia and Distress Levels of the Caregivers

The most frequently reported physical, cognitive, and behavioral/emotional problems presented by the person with dementia, as reported by the caregiver, and the corresponding mean distress levels for each symptom, are presented in Table 2. The most frequently reported difficulties were loss of memory (98%), depression (90%), disorientation (90%), motor problems (83%), dependency (83%), and lack of interest (82%). The least frequently reported problems included inappropriate sexual behavior (9.6%), irritability (11%), hallucinations (23%), lack of initiative (37%), and anosognosia (38%). Despite the low frequency, the mean highest distress levels were associated with inappropriate sexual behavior (3.28), inappropriate social behavior (3.18), aggression

(2.97), lack of initiative (2.96), and hallucinations (2.94).

#### **Psychosocial Functioning of Caregivers**

Thirty-one percent of the caregivers reported no or little burden, 32% mild-to-moderate burden, 27% moderate to severe burden and 10% severe burden. Approximately 8% (8.5%) reported having excellent health, 2.8% very good, 25.4% good, 59.2% fair, and 4.2% poor health; 60.3% of the caregivers did not report any symptoms of depression, 23.3% reported mild symptoms of depression, 13.7% had moderate to severe depression, and 2.8% had moderately severe depression. Approximately 8% (8.2%) felt slightly dissatisfied with their lives, 1.4% felt neutral, 2.8% were slightly satisfied with their lives, while 79.4% felt satisfied and 8.2% reported feeling extremely satisfied with their lives.

# Relationship Between the Problems of Patients With Dementia and the Psychosocial Functioning of Caregivers

The relationship between the problems of a patient with dementia and the psychosocial functioning of a caregiver was initially analyzed using Spearman correlations (see Table 2). The number of cognitive and behavioral/emotional problems presented by the person with dementia, as reported by the caregiver, were positively correlated with caregiver PHQ-9  $(\rho = .34, P < .01, \rho = .40, P < .001)$  and ZBI scores  $(\rho = .52, P < .001, \rho = .58, P < .001)$ . The number of behavioral/emotional problems reported was negatively correlated with ISEL-12 scores ( $\rho = -.29$ , P < .05). Physical problems identified by caregivers were not associated with the psychosocial functioning of caregiver. The problems of patients with dementia were not associated with SWLS or SF-36 general health scores.

## Independent Associations Between Problems of Patients With Dementia and the Psychosocial Functioning of Caregivers

To determine whether the significant relationships found between the problems of patients with dementia and the psychosocial functioning of caregivers were independent of sociodemographic and caregiving variables theoretically believed to influence psychosocial functioning based on previous literature, various multiple linear regression analyses were

Table 3. Type of Dementia Patient Problems and<br/>Caregiver Burden (ZBI)

Variable	β	<i>t</i> value	P Value
Age	.332	2.118	.038
Years of education	.028	0.192	.848
Gender	.034	.366	.716
Socioeconomic status	045	-0.456	.650
Relationship to the patient	.001	0.008	.994
Time caregiving	255	-2.829	.006
Hours per week providing care	.105	0.965	.338
Behavioral problems	.413	3.639	.001
Cognitive problems	.260	2.359	.022

Abbreviation: ZBI, Zarit Burden Interview.

conducted. Because problems of patients with dementia were expected to predict the psychosocial functioning of caregivers, the dependent variables were PHO-9 total scores, ZBI total scores, or ISEL total scores. Data were entered in sets. First, the socioeconomic variables (age, gender, years of education, and SES) were entered. Then, caregiving variables, such as relationship to the patient (spouse or child), number of months caring for the patient, and number of hours a week caring for the patient, were entered. Finally, the category of problems of patients with dementia (either cognitive or emotional/behavioral, depending on the model) was entered into each regression model. After controlling for these sociodemographic and caregiving factors, cognitive problems of patients with dementia were predicted by ZBI scores ( $R^2$  change = 0.23, P < .001;  $\beta = .49$ , P < .001) and PHQ-9 scores  $(R^2 \text{ change} = .08, P < .05; \beta = .29, P < .05)$ , and emotional/behavioral problems of patient with dementia were predicted by ZBI scores ( $\hat{R}^2$  change = .29, P < .001;  $\beta = .57$ , P < .001), PHO-9 scores ( $R^2$  change = .12, P < .01;  $\beta = .37$ , P < .001), and ISEL scores  $(R^2 \text{ change} = .06, P < .05; \beta = -0.25, P < .05).$ 

# Type of Problems of Patients With Dementia That Best Predict Psychosocial Functioning of Caregivers

To determine the relative importance of cognitive and emotional/behavioral problems of patients with dementia in predicting burden and depression of caregivers, 2 additional multiple linear regression analyses were conducted following the procedure described above. In the last set, however, both cognitive and emotional/behavioral problems were entered into the regression model for ZBI scores and PHQ-9 scores (see Tables 3 and 4). Both types of problems of patients with dementia were significant predictors

Variable	β	t Value	P Value
Age	.210	1.069	.289
Years of education	.213	1.160	.251
Gender	057	-0.486	.628
Socioeconomic status	192	-1.534	.130
Relationship to the patient	.181	0.878	.384
Time caregiving	186	-1.635	.107
Hours per week providing care	.135	0.984	.329
Behavioral problems	.291	2.040	.046
Cognitive problems	.123	0.885	.380

Table 4. Type of Dementia Patient Problems and<br/>Caregiver Depression

of caregivers ZBI scores, independent of sociodemographic and caregiving factors (cognitive problems  $\beta = .26$ , P < .05; emotional/behavioral problems  $\beta = .41$ , P < .001). However, emotional/behavioral problems of patients with dementia, but not cognitive problems, were a significant predictor of caregivers PHQ-9 scores ( $\beta = .29$ , P < .05 and  $\beta = .12$ , P = NS, respectively).

## Mediators of the Relationship Between Problems of Patients With Dementia and Psychosocial Functioning of Caregivers

Because ZBI and PHO-9 scores were highly correlated (r = .71, P < .001), even independent of sociodemographic and caregiving variables (r = .65, P <.001), it was hypothesized that the relationship between emotional/behavioral problems of patients with dementia and depression might be mediated by burden. To test this hypothesis, the method for establishing mediation proposed by Kenny and Baron<sup>44</sup> was used. In this method, the predictor was the emotional/behavioral problems of patients with dementia and the outcome variable was the PHQ-9 scores. The mediating variable tested was ZBI scores. First, the predictor must be associated with the outcome. This effect was established in Table 4. Second, the predictor must be associated with the mediator. This effect was established in Table 5. Third, the mediator variable must predict the outcome, which is true based on the correlations reported at the beginning of the paragraph. Finally, to establish total mediation, the effect of the predictor on the outcome controlling for the mediator should be zero. If the effect of the predictor on the outcome is lessened controlling for the mediator, then partial mediation is present. When controlling for ZBI scores, emotional/behavioral problems is no longer a significant predictor of PHQ-9 scores ( $\beta = .02, P = NS$ ),

Table 5. Regression Model Showing that theRelationship Between Dementia Patient Problemsand Depression (PHQ-9) is Mediated by Burden(ZBI)

Variable	β	t Value	P Value
Age	.047	0.320	.750
Years of education	.076	0.615	.541
Gender	092	-1.050	.298
Socioeconomic status	112	-1.172	.246
Relationship to the patient	.050	0.398	.692
Time caregiving	.036	0.382	.704
Total Zarit Score	.780	6.534	.000
Cognitive problems	084	-0.746	.459
Behavioral problems	.023	0.189	.851

Abbreviations: PHQ-9, Patient Health Questionnaire; ZBI, Zarit Burden Interview.

suggesting that ZBI scores almost totally mediated the relationship between emotional/behavioral problems and PHQ-9 scores (see Table 5).

#### Discussion

## Prevalence of Problems of Patients With Dementia and Caregiver Distress

In the current study, cognitive problems such as loss of memory and disorientation, psychological problems including depression and lack of interest, and physical problems like motor malfunctions and dependency were problems of patients with dementia, most commonly reported by caregivers. These results are not surprising given that past literature documents increased behavioral/emotional and cognitive problems associated with dementia,<sup>45,46</sup> particularly poor memory and thinking processes.<sup>47,48</sup>

Interestingly, infrequently reported patient problems tended to cause the most distress in caregivers. For example, inappropriate sexual behavior was least reported (by only 9.6% of the sample), but resulted in the highest levels of distress (3.28). The distress reported due to inappropriate social behavior (37%, 3.18) and hallucinations (23%, 2.94) in patients with dementia also support the conclusion of previous studies indicating that high levels of caregiver distress is associated with behavioral problems in particular.<sup>49,50</sup> Meiland et al<sup>51</sup> and Georges et al<sup>48</sup> reported that apathy and personality changes caused high levels of distress in caregivers, but these patient symptoms were not measured in the current study.

#### **Psychosocial Functioning of Caregivers**

Approximately 70% of caregivers of patients with dementia felt some type of burden related to their caregiving role, which coincides with previous literature.<sup>27,28,45,51-54</sup> The rates of burden in the current study are most similar to the 68% reported by Papastavrou et al.<sup>7</sup> Over half of caregivers reported fair health and 4% reported bad health, suggesting that caregiving may negatively influence health, which has been documented by others.9,55,56 Nearly 40% of caregivers of patients with dementia reported some level of depression. Some studies of caregivers of patients with dementia have documented higher rates of depression, eg, between 43% and 65%, 57,7 while others have found rates as low as 10%.<sup>5</sup> Such discrepancies may be a result of the different instruments used to measure depression. For example, the majority of past studies utilized the Center for Epidemiological Studies Depression Scale (CES-D)7,14,58-66 or the Beck Depression Inventory (BDI),67-70 which encompass more cognitive symptoms of depression than the PHO-9, which was used in this study. Alternately, it may be due to the sample size and/or the characteristics of the sample. Sample sizes of dementia caregivers in previous research have ranged from 32 to 643 individuals<sup>7,9,14,58-72</sup> and differ in terms of mean time spent caring for loved ones with dementia, hours per week caregiving, and other factors that might affect depression rates. It is fair to conclude that depressive symptoms are commonplace in caregivers of patients with dementia.<sup>9,73,74</sup> Furthermore, some studies suggest that many caregivers are at risk of experiencing clinical depression<sup>62,75,76</sup> and that depression in caregivers can last beyond institutionalization or death of the patient.<sup>58,77-79</sup>

Almost 90% of caregivers reported feeling satisfied or extremely satisfied with life, and only 8% report being dissatisfied. These percentages coincide with findings from Andren & Elmstahl<sup>54</sup> reporting high life satisfaction in caregivers. However, George and Gwyther<sup>4</sup> and Haley et al<sup>49</sup> reported low satisfaction with life in caregivers of patients with dementia. The high rates of life satisfaction in the present study may be due to cultural factors. Latin American culture emphasizes high respect for elders and people with disabilities. This culture also instills a sense of obligation for their care.<sup>80</sup> Familism, or valuing family over individual and/or community needs, is a strong, almost universal value generally held by individuals from Latin America and are likely to be held by the caregivers sampled in this study, thus resulting in high reported life satisfaction.

# Relationship Between Problems of Patients With Dementia and the Psychosocial Functioning of Caregivers

In this study, the number of cognitive and behavioral/emotional problems were positively correlated with burden and depression of caregivers and negatively correlated with social support of caregivers. As reported in previous studies, no correlation was found between physical problems of patients and psychosocial functioning of caregivers. The findings of the present study regarding the inverse relationship between cognitive/behavioral/emotional problems of patients with dementia and social support of caregivers coincide with previous literature.<sup>27,50</sup> However, the literature on problems of patients with dementia and burden/depression of caregivers is more complex.

*Caregiver burden.* Previous research examining very specific problems of patients with dementia indicates that behavioral problems are associated with caregiver burden.<sup>45,81-96</sup> The findings of the current study coincide with previous studies. However, one study did not find an association between caregiver burden and behavior/function of patients with dementia.<sup>33</sup> The sample recruited by Zarit and colleagues<sup>33</sup> reported very few behavioral problems presented by the person with dementia. In contrast, in the current study, most of the neurobehavioral problems identified were frequently reported. It may be that a relationship between behavioral problems of patients with dementia and caregiver burden only exists when the problems are commonplace.

Regarding the association between cognitive problems of patients with dementia and caregiver burden, some studies report an association,<sup>84,97-101</sup> while others do not.<sup>33,53,81,88</sup> The studies that have not found a relationship between problems of patients with dementia and caregiver burden have used an objective measure of patient cognitive function as administered by a trained evaluator, such as the Clifton Assessment Schedule, the Mini-Mental State Examination, and the Kahn Mental Status Questionnaire. The current study, in contrast, found that higher levels of caregiver burden were associated with more caregiver-reported patient cognitive problems. Thus, it appears that caregiver burden influences the perception of cognitive problems of patients in this sample, which seems to explain why the findings of the current study coincide with others who have not used an objective measure of cognitive function of patients.

Caregiver depression. As with burden, previous research examining very specific problems of patients with dementia indicates that neurobehavioral problems are associated with caregiver depression.<sup>50,82,84,86,102-107</sup> The findings from the present study coincide with prior research. In contrast, 2 studies did not find an association between behavioral problems of patients with dementia and caregiver depression.<sup>49,108</sup> Brodaty and Hadzi-Pavlovic<sup>108</sup> used the Problem Behaviour Checklist, which generates 5 subscales, including dependency, demand, disturbance, disability, and wandering. Only one of the subscales, disturbance, fits the definition of neurobehavioral problems used in the current study. Haley and colleagues<sup>49</sup> used the Memory and Behavioral Problems Checklist, which combines cognitive and behavioral problems presented by the person with dementia. Since the other problems included in these measures are more physical and/or cognitive in nature, the relationship with caregiver depression in these studies may have been confounded.

As with caregiver burden, the relationship between cognitive problems of patients with dementia and caregiver depression is not well-established. Fewer studies document an association between cognitive impairment of patients with dementia and caregiver depression,<sup>50,76,83,97,109,110</sup> and 2 studies did not find this relationship.<sup>49,105</sup> As discussed previously in the section on the relationship between cognitive problems of patients with dementia and caregiver burden, the 2 studies that did not find a relationship between cognitive problems of patients with dementia and caregiver depression were those that used the Mini-Mental State Examination to evaluate cognitive function of patients with dementia. A relationship between caregiver-reported cognitive problems of patients with dementia and caregiver depression was found in the current study, and these findings suggest that caregiver depression affects the perception of patient cognitive problems in this sample.

# Relative Importance of Cognitive Versus Emotional/Behavioral Problems on Caregiver Depression and Burden

Most of the previous studies have not controlled for caregiver sociodemographic and dementia patient factors that might influence caregiver burden and/ or depression.<sup>33,53,83,86,87</sup> In some cases, these variables (e.g., caregiver age, gender, years of education, socioeconomic status, relationship to the patient, number of months in caregiving role, number of

hours/week spent caregiving) may account for the disparate findings in the relationship between problems of patients with dementia and burden/ depression of caregivers. The current study found that, independent of these sociodemographic and caregiving factors of caregivers, cognitive problems of patients with dementia predicted burden and depression, and emotional/behavioral problems of patients with dementia predicted burden, depression, and decreased social support. Furthermore, both cognitive and emotional/behavioral problems were strong independent predictors of burden, but emotional/behavioral problems were a stronger predictor of depression than cognitive problems.

# Mediator of the Relationship Between Emotional/Behavioral Problems of Patient and Caregiver Depression

In the current study, caregiver burden mediated the relationship between patient emotional/behavioral problems and caregiver depression. Similar results were found by Clyburn et al<sup>22</sup> in which emotional/ behavioral problems were related to higher burden, which created more depression in caregivers. At the outset, it seems that it is the behavioral problems presented by the person with dementia, as reported by the caregiver, that cause depression. However, these mediator results indicate that burden is the real cause of depression in these caregivers. Therefore, rehabilitation professionals working to alleviate depression in caregivers are likely to achieve results by intervening to decrease levels of burden.

# Limitations

The results of the current study should be interpreted with caution. As discussed previously, the measures of problems of patients with dementia were reported by the caregivers, and psychosocial characteristics of caregivers may have confounded the assessment of patient problems. The sample was recruited from Bogota, the capital of Colombia, and results may not be generalizable to Colombian caregivers living in rural areas or other Latin American caregivers from resource-poor areas where support services may not be available.

# **Future Studies**

The results of the current study suggest a need for large, prospective, longitudinal studies with objective

measures of problems of patients with dementia and psychosocial outcomes of caregivers. The sample should be representative of individuals from all social classes and geographic areas and allow for stratification based on gender, as gender of the caregiver has been found to influence psychosocial outcomes in previous work.<sup>111,112</sup> Furthermore, future research could begin to examine the effective and ineffective coping strategies used by caregivers to manage stress and its relationship with burden and depression. Latinos tend to have more emotion-focused coping mechanisms, which may contribute to the high levels of burden found in the current study. Because caregiver burden is a predictor of nursing home admission in industrialized nations,<sup>113,114</sup> from a public health and medical expenditure perspective, more research is needed to examine specific determinates of burden in this population that lead to nursing home admission, such as poor coping and low social support. Assistance with day-to-day activities and social support, including information and education, career support groups, community dementia teams, home nursing, personal care, day centers, respite care, family therapy, and care homes may also play a role in improving caregivers' quality of life and emotional well-being. Insight into predictors of burden that mediate nursing home admissions could be helpful in designing programs aimed at diminishing the experience of burden by caregivers, which may perhaps lead to a delay in nursing home admissions. Such studies would form the justification for and a foundation on which to build family-based intervention programs tailored to the specific needs of family member caregivers.

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