Positive Aspects of Caregiving and Caregiver Burden: A Study of Caregivers of Patients With Dementia

Ibrahim Abdollahpour, PhD¹, Saharnaz Nedjat, PhD², and Yahya Salimi, PhD³

Abstract

Background: Now positive aspect of caregiving (PAC) is well-defined as caregiver gains, satisfaction, meaningful life, and enhanced family relationship. The adjusted association of PAC and caregiver burden is not well acknowledged. This study investigated the association of caregiver burden and PAC adjusting for potential confounders.

Methods: This was a cross-sectional study that recruited 132 caregivers. A linear regression model with PAC was used to estimate the adjusted associations.

Results: The caregiver burden was negatively associated with PAC (mean difference in PAC per a 1-unit increase in caregiver burden = −0.12, 95% confidence interval: −0.18 to −0.056, P < .001). This association remained after adjustment for caregivers’ age and marital status as well as patients’ dependency level. Conclusion: The negative significant association of caregiver burden with PAC reinforces the need for interventional and/or educational programs aiming at decreasing the overall imposed burden. This can play an important role in improving caregivers’ general health and quality of life.

Keywords
caregiver burden, dementia, linear regression model, positive aspect of caregiving

Introduction

As a result of global population aging, the need for caregiving in geriatric diseases, such as dementia, has extended throughout the world.¹² Universal estimates have shown just about 44 million people with dementia, and this will increase to 76 million patients in the next 2 decades.³ Moreover, the majority of these patients will be from developing countries who are supported by informal (family) caregivers. In the United States, estimates demonstrate that 15.5 million American caregivers provide almost 18 billion hours of informal caregiving valued at more than US$220 billion.⁴ The average 92 hours caring per month, nearly 15% job quit during the last year among employed caregivers,⁵ and the imposed costs for transportation and shared housing are some reasons for this enormous cost. This cost is around 1% of the world gross domestic product.⁷

In developing countries, such as Iran, inadequate Alzheimer services have imposed a more important role on the family caregivers as the main source of caregiving.⁸⁻¹⁰ Most of existing models represent caregiving experience as a complex multidimensional phenomenon,¹¹⁻¹⁶ which might be affected by patient characteristics, disease-related factors, patients and caregivers’ sociodemographical factors, and caregiving-related factors.¹⁷

Although the majority of what we know about caregiving is coming from its negative aspects, positive aspect of caregiving (PAC) is important as well.⁹,¹⁸ Positive aspect of caregiving has been defined as “the gains or satisfaction feelings resulting from the caregiving experience.”¹⁹,²⁰ Dependency feeling, fulfillment, bring family members closer together, companionship and more meaningful life and spiritual/moral remuneration¹⁸,¹⁹ were all reported as PAC.

Although caregiving is generally considered as an imposed and highly stressful task, many caregivers have reported some positive aspects of caregiving.¹⁸,¹⁹,²¹ Even though PAC could play an important role in reducing the mental, physical, and social issues of family caregivers,¹⁸,¹⁹,²²,²³ it is still considered as a less-investigated subject.¹⁸,¹⁹,²⁴ Some variables including sex, age, and relationship of the main caregiver with patient was shown to be associated with PAC.²⁵,²⁶ For example, wife caregivers reported less positive experiences in Lin et al’s study.²⁵ Moreover, Roff et al have shown race as an important factor in PAC. In their large study conducted on 618 caregivers,
the PAC scores were higher in African Americans compared to Caucasians.21 Liew et al in a cross-sectional study of 334 Chinese caregivers demonstrated that several factors including mental well-being, the use of active management as a caregiving strategy, along with educational and supportive programs could significantly predict gain.27 Self-efficacy effectively associated with PAC according to another study by Semiatin and O’Connor conducted on 57 family caregivers. This finding was remained after adjusting for demographic variables as well as patients’ neuropsychiatric symptoms and caregivers’ depression.22

The conceptual differences between caregiver burden and PAC logically can suggest different factors related to these 2 constructs.27 Identifying factors associated with PAC can play an important role in the caregivers’ health and patients’ well-being. Importantly, it can offer insight into measurement and even intervention methods. We hypothesized that individuals with higher levels of caregiver burden would have lower PAC. In order to test the study’s main hypothesis, the authors investigated the potential association of caregiver burden and PAC in family caregivers of patients with dementia, in Iran.

Methods
Participants
This was a cross-sectional study that recruited 153 caregivers using convenient sampling, from September to May 2011. We used Iran Alzheimer’s Association (IAA) for enrollment of study caregivers. Iran Alzheimer’s Association is the referral center for registering patients with Alzheimer and dementia, which recruited its patients through a referral system in Iran. All patients in IAA had a clinical diagnosis of dementia by at least 1 neurologist, and magnetic resonance imaging was used by the same neurologist in making the diagnosis. In this study, all recruited patients were diagnosed with dementia due to Alzheimer disease. After clarification of the study’s main goals, all of the main caregivers who daily referred to the IAA were requested to participate in the study. We continued the sampling process to the point where the sample size reached to a predetermined sufficient count. Only family members who were the primary caregivers of patients were included in the study and those who were formal or friend caregiver were excluded. The lack of dementia in the study caregivers was also considered as the study inclusion criteria. When there was more than 1 caregiver for the patients, the one who spent more time was selected as the main caregiver. Informed consent forms were also obtained.

Measurements
The data collection was interview based and conducted by trained interviewers. Positive aspect of caregiving questionnaire (PACQ),20 Iranian caregiver burden questionnaire,28 Barthel Index,29 and a sociodemographic checklist were used to collect the corresponding data. Iranian caregiver burden questionnaire is a 29-item scale developed for measuring the caregiver burden in Iranian caregivers. Besides some items concerning the cultural properties of Iranian caregivers, its content is quite similar to Zarit burden interview. The validity and reliability of this questionnaire have already been demonstrated.28 The attainable score for caregiver burden and PAC were 0 to 116 and 0 to 40, respectively. We used a single-item quality of life (QOL) as well as a single-item self-rated health question with 5 possible answers to measure caregivers’ QOL and general health, respectively.30 We used PACQ, a 10-item scale with attainable score of 0 to 40, for measuring PAC.20 It includes 2 domains: (1) patient and caregiver relationship including “more meaningful life” and “providing a compensation opportunity” items and (2) caregiver’s psychological well-being including “Spiritual/moral remuneration,” “become a better human,” and “bring family members closer together” items. Positive aspect of caregiving questionnaire have shown an acceptable content and construct validity as well as reliability indices.20 Its relevancy, clarity, and comprehensiveness as content validity indices were 97%, 93%, and 93%, respectively. Its intraclass correlation coefficient and Cronbach’s α were 0.905 and 0.785, respectively.20 Barthel index as a valid and reliable scale was used for measuring the patients’ dependency level when performing their activities of daily living (10 activities).29 Using a well-done standard backward–forward translation, the Persian version of this questionnaire was prepared. Data on age, marital status (unmarried-married), sex, and the job status of the main caregivers were also obtained. The questionnaire also included age, gender, marital status, education, number of caregivers, number of children, as well as insurance status of patients. The global deterioration scale was also used to determine the disease stage.

Data Analysis
We used a multiple linear regression model with PAC as the response and caregiver burden as the main predictor. We examined a large number of variables for clarifying whether they had the confounding criteria (causally related to the outcome, associated with the exposure of interest, not an intermediate on the pathway, and ~10% change in the coefficient),31 including age, sex, marital status, and education level for both caregivers and patients. Moreover, the socioeconomic status of caregivers, patients’ dependency level, and the grade of disease were all examined.9,17 The assumption of the linear regression model was also checked. The adjusted β for the caregiver burden is estimated after adjusting for the following potential confounders: age and marital status of the main caregiver along with the patient dependency level. All statistical analyses were done using Stata version 12 (STATA Corp, Texas).

Results
One hundred thirty-two family caregivers fulfilled the study scales. As shown in Table 1, the mean (standard deviation [SD]) of PAC and caregiver burden were 27.5 (8.10) and 55.2 (23.70), respectively. While 80% of caregivers were
married, only 25% of them were employed. Eighty-nine percent of the patients were insured by either the Iran Health Insurance Organization or the Social Security Organization. The characteristics of the study caregivers and patients are shown in Table 1.

The basic assumptions of multiple linear regression model (including normal distribution of the variables as well as the lack of multicollinearity) were met. Table 2 shows the adjusted $\beta$ (95% confidence interval [CI]) for the association between caregiver burden and PAC as the dependent variable. As shown in this table, the caregiver burden was negatively associated with PAC after adjusting for the potential confounders (mean difference per a 1-unit increase in caregiver burden ($\beta = -0.12; 95\% \text{ CI} \ [-0.18 \text{ to } -0.056]; P < .001$; see Table 2). In other words, the average difference in PAC between caregivers with burden scores of 100 and 20 would be $80 \times 0.12 = 9.6$ points, which is quite substantial. Caregivers’ age and marital status were the other remaining covariates having significant association with PAC in the linear regression model.

Table 1. Distribution of Clinical and Sociodemographic Variables of Patients With Dementia and Their Caregivers.a

<table>
<thead>
<tr>
<th>Variables</th>
<th>Patients With Dementia, n (%)b</th>
<th>Main Caregivers, n (%)b</th>
</tr>
</thead>
<tbody>
<tr>
<td>PAC mean, mean (SD)</td>
<td>–</td>
<td>27.5 (8.10)c</td>
</tr>
<tr>
<td>Caregiver burden, mean (SD)</td>
<td>–</td>
<td>55.2 (23.70)c</td>
</tr>
<tr>
<td>Barthel index (degree of dependency), mean (SD)</td>
<td>65.3 (30)c</td>
<td>–</td>
</tr>
<tr>
<td>Patients’ grade of disease (based on GDS), mean (SD)</td>
<td>5.4 (1.13)</td>
<td>–</td>
</tr>
<tr>
<td>Patients’ grade of disease categories (based on GDS)</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>27 (20.61)</td>
<td>–</td>
</tr>
<tr>
<td>5</td>
<td>36 (27.48)</td>
<td>–</td>
</tr>
<tr>
<td>6</td>
<td>43 (32.82)</td>
<td>–</td>
</tr>
<tr>
<td>7</td>
<td>25 (19.08)</td>
<td>–</td>
</tr>
<tr>
<td>Number of secondary caregivers, mean (SD)c</td>
<td>–</td>
<td>2.74 (1.7)</td>
</tr>
<tr>
<td>Number of children, mean (SD)</td>
<td>4.77 (2)</td>
<td>–</td>
</tr>
<tr>
<td>Age, mean (SD), years</td>
<td>77.1 (7.4)</td>
<td>53 (13)</td>
</tr>
<tr>
<td>Gender (female)</td>
<td>82 (62.1)</td>
<td>111 (84.0)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>70 (53.0)</td>
<td>101 (80.2)</td>
</tr>
<tr>
<td>Unmarried (single, widowed, divorced)</td>
<td>62 (47.0)</td>
<td>31 (19.8)</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>–</td>
<td>33 (25.0)</td>
</tr>
<tr>
<td>Other (unemployed, housekeeper, retired)</td>
<td>–</td>
<td>99 (75.0)</td>
</tr>
<tr>
<td>Insurance status (insured)</td>
<td>116 (89)</td>
<td>–</td>
</tr>
</tbody>
</table>

Abbreviations: GDS, global deterioration scale; PAC, positive aspect of caregiving; SD, standard deviation.

a$N = 132$.
b$N$ (%), except where otherwise indicated.
cThe attainable range for caregiver burden is (0 to 116), for PAC (0 to 40), and for the Barthel index (0 to 100).
dOther patients’ children who sometimes support the primary caregiver.

Table 2. Multiple-Linear Regression Model Presenting the Adjusted Association Between Caregiver Burden and Positive Aspects of Caregiving.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Adjusted $\beta$ (95% CI)</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver burden</td>
<td>$-0.12$ ($-0.18$ to $-0.056$)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Age of the main caregiver</td>
<td>$-0.15$ ($-0.26$ to $-0.037$)</td>
<td>.009</td>
</tr>
<tr>
<td>Marriage status of caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>$-4.67$ ($-8.12$ to $-1.21$)</td>
<td>.009</td>
</tr>
<tr>
<td>Patients’ dependency level</td>
<td>$-0.04$ ($-0.08$ to $0.008$)</td>
<td>.109</td>
</tr>
</tbody>
</table>

*The coefficient represents the difference between unmarried versus married caregivers.

Importantly, older ($\beta = -0.15; 95\% \text{ CI} [-0.26 \text{ to } -0.037]; P = .009$) and unmarried caregivers ($\beta = -4.67, 95\% \text{ CI} [-8.12 \text{ to } -1.21]; P = .009$) appeared to experience fewer positive aspects of caregiving.

Figure 1 shows the scatterplot of PAC versus caregiver burden. As is shown, there is a rather clear decreasing trend in PAC with increasing caregiver burden.

### Discussion

After adjusting for the measured confounders, caregiver burden showed a significant negative association with PAC. This finding suggests that the PAC and caregiver burden are not exclusively opposite constructs. Moreover, it can reinforce the previous findings of Rapp and Chao had demonstrated that the concept of strain and gain is not merely contrary.32 In line with our finding, Rapp and Chao have reported a moderate inverse significant correlation between caregiver burden and caregivers’ gain.32 Appraisal of the caregiving role24 as well as “the experience of personal growth and enhanced interpersonal relationships”27 were frequently suggested as possible definitions for gain. This means that the PAC is not as the same as the concept of gain and this should be considered when interpreting...
the reported inverse association between gain and caregiver burden in the study by Rapp and Chao. Similarly, Cohen et al reported that positive feeling in caregivers has a negative significant association with the negative outcomes of caregiving including caregiver burden and depression. Inconsistently, there was not any statistically significant association between higher caregiver burden and caregiving satisfaction in the study by López et al. Moreover, Pinquart and Sörensen in his meta-analysis demonstrated that different types of interventions on caregivers of patients with dementia may have had a significant small effect on reducing caregiver burden. As we previously demonstrated, caregiver burden was shown as the strongest predictor of both caregivers’ health and QOL. Accordingly, reducing caregiver burden can be considered as a practical step in enhancing PAC. Similarly, identifying the main factors associated with PAC can be helpful in improving the caregivers’ general well-being as well as the quality of care of patients with dementia.

In the current study, the caregivers experienced a moderate to high PAC (mean [SD]: 27.5 [8.10]). However, López et al and Rapp and Chao, using a different scale of PAC, had reported a high level of caregiving satisfaction and gain in their studies. However, reporting positive experience of caregiving is a phenomenon that might be dependent on several variables including sex, age, and relationship of the main caregiver with patient. This could somewhat limit the comparability of findings from different studies.

There are some limitations when interpreting the study findings. First, the cross-sectional nature of design limits the cause–effect interpretation of the detected associations. Therefore, this needs to be repeated in the further studies. Second, some degree of selection bias could occur for nonrandom method of study sampling. However, considering the mental and physical circumstances of patients and their caregivers, random sampling was not employed.

The well-acknowledged inverse association of caregiver burden with PAC remained after adjusting for some potential confounders. This finding may have an important implication for development of the supporting interventional and/or educational programs, aiming at alleviating the overall imposed burden. For example, interventional programs in order to enhance the caregivers’ abilities for managing both daily tasks and caregiving role including problem-solving skills and self-efficacy techniques are recommended. Likewise, educational programs for decreasing the incidence of depression along with subjective or chronic stress are also suggested. The social support services and general group supports would be important in improving the QOL, mental and physical health, and well-being of dementia caregivers. It reinforces the need for social support and services utilization for increasing general health and QOL of caregivers.

Authors’ Note
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