ORIGINAL RESEARCH

Sociodemographic and Clinical Variables Related to the Overburden of the Informal Caregivers of Patients Hospitalized for Chronic Obstructive Pulmonary Disease Exacerbations

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Objective: To increase our knowledge of the patient variables related to the overburden of the caregivers of patients with acute exacerbations of chronic obstructive pulmonary disease (AECOPDs).

Methodology: This was a cross-sectional study of patients with severe COPD who have informal caregivers. We performed a multivariate analysis of sociodemographic (economic situation, care, dependence, social risk, and use of social services) and clinical (degree of dyspnea, previous hospitalizations, disease impact, pulmonary function, and comorbidity) factors and related these to the burden of informal caregivers, as evaluated using the Zarit scale.

Results: The study included 91 patients, age 72.6±8.7 years and 80 were male (89.7%); the mean modified Medical Research Council dyspnea scale (mMRC) score was 2.5±0.8; mean FEV_1 was 39.5 ± 13.2%; and 70 patients (76.9%) were dependent for basic activities. Of the informal caregivers, 90 (90.9%) were women, 49 (49.4%) were partners or spouses, and 29 (29.6%) were daughters. The mean Zarit questionnaire score was 51.4±14.2, with 63 of carers (69.2%) perceiving some overburden, and 34 (37.4%) describing the overburden as mild–moderate. The variables related to informal caregiver overburden in the multivariate study were the previous use of social resources [OR = 8.1 (95% CI = 1.03–69.9); $p = 0.04$], degree of mMRC dyspnea 3–4 [OR =4.7 (95% CI = 1.7–13.2); $p = 0.003$], and two or more admissions for AEPOC in the previous year [OR = 4.5 (95% CI = 1.7–13.2); $p = 0.003$]. Of the informal caregivers of patients who had presented two or more of these variables, 92.3% perceived an overburden.

Conclusion: The variables associated with overburden are easily accessible in patient medical records, or can be obtained by interviewing patients or their relatives. This information would allow to detect and assess the overburden of informal caregivers to provide an early warning of this problem.

Keywords: COPD, hospitalizations, caregiver overburden, predictors

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Introduction

Chronic obstructive pulmonary disease (COPD) is a very prevalent disease which results in many deaths, a high degree of disability, and significant consumption of health and social resources.[1,2] Because of the progressive aging of the population and continued exposure to inhaled toxic substances, its impact is expected to increase in

the coming decades.[3] Chronic symptoms (mainly dyspnea) and a limited ability to carry out daily life activities prevent a remarkably high number of patients with advanced COPD from leading a normal life from a physical, psychological, and social point of view.[4–6] Part of this situation is transferred to caregivers, mainly from the family environment, because they must adapt psychologically and emotionally to this fact by reorganizing their own habits.[7–10] These informal caregivers, who are usually close relatives such as spouses or daughters, continue to be an essential element of the health and social care of patients with COPD, and so their well-being should also be a key objective for professionals providing care to COPD patients.[7,8,11,12]

There is evidence that being cared by a family member is beneficial to COPD patients because it can increase their adherence to medication and physical activity guidelines and can reduce tobacco consumption, which often translates into less consumption of healthcare resources.[7,8] However, the physical and emotional burden that falls upon informal caregivers can have a detrimental effect on their own physical and mental health, thereby worsening their quality of life and social relationships, which can ultimately negatively impact the COPD of patients they are caring.[7–12] Thus, a key factor in the provision of adequate comprehensive care for COPD seems to be the early recognition of this situation.[11,12]

However, unlike other chronic diseases, this aspect is not well studied for COPD, and the scarce literature available on this topic is very heterogeneous or qualitative in nature, thereby limiting its usefulness for interpretation.[7,8,13] Although multiple questionnaires to detect caregiver overburden are available[13] and their use is recommended in many institutional documents,[14–16] they are not routinely applied in clinical practice.[4,11] In addition, until now, little robust and impartial work has been done to study the variables from the clinical or social sphere of COPD patients that would allow the burden of their caregivers to be reliably predicted.[7,8,17–20] Thus, the objective of this study was to improve our understanding of the variables that affect the burden of the caregivers of patients with COPD exacerbations, which could contribute to the timelier detection of this problem and implementation of more specific measures for its detection.

Methods
Design and Setting
This work forms part of the SocioEPOC study. This study was approved by the Galicia Ethics and Research Committee (reference number 2016/524). This was a prospective cohort study in which, over 1 year (from January 2nd to December 31st 2017) patients with an index admission (first admission during the study period) to the Pneumology Service at a third-level public hospital (with a reference population of 375,000 inhabitants) and with a primary diagnosis of an acute exacerbation of COPD (AECOPD) were consecutively included. Patients who declined to participate or for whom the diagnosis of severe COPD or AECOPD was ruled out during admission or follow-up were excluded from the study. All patients included and their caregivers signed the informed consent to participate in the study. This study was conducted in accordance with the Declaration of Helsinki.

The methodology used for this study was previously published elsewhere in a greater detail.[4,21] After the third or fourth day of hospital admission, we interviewed the patient and their informal caregiver, and completed the information by reviewing the electronic medical records of the COPD patient, including social, demographic, and clinical data. This study included patients who had informal caregivers at the time of inclusion. According to the academic literature, this term refers to anyone who does not belong to the formal healthcare services system who attends to the care needs of a dependent and who does not receive any financial compensation for the help they provide.[7–13]

Information Collection and Definition of Variables
Information was obtained regarding both the COPD patient social sphere and clinical variables by administering several validated questionnaires during a personal interview with the patients. From the social perspective, we included their place of residence, availability of their own means of transport, monthly income, cohabitation situation, and availability of a caregiver (and whether this was paid or informal care), previous contact with social services, situation prior to admission regarding both dependence to carry out the basic activities of daily life (using the Barthel index [22]) and instrumental dependence (using the Lawton and Brody indexes [23]), and the social or family situation using the Gijón Socio-Family Assessment scale.[24]

We registered demographic and clinical variables including age, sex, body mass index, hospital admissions

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for COPD, respiratory sample cultures in the 12 months prior to admission, disease impact, and degree of dyspnea prior to COPD using the COPD Assessment Test (CAT) questionnaire,[25] modified Medical Research Council dyspnea scale (mMRC; [26]), and the absolute FEV_1 value (with respect to the reference value) in the last spirometry the patient had performed. The coexistence of other comorbidities was also recorded using the Charlson index[27] and Goldberg anxiety and depression scale.[28] We used the values from the indexes and questionnaires (mMRC and Goldberg) to create other dichotomous variables, as indicated in the results section. We use the cut-off points from which a clear increase in events is observed.

When there was a non-formal caregiver, their burden was also evaluated using the Zarit scale, validated in Spanish. This instrument explores the negative effects the task of caring can have on the health of the caregiver in different areas of their life: physical and mental factors, social activities, and financial resources. The Zarit scale comprises 22 items, and the score for each item ranges from 0 (never) to 4 (almost always), with overall scores lower than 46 points indicating the lack of perception of overburden and scores exceeding 55 points indicating intense overburden.[29,30] All the social variables were assessed as dichotomous variables, based on their respective recommended cut-off points.[22–24,29,30]

Statistical Analysis

For the qualitative variables, we described the number of cases and their percentage prevalence, while we calculated the mean and standard deviation (SD) for the numerical variables. Contingency tables were constructed with the number of cases and their percentage for the dichotomous variables, and these were compared using Chi-squared or Fisher exact tests. Numerical variables were compared using Student's t-tests. To evaluate the variables that were independently related to caregiver overburden, we carried out a logistic regression analysis, adjusted by other variables such as age and gender of the patient, which included all the variables with p<0.10 in the univariate study. In addition, we calculated the odds ratios (ORs) with their 95% confidence intervals (95% CIs). The numerical variables selected for inclusion in the model were converted to dichotomous variables before their use. All the analyses were performed by using SPSS software (Version 25; IBM Corp, Armonk, NY, USA).

Results

The SocioEPOC Cohort comprised 253 patients; a detailed description and analysis of all the variables collected for these patients has already been published.[6,21] Briefly, 63 (24.9%) of the patients lived alone, 71 patients lived with others, but those household members did not have a caregiver role, and 119 (47%) had a primary caregiver, of which 20 (16.8%) were paid and 99 (83.2%) were informal caregivers. These data are shown in the study flowchart presented in Figure 1. Of the informal caregivers, 90 (90.9%) were women; 49 (49.4%) were partners or spouses (3 were male), 29 (29.6%) were children (4 were male), 3 (2.4%) were mothers, and 18 were other relatives or loved ones (2 were male).

Eight of the primary caregivers declined to complete the Zarit scale questionnaire. Among the 91 who did complete it, mean score was 51.4 ± 14.2 with 63 (69.2%) reporting the perception of some overburden, which was mild–moderate (46–55 points) in 34 (37.4%) cases and intense (score ≥ 56) in 29 cases (31.9%); 25 caregivers (27.5%) did not report any overburden. No differences were found in the Zarit scale scores obtained according to caregiver sex or their kinship or relationship with the COPD patient. The demographic, clinical, and social variables of the COPD patients who had an informal caregiver in the SocioEPOC Cohort are described in Tables 1 and 2, where they are compared according to whether their caregiver was overburdened or not according to their Zarit scale score.

The clinical variables that were related to informal caregiver burden in the univariate study were level of dyspnea, number of previous hospital admissions, and the presentation of depression; the social variables related to informal caregiver burden in the univariate study were
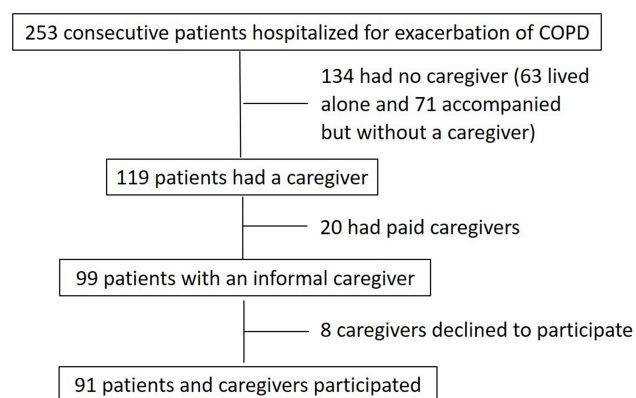

Figure 1 Flowchart showing the inclusion of patients in this study.

Table 1 Demographic, Clinical, and Social Variables of the COPD Patients That Had Informal Caregivers and a Comparison According to Whether These Carers Presented Overburden

Characteristics of the Patients	Total (91)	Caregivers without Overburden N = 28	Caregivers with Overburden N = 63	P[#]
Male (sex)[a]	80 (89.7%)	23 (82.1%)	57 (90.5%)	0.30
Age (years)[b]	72.6 ± 8.7	70.8 ± 8.1	73.6 ± 8.9	0.12
BMI (kg/m^2)[b]	28.3 ± 6.3	28.6 ± 7.1	28.2 ± 6.1	0.71
Active smoker[a]	23 (25.3)	9 (32.2)	14 (22.4)	0.42
Number of admissions in the previous year[b]	1.01 ± 1.3	0.6 ± 0.6	1.1 ± 1.5	0.04
≥ 2 admissions within the previous year[a]	25 (27.5)	3 (10.7)	22 (34.9)	0.02
Positive sputum culture within 12 months prior to admission[a]	24 (26.7)	6 (21.4)	18 (29.0)	0.60
CAT score[b]	21.0 ± 7.3	20.0 ± 7.5	21.4 ± 7.2	0.30
Dyspnea (mMRC)[b]	2.5 ± 0.8	2.1 ± 0.8	2.7 ± 0.8	0.003
Dyspnea 3–4 (mMRC)[a]	52 (57.1)	9 (32.1)	43 (68.3)	0.002
FEV$_1$ value (% reference)[b]	39.5 ± 13.2	40.6 ± 12.4	39.1 ± 13.7	0.53
FEV$_1$ value (mL)[b]	1040.4 ± 453.3	1047.6 ± 435.7	1037.5 ± 464.9	0.91
Charlson´s index[b]	1.8 ± 0.9	1.8 ± 1.0	1.7 ± 0.9	0.5
Goldberg´s questionnaire (total)[b]	6.4 ± 4.0	5.7 ± 4.0	6.7 ± 4.0	0.21
Goldberg´s depression[a]	49 (54.4)	10 (35.7)	39 (62.9)	0.02
Goldberg´s anxiety[a]	44 (48.9)	12 (42.9)	32 (51.6)	0.41
At-home oxygen therapy[a]	52 (57.8)	15 (50.0)	38 (61.3)	0.36
Primary studies[a]	80 (87.9)	25 (89.3)	55 (87.3)	0.99
Rural area of residence[a]	48 (52.7)	18 (64.3)	30 (47.6)	0.17
Monthly income < 800 €[a]	42 (46.7)	14 (51.0)	28 (44.4)	0.65
Does not have own transport[a]	70 (76.9)	19 (67.9)	51 (81.0)	0.18
Previous use of social services resources[a]	15 (16.5)	1 (3.6)	14 (22.2)	0.03
Barthel´s questionnaire[b]	78.1 ± 19.8	84.3 ± 16.9	75.2 ± 20.5	0.004
Dependency for basic activities (Barthel questionnaire)[a]	70 (76.9)	18 (64.3)	52 (82.5)	0.05
Lawton & Brody questionnaire[b]	3.4 ± 2.3	4.43 ± 2.3	3.1 ± 2.2	0.01
Dependency for instrumental activities (Lawton &Brody questionnaire)[a]	85 (93.4)	24 (85.7)	61 (96.8)	0.05
Gijón´s socio-familiar questionnaire[b]	10.1 ± 2.1	9.1 ± 2.2	10.2 ± 1.8	0.01
Risk/problem according to Gijón´s socio-familial questionnaire[a]	53 (58.2)	13 (46.4)	40 (63.5)	0.10

Notes: [a]Expressed by their total number and their % in parentheses.[b]Expressed as mean ± standard deviation. [#]The p-value refers to the comparison of the frequency or value of this variable in each of the groups.
Abbreviations: CAT, COPD Assessment Test; FEV$_1$, forced expiratory volume in the first second; BMI, body mass index; mMRC, modified Medical Research Council dyspnea scale.

Table 2 Result of the Logistic Regression Analysis of the COPD Patient Variables Related to Caregiver Burden

Variable	Adjusted OR (IC 95%)	P
Male sex	1.9 (0.38–9.4)	0.42
Age	1.03 (0.96–1.1)	0.39
≥ 2 hospital admissions within the previous year	4.5 (1.1–18.3)	0.03
Dyspnea 3–4 (mMRC)	4.7 (1.7–13.2)	0.003
Goldberg´s depression	2.2 (0.7–6.8)	0.14
Previous use of social services resources	8.1 (1.03–69.9)	0.04
Dependency for basic activities (Barthel questionnaire)	0.94 (0.24–3.6)	0.93
Dependency for instrumental activities (Lawton&Brody questionnaire)	2.6 (0.2–28.9)	0.42

Abbreviation: COPD, chronic obstructive pulmonary disease.

previous use of social resources, any type of dependency for activities, and detection of a problem in social relationships. The variable with the greatest association according to the logistic regression model we employed was the previous use of social services, followed by an mMRC dyspnea score of 3–4 and having had 2 or more admissions because of disease decompensation in the year prior to their inclusion in the study (with the latter two showing a similar degree of association). These results did not change when sex and age of the COPD patients were included in the model.

Of the COPD patients who did not present any of these variables, 9 out of 26 (34.6%) of the informal caregivers had perceived some overburden; of those who had shown one of these variables, 30 out of 39 (76.9%) of the informal caregivers had perceived some overburden; and of those COPD patients that had exhibited at least two of these variables, 24 out of 26 (92.3%) of the informal caregivers had perceived some overburden (p = 0.0001).

In relation to caregivers, the Zarit score of overburden in male caregivers (n=9) was 50.8 ± 17.9, and in women (n=82) 51 ± 13, p=0.95. According to the degree of kinship, the Zarit score in partners (n=47) was 49.8 ± 10.5 and in other caregivers (n=44) 50.9 ± 17.2, p=0.75.

Discussion

The present work provides novel information because it shows that some social and clinical COPD patient variables can be used to help detecting potential physical, mental, or social alterations in their caregivers. Thus, by reviewing and noting these variables in the COPD patient

medical history or by asking a few simple questions, the overburden of most informal caregivers can be detected. In the Spanish healthcare system, caregivers are key in COPD care, especially among the most dependent or vulnerable COPD patients.[7–12] Hence, the well-being of caregivers influences the quality of life, evolution, and consumption of health resources by COPD patients,[7–12] thereby making the results of this work especially relevant to clinical practice.

In this present study, the mean hospital stay length and number of readmissions were significantly higher among patients with overburdened caregivers compared to those who did not feel overburdened (data not shown). Therefore, the implementation of specific interventions to alleviate this overburden (home help or "respite" services, psychological support, or other material or financial support) could help to improve the efficiency and safety of care for these patients.[7,8,12] To the best of our knowledge, no previously published studies have performed such a complete analysis of all these possible predictor variables in COPD patients. Most of available studies use small cohorts or are case studies, and have applied qualitative or semi-qualitative evaluation methods (which made extrapolation of their findings difficult), or have only analyzed a limited number of demographic, social, or clinical factors, especially in terms of psychological variables in the latter case.[7,8]

We did not find any studies that had examined the use of, or previous contact with, social services by the COPD patient caregivers. Nor did we find any studies that had explored the relationship between this the use of social services and a poorer psychological, clinical, or social situation among caregivers, even though this was the variable that was most strongly associated with overburden in this present study. This data reinforces the idea that health and social services records should be integrated into patient electronic medical records to facilitate the detection of caregiver overburden.

Together with fatigue, cough, and altered sleep patterns, the main symptom of COPD patients that limits their activities of daily living is dyspnea.[31] This affects family life to the point that their living habits must change, forcing them to stop sharing activities and obliging the patient and their family to implement strategies to minimize the consequences of these symptoms.[8,31] Indeed, in some studies, dyspnea combined with some emotional variables was most strongly associated with caregiver overburden.[18,32]

As mentioned in recently published work,[18] and in agreement with our own results, the number of previous severe exacerbations is another key factor related to alterations in family quality of life. Hospitalizations usually seriously disrupt the lives both of patients and their caregivers and are also one of the most powerful predictors of readmission in the following months.[4] For this reason, it would be especially useful for the social services at hospital centers to take advantage of COPD patient hospitalization events to try to detect these situations and plan interventions to help alleviate the perception of overburden among COPD patient caregivers.

In other studies, other COPD patient variables such as low socioeconomic status or lower educational levels, a greater degree of depression or anxiety, or dependence to carry out activities have been shown to predict increased involvement of the psychological or clinical spheres among COPD patient caregivers.[8,18,33] In our univariate analysis, only the latter two variables were related to caregiver overburden, although their correlation lost its significance when we adjusted for the remaining variables. Of note, this type of multivariate analysis was not carried out in most previously published articles, or when it was performed, an extremely limited number of variables were used. Moreover, the populations studied by in many previous studies was substantially different to the one we examined here, thus making comparison between them difficult.

In our study, dependence to carry out activities may not have been related to caregiver overburden, because the discriminative capacity of these variables was likely much lower in our hands than in previous studies in the same cohort[4,21] or in other studies with larger samples of patients with different profiles.[33] This was because of the specific profile of the COPD patients with a regular informal caregiver that were examined in our work—almost all of which had some degree of dependence, a high frequency of hospitalizations, and a significant need for care.

Finally, it is important to mention that our work had some limitations. First, this was a single-center study and so its results may not reflect the social and health realities of other areas in Spain, even though the clinical characteristics of the patients we included were like those described in extensive audits.[34] Second, our sample size was small for some variables, although there were strong associations found for some of them. Third, given that the COPD patients included in this study were recruited after being hospitalized, the corresponding degree of overburden described by their caregivers may have been disproportionately higher than that in other studies, perhaps influencing our findings.[7,8] However, this population of patients with COPD is especially at risk of mortality and of increased consumption of resources and therefore, the detection of problems in their social sphere, paying special attention to the situation of their caregivers, should be prioritized.[1,2,12,14–16] Fourth, some limitations are associated with the questionnaires and scales we used to detect overburden, although the Zarit scale has been used previously in a similar context[13] and was validated for use in Spanish[8,29,30] to assess emotional, physical, social, and economic factors. Finally, only the degree of kinship/relationship with the COPD patient and sex of the caregivers was included and so other variables such as age or the presence of comorbidities may have also influenced the perception of increased overburden. However, this fact does not detract from the other results described in this study. Initially the study was not designed to test the burden of caregivers and therefore we did not collect information on particular characteristics. But most caregivers were spouses or daughters, in any case cohabitants with the case. Therefore, they share a similar socioeconomic status. They also share the same living area along with distance to hospital.

In addition to the previously mentioned advantages of this research, this work included more COPD patient variables from multiple spheres (demographic, clinical, and social) than prior work, we included data from social workers and clinicians with extensive experience, and performed consecutive case sampling over a year (all of them during hospitalization for a COPD exacerbation), all of which limited the possibility of selection biases and made the sample more representative. Furthermore, the free and universal health coverage provided in Spain, together with the fact that our hospital is the direct reference area (without intermediate healthcare centers or regional hospitals) for almost 400,000 people, reinforce the likelihood of the representativeness of our population sample.

In conclusion, accessible variables are available in the medical records of COPD patients (or can be obtained by interviewing them or their relatives) that would help alert social workers to the overburden of informal caregivers. These could serve as useful early warning signs for this problem, allowing social services to plan specific interventions to help minimize caregiver overburden. In addition, it has been shown that decreasing caregiver burden reduces the COPD patient health system burden, thereby also reducing their hospital stays and readmissions.

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Disclosure

The authors reported no conflicts of interest for this work.

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