CAREGIVER BURDEN IN CAREGIVERS OF HOSPITALIZED OLDER ADULTS AND ITS ASSOCIATED FACTORS

Sobrecarga do cuidador em cuidadores de idosos hospitalizados e seus fatores associados

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AIM: Acute care has some complications in the older adult, a frequently overlooked complication is caregiver burden. Scarce information is available on this matter. Therefore, the objective is to describe the factors associated with caregiver burden at the moment of discharge of a hospitalized older adult, in the Mexican healthcare context. **METHOD:** This is a secondary analysis of a hospital. Bivariate and multivariate analyses were performed with caregiving burden (measured with the Zarit scale) as the dependent variable. Other variables were tested in order to assess their association with caregiver burden: sociodemographic, health-related, depression, functionality, social support and hospital length of stay, caregiver expenses, quality of life and satisfaction with received care. **RESULTS:** A total of 111 older adults with their respective caregivers were assessed. From this sample, the mean age for older adults was 73 years (\pm standard deviation 7.9 years) and 65.7% (n = 73) were women. Caregiver burden was present in 39.6% (n = 44) of the individuals. Regarding the multivariate analyses, the only variable independently associated with caregiver burden was depression in the older adult, odds ratio 1.12 (95% confidence interval 1–1.25, p = 0.045). **CONCLUSIONS:** In concordance with previous work on this matter, according to our results depression in the older adult was a trigger of caregiver burden at discharge of acute care.

KEYWORDS: caregivers; aged; geriatric assessment; depression.

OBJETIVO: Os cuidados intensivos têm algumas complicações em idosos, e uma frequentemente negligenciada é a sobrecarga do cuidador, sobre a qual pouca informação está disponível. Desse modo, o objetivo deste trabalho é descrever os fatores associados com a sobrecarga do cuidador na alta hospitalar de um paciente idoso no contexto médico mexicano. **METODOLOGIA:** Esta é uma análise secundária de um hospital. Foram realizadas análises bivariadas e multivariadas tendo a sobrecarga do cuidador (medida com a escala de Zarit) como variável dependente. Outras variáveis foram testadas com o propósito de avaliar a sua associação com a sobrecarga do cuidador: sociodemográficas, de saúde, depressão, funcionalidade, apoio social e duração da estadia hospitalar, despesas do cuidador; qualidade de vida e satisfação com o cuidado recebido. **RESULTADOS:** Ao todo, 111 idosos com seus cuidadores foram avaliados. Dessa amostra, a idade média dos idosos foi de 73 anos (± desvio-padrão de 7,9 anos) e 65,7% (n=73) eram mulheres. A sobrecarga do cuidador estava presente em 39,6% (n=44) dos indivíduos. Com relação às análises multivariadas, a única variável independentemente associada com a sobrecarga do cuidador foi a depressão nos idosos, com razão de probabilidade de 1,12 (95% intervalo de confiança 1–1.25, p = 0.045). **CONCLUSÕES:** Em conformidade com trabalhos anteriores realizados sobre este assunto, de acordo com os nossos resultados a depressão nos idosos foi um gatilho para a sobrecarga do cuidador na alta dos cuidados intensivos.

PALAVRAS-CHAVE: cuidadores; idoso; avaliação geriátrica; depressão.

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INTRODUCTION

This increase in life expectancy (lifespan) does not imply an improvement in health (health-span), due to the often reduced functional, emotional and cognitive abilities of the elderly, along with the shortage of specialized resources to take care of the special needs of older adults. It is well-recognized that the chronic diseases in older adults are the beginning of a path that takes a fully functioning individual onto limitations in the performance of the activities of daily living (ADL) or instrumental activities of daily living (IADL), leading to loss of independence and the need for help from another person — the so-called "caregiver". 1

The interaction between the caregiver and the person of care (usually a close relative) can be rewarding for both, leading to an improved health status in the elderly.^{2,3} However, inappropriate care (i.e., from caregiver) can lead to burden and in some cases, to adverse health outcomes for both, the patient and the caregiver. 4 Therefore, it is essential to state that there is an interplay between a number of factors that could lead to a proper care, or, in counterpart, to a caregiver burden.⁵ In addition, personal characteristics of the caregiver are also related to the quality of caregiving, such as age, sex, mental status and physical health.6 Likewise, previous studies have shown that the typical profile of the primary elderly caregiver is: a woman, middle-aged (45-65 years), housewife, low education level, with a close family relationship (mother, daughter or wife) with the older adult which is why they usually reside with him; however, it is not clear if this profile of caregiver provides better care.

Moreover, social features such as financial resources, cultural beliefs and social organization seem to have a great impact in this care interaction. ^{6,8} In this way, diseases with a higher need of physical care (moving, transferring, cleaning, etc.), tend to jeopardize care. ^{6,9}

As previously stated, there is a higher frequency of diseases in older adults that are associated with high hospitalization rates. When discharged, these individuals require of care, ¹⁰ a situation faced *de novo* by the family — who usually has no skills on this matter — or increasing the need of care of an already dependent older adult; both scenarios have the potential of increasing the risk of caregiver burden and its negative consequences. ¹¹ There is scarce data on the effect of the new health status of a recently discharged from acute care older adult, both on the family — suddenly transformed in a caregiver group — and in the current caregiver who is acutely exposed to higher care needs; however it is expected to be a complex response that involves mental (e.g., anxiety, depression, etc.) and physical strain. ¹²

Previous research^{11,12} has suggested that acute stress experienced by caregivers during hospitalization of a sick relative should be addressed by the health team. This should be done in an effort to reduce unintended negative consequences for both the caregiver and the hospitalized older adult, which may contribute to the collapse of primary care; causing the inability to continue to fulfill its role, promoting chronic institutionalization of the older adult, hospital readmissions, increased mortality and finally affecting the dyad. Therefore, the purpose of this study is to describe the factors associated with caregiver burden at the moment of discharge of a hospitalized older adult.

METHOD

Study groups and procedures

This report is a secondary analysis of a cohort study to test the impact of a geriatric unit compared to an internal medicine ward. Full description of the study is available elsewhere. 13 In brief, two groups of hospitalized older adults from the main health and social security system of Mexico (Instituto Mexicano del Seguro Social [IMSS]) were followed-up from their admission — to the geriatric unit or internal medicine ward — until their discharge. The study included patients 60-years or older who had at least one geriatric problem (falls, slow walking speed, tiredness, sorrow, depression, memory complaints, difficulty with instrumental activities, and bathing) assessed at the first visit after admission. Subjects with altered consciousness, not able to communicate, admitted from the intensive care unit, under assisted mechanical ventilation or with parenteral nutrition were excluded. From a total of 590 eligible subjects, 15 refused to participate and 464 did not fulfilled the selection criteria.

Participants were invited to the study in the first 48 hours after arriving to their corresponding wards. If they accepted, oral consent was obtained, from the patient and the caregiver. A baseline questionnaire was practiced in the same time frame; in addition, daily follow-up was performed (not used for purposes of this work). Prior to discharge a final questionnaire was done, were the caregiver burden questionnaire was applied.

Measurements

The dependent variable was caregiver burden. In order to measure this construct, a validated Zarit caregiver burden 22-item scale in Spanish¹⁴ was used with a cut-off value of \geq 24 points (considered as high burden), this score has been used in other studies with a concurrent validity with

depression (those caregivers with a higher probability of being depressed).¹⁵

Two sets of variables were used, one for the older adult itself and other for the caregiver. Functional status was assessed using both the Barthel Index and the Lawton ADL Scale, and a validated Spanish version of the Lawton and Brody IADL scale. 16,17 The Spanish versions of the 30-item Geriatric Depression Scale (GDS), 18,19 and the Mini-mental State Examination (MMSE) were used. 20 Quality of life was measured with the visual analogue scale (0 to 100 points, the highest the better quality of life) of the EuroQoL (EQ VAS).²¹ Moreover, the Acute Physiology and Chronic Health Evaluation II (APACHE II) score was included in the assessment of hospital mortality risk of acutely ill patients.²² The service where the older adult was hospitalized was registered (i.e., geriatric unit versus internal medicine ward) along with the length of stay. A variable for satisfaction derived from the Client Satisfaction Questionnaire was asked "How would you rate the quality of the care you received during this hospitalization?" with two possible mutually exclusive answers: well (satisfied) and average/bad (not satisfied). Comorbidity information was summarized using the Charlson Index, which has a score that ranges from 0 to 34 (the highest the score the highest the comorbidity burden).²³ Finally, to assess previous social support, the Díaz-Veiga²⁴ tool was applied, which explores the number of available persons to help, frequency of availability and the satisfaction with support. The caregiver characteristics that were considered were: age in years, sex, mean expenses during hospitalization (i.e., out-of-pocket expenses) and satisfaction with care of his/her relative.

Ethical considerations

National Scientific Research Commission at IMSS approved the study; with the following registration number: 2005785-170. Also, research was carried out in compliance with the latest version of the Helsinki Declaration. As previously described, both the older adult and their caregiver signed informed consent.

Statistical Analysis

Descriptive statistics for the variables were performed, with means and standard deviations (SD) for continuous variables and frequencies (absolute and relative) discrete ones. The bivariate analysis contrasted all the variables according to the caregiver burden, using chi-square tests for discrete variables and t-tests for the continuous ones. Finally, the multivariate analysis was performed with a logistic regression model for each of the variables and a second model with all the variables present; using the caregiver burden status as the dependent

variable. Strength of association was reported in odds ratios (OR) with 95% confidence intervals (CI). A p-value of 0.05 was considered to be significant. All analyses were performed with STATA® 12.

RESULTS

A total sample of 111 older adults with their respective caregivers was surveyed. The mean age for the patients was 73 years (\pm SD 7.9) and 65.7% (n = 73) were women, 46.8% were married and the sample had a mean of 5 years of education (\pm SD 3.8). The mean APACHE II score was of 11.1 (\pm SD 4.7), with an average of Charlson Index of 5.4 (\pm SD 3.2) and the mean of initial diagnosis of 5.1 (\pm SD 1.9). The length of stay mean was of 12.5 days (\pm SD 35.8). Regarding the caregivers, the mean age was of 48.1 years (\pm SD 15.2) and 77.2% (n = 85) were women. Up to 44 (39.6%) individuals had caregiver burden, 83.5% (n = 86) were satisfied with the care provided and an average of 18.4 USD (\pm SD 37.3) of expenses per day was found (see Table 1).

When contrasting the variables according to the caregiver burden status in the bivariate analysis, those caregiving for male older adults had higher frequency of burden (p = 0.043); also, those caring for participants with higher GDS score (11.9 vs. 9.7, p = 0.04) had higher Zarit scale scores. Additional features of the polled that had a p < 0.005 were as follows: lower quality of life measured by the EuroQOL-VAS score (57.7 vs. 69.3, p = 0.021), higher number of initial diagnoses (5.7 vs. 4.7, p = 0.007) and a higher Charlson Index score (6.2 vs. 4.9, p = 0.029). The rest of the variables did not differ significantly. However, two variables from the caregiver, satisfaction with healthcare (p = 0.051) and the sex of the caregiver (p = 0.079) surpassed slightly the cutoff value (see Table 1).

Regarding the logistic regression models, sex EuroQOL-VAS and Charlson Index, had a p < 0.005 unadjusted. In the fully adjusted model, the GDS score was the only variable that remained below the cutoff value with an OR of 1.12 (95%CI 1–1.25, p = 0.045). This model had an R^2 of 0.13, p < 0.001 (see Table 2). There were no significant interactions.

DISCUSSION

According to our results, from several characteristics of the older adults hospitalized in acute care and their caregivers, only depression in the patient was independently associated with caregiver burden. To our knowledge this work is one of the few available on caregiver burden associated with other conditions different from dementia –the current paradigm of caregiver burden in older adults⁵ — and that is realized

Table 1 Bivariate analysis* of main characteristics of the hospitalized older adult and its corresponding caregiver, contrasting those with and without burden (Zarit scale score dichotomized, > 24 points considered as burdened).

	Total (n = 111)	With burden (n = 44)	Without burden (n = 67)	p-value	
Older adults					
Age in years, mean (SD)	73 (7.9)	73.1 (7)	73 (8.4)	0.968	
Sex, n (%)					
Male	38 (34.3)	20 (45.4)	18 (26.8)	0.047	
Female	73 (65.7)	24 (54.6)	49 (73.2)	0.043	
Married, n (%)	52 (46.8)	19 (43.1)	33 (49.2)	0.531	
Number of persons living with the older adult, mean (SD)	3.8 (2.5)	3.7 (2.4) 3.8 (2.6)		0.807	
Number of persons available to support, mean (SD)	2.9 (0.8)	2.9 (0.8)	2.8 (0.8)	0.441	
Frequency of availability of persons available to support score, mean (SD)	6.8 (2.3)	6.9 (2.5)	6.7 (2.2)	0.573	
Satisfaction with social support score, mean (SD)	7.3 (2.8)	7.1 (3.1)	7.4 (2.5)	0.545	
Education level in years, mean (SD)	5 (3.8)	5.7 (3.5)	4.6 (4)	0.129	
Barthel ADL score, mean (SD)	84.6 (24.8)	79.7 (27.6)	87.8 (22.5)	0.095	
Lawton IADL score, mean (SD)	9.1 (5.1)	8.6 (5.5)	9.4 (4.7)	0.45	
GDS score, mean (SD)	10.6 (5.41)	11.9 (4.7)	9.7 (5.7)	0.04	
MMSE score, mean (SD)	19.3 (6.3)	18.7 (6.5)	19.7 (6.3)	0.414	
EuroQoL-VAS, mean (SD)	64.6 (26.2)	57.7 (28.7)	69.3 (23.4)	0.021	
APACHE II, mean (SD)	11.1 (4.7)	11.5 (4.9)	10.9 (4.6)	0.503	
Number of initial diagnoses, mean (SD)	5.1 (1.9)	5.7 (2.2)	4.7 (1.5)	0.007	
Charlson Index, mean (SD)	5.4 (3.2)	6.2 (3.9)	4.9 (2.5)	0.029	
Number of drugs at admission, mean (SD)	3.4 (2.2)	3.7 (2.5)	3.3 (2.1)	0.43	
Length of stay in days, mean (SD)	12.5 (35.8)	11.1 (12.2)	13.5 (45.2)	0.743	
Admitted to the GEMU, n (%)	37 (33.3)	15 (40.5)	22 (59.4)	0.891	
Caregivers					
Age in years, mean (SD)	48.1 (15.2)	47.3 (14.7)	48.7 (15.6)	0.646	
Sex, n (%)					
Men	25 (22.8)	6 (13.9)	19 (28.4)	0.079	
Women	85 (77.2)	38 (86.1)	48 (71.6)		
Satisfied with healthcare, n (%)	86 (83.5)	29 (33.7)	57 (66.2)	0.051	
Mean expenses by day in USD, mean (SD)	18.4 (37.3)	13.9 (16.7)	21.4 (4)	0.301	

^{*}Bivariate analyses were performed with t-tests for continuous variables and x² for categorical ones; ADL: activities of daily living; SD: standard deviation; GDS: geriatric depression scale; MMSE: mini-mental state examination; EuroQoL-VAS: European quality of life visual analogue scale; APACHE II: Acute Physiology and Chronic Health Evaluation II; GEMU: geriatric evaluation and management unit; USD: United States dollars.

Table 2 Unadjusted and fully adjusted odds ratio with a logistic regression.

	Unadjusted OR (95%CI)	p-value	Adjusted OR (95%CI)	p-value
Sex (female reference)	2.26 (1.01–5.06)	0.045	2.11 (0.76-5.81)	0.147
Education level in years	1.08 (0.97-1.19)	0.132	1.06 (0.93-1.21)	0.361
EuroQoL-VAS	0.98 (0.96–0.99)	0.025	0.99 (0.97-1.01)	0.527
GDS score	1.07 (1.01–1.16)	0.043	1.12 (1–1.25)	0.045
Number of initial diagnoses	0.96 (0.7–1.32)	0.833	1.21 (0.76-1.91)	0.411
Charlson index	1.14 (1.01–1.29)	0.034	1.01 (0.86-1.19)	0.859
Caregiver sex	2.44 (0.88–6.72)	0.084	3.18 (0.89–11.36)	0.075
Satisfied with healthcare	2.8 (0.96–8.13)	0.057	0.72 (0.17–2.95)	0.656

OR: odds ratio; CI: confidence interval; EuroQoL-VAS: European quality of life visual analogue scale; GDS: geriatric depression scale.

in the context of acute care. In this work, older adults face acute processes that may end in a higher demand of care by siblings in a hospital scenario, depicting another side of the older adult complex interaction with their family, now in a health context.

There are few reports of the prevalence of caregiver burden in geriatric hospitalized patients. Desbiens et al.²⁵ conducted a study on stress in caregivers of hospitalized patients and found that in 26.1% of the cases caring for the patient added tension to caregivers' lives. We found higher prevalence of caregiver burden (39.6%), but, differently from our study, stress was measured in the place of burden in their study. There is, however, a paucity of evidence in the current literature regarding the prevalence of caregiver burden in hospitalized geriatric patients.

Characterization of the caregivers was like other reports. For example, Lin and Lu²⁶ found that 63.2% of the caregivers were women in a group of older adults hospitalized because of hip fracture, and had an average age of 53.1 years. Moreover, Saunders also characterized the primary caregiver of a group of older adults hospitalized with heart failure as: women (84%) with an average age of 58.1 years, married, living with the patient object of their care, and spending up to ten hours in caregiving.²⁷ According to our results, caregivers were women (with a higher frequency, 77.2%) and with an average of 48.1 years (younger than in previous reports).

Depression in the older adult was the only factor independently associated with caregiver burden, which coincides with previous work on this matter, reporting that the caregivers of patients with depression had higher burden scores. Depression is associated with unfavorable health outcomes, poor physical and functional performance, poor adherence and self-care, loss of disability-free years, frequent hospital readmissions, increased hospital stay, and increased medical care costs, factors that may contribute to the burden of primary caregivers. ²⁸

In community-dwelling older adults with heart failure, depression of the patient has resulted in higher caregiver burden.²⁹ In addition, caregivers have reported direct consequences in their interpersonal relationships with their depressed family member, such as: worrying, stress, anguish and the need of constantly supervise and help,³⁰ situations that may become even more burdensome in a recent hospital discharge. It is believed that the management of emotions requires skills other than those used in the care of other conditions. Overall, mental illnesses are more difficult to deal with and pose higher risks both to the caregiver and to the care recipient.

Another finding with marginal significance in our work was the relationship between the disability of the hospitalized elderly and caregiver burden, found in the same way in the article published by Lin and Lu²⁶ which describes that the greater the independence of the patient the lower is the incidence of caregiver burden. Moreover, Yeh and Chang concluded that the ADL dependence of care recipients was a significant predictor of the collapse of caregivers.³¹

Both depression and disability point to two different phenomenon that concur in an acutely sick older adult, that suddenly falls in the need of help from its relatives. On the one hand the caregiver must deal with emotional stress of the depressive symptoms and in the other to physical strain of disability, ending in the caregiver burden condition.

This work has several limitations, such as the lack of more variables both from the patient, but also from the caregiver, such as the one described in the Saunders study.²⁷ Moreover, as previously stated by Mendez-Luck et al. our population has different beliefs regarding caregiving, and in some cases, they have rewarding feelings or a sense of higher responsibility that in turn makes caregiving somehow easier;^{2,3} which should preclude the generalization of our findings to other contexts. Finally, the marginal significance of some variables (type II error), could point to a lack of power for demonstrating these associations.

CONCLUSION

Affective problems are addressed in the so-called geriatric assessment, and if detected they are treated. However, in a hospital scenario, depression is a trigger for caregiver burden and could be halted with proper detection and treatment in acute care contexts. Further research should aim at finding other characteristics both of the older adult and the caregiver in order to implement strategies that could diminish the frequency of burden.

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CONFLICT OF INTERESTS

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