



ELSEVIER

respiratoryMEDICINE

Assessment of the burden of caregiving for patients with chronic obstructive pulmonary disease

Renata A. Pinto^a, Marcelo A. Holanda^b, Marta M.C. Medeiros^b,
Rosa M.S. Mota^c, Eanes D.B. Pereira^{b,*}

^aDepartment of Medicine, Federal University of Ceará, Brazil

^bAssociate Professor, Department of Medicine, Federal University of Ceará, Brazil

^cAssociate Professor, Department of Mathematics and Applied Statistic, Federal University of Ceará, Brazil

Received 13 March 2007; accepted 1 June 2007

Available online 12 July 2007

KEYWORDS

Caregivers;
Disease burden;
COPD;
Quality of life

Abstract

Objective: To determine the effect of chronic obstructive pulmonary disease (COPD) on the quality of life of caregivers.

Design and methods: A cross-sectional study was carried out with forty-two COPD patients and their primary caregivers. Patients were assessed with the medical outcome survey short form (SF-36), the physical and mental component summary (PCS and MCS), Saint George's respiratory questionnaire (SGRQ), 6-min walking test, and spirometric and blood gas measurements. Caregivers were assessed using the medical outcome survey short form (SF-36), the physical and mental component summary (PCS and MCS), the 5-point Likert scale for measuring caregiver/patient relationships and the caregiver burden scale (CB scale).

Results: The majority of caregivers were female (85.3%), married (59%) and had low levels of income and schooling. The mean age was 51.6 ± 16 years. Mean caregiver PCS and MCS scores were 45.9 ± 10 and 46 ± 12 , while the mean total burden score was 1.79 ± 0.6 . The regression analysis showed caregiver/patient relationship quality, caregiver MCS scores and patient PCS scores to be important predictors of burden and explained 63% of the variance.

Conclusions: COPD causes a significant impact on the quality of life of caregivers. The two most important predictors of COPD burden are the relationship between caregivers and patients and caregiver MCS scores.

© 2007 Elsevier Ltd. All rights reserved.

*Corresponding author. Department of Medicine, Federal University of Ceará, Rua Barbara de Alencar 1401, CEP 60140000 Fortaleza, Ceará, Brazil. Tel.: +55 85 32243541; fax: +55 85 32641618.

E-mail address: eanes@fortalnet.com.br (E.D.B. Pereira).

Introduction

Chronic obstructive pulmonary disease (COPD) is now a major public health concern. Deaths attributable to COPD in Latin

America have increased by 65% in the last decade. For example, a multi-center survey on the COPD burden in Latin America carried out by the PLATINO Project (Proyecto Latinoamericano de Investigación en Obstrucción Pulmonar) found a COPD prevalence of 15.8% in the city of São Paulo, Brazil.¹

Elderly and highly disabled patients with COPD have a high prevalence of depressive symptoms² and consequently lower self-reported health-related quality of life (HRQL).^{2,3} Anxiety and depressive symptoms are common in patients affected by COPD, even when their disease is mild in terms of forced expiratory volume and respiratory symptoms.⁴

Patients with COPD face functional physical limitations and eventually require the help of others at certain times in their lives. However, it is well known that the caregivers of patients with chronic disease experience a high degree of distress.⁵

The issues identified in studies on caregivers of different groups of chronically ill patients seem relatively consistent across these disability groups and include depression,^{6,7} overload,⁸ burden,⁹ and personal health issues.^{9,10}

Research has tended to focus on caregiving associated with specific populations, such as elderly subjects with physical and mental dependence,^{11–13} patients with chronic conditions such as rheumatoid arthritis,¹⁴ patients receiving long-term mechanical ventilation¹⁵ and patients with tracheostomy.¹⁶ Studies with caregivers of COPD patients are scarce and not all of these studies have used regression models to evaluate quality-of-life variables.^{17–20}

It is important to learn more about the characteristics of caregivers in order to optimize the use of support or intervention measures and reduce negative impacts on caregiver lifestyle and quality of life. Such studies may also contribute to keeping chronic patients out of the hospital and postponing institutionalization.

Our objective was to evaluate the effect of COPD on the quality of life of primary caregivers.

Methods

Patient selection

Forty-two patients diagnosed with COPD according to global initiative for chronic obstructive lung disease (GOLD)²¹ criteria were studied at the pulmonology outpatient clinic of a teaching hospital in Fortaleza (Ceará, Brazil) from September 2005 to March 2006. The hospital is a public tertiary care facility providing health care mostly for patients from low-income settings.

Caregiver selection

Forty-two primary caregivers of COPD patients were studied. A primary caregiver was defined as a person who provides most of the care required by the patient during the course of the disease and is most intimately aware of the patient's needs.

Exclusion/inclusion criteria

All COPD patients accompanied by a primary caregiver attending our pulmonology outpatient clinic for a routine

day-time consultation were referred to the study coordinator. After being informed about the study objectives, patients and caregivers were invited to participate in the study and requested to give their written consent. Patients attending the clinic without a primary caregiver were scheduled for interviews at a later time. The exclusion criteria were refusal of the caregiver or patient to participate, non-attendance of scheduled interviews, caregiver profile different from the study definition, presence of a disease more disabling than COPD and presence of severe cognitive deficiency in the patient or caregiver preventing them from understanding the questionnaire.

Study design and measurements

The study was cross-sectional and was approved by the institutional review board of the teaching hospital. Patients included in the study were interviewed for socio-demographic data such as gender, age, marital status, current job, schooling and individual income.

Clinical patient data included disease duration, functional class according to GOLD, 6-min walking test and spirometric and arterial blood gas measurements.

The forced expiratory volume in 1 s (FEV₁), forced vital capacity (FVC) and FEV₁/FVC were determined in the lung function laboratory.²² According to the GOLD expert panel,²¹ the patients were classified into four functional classes based on post-bronchodilator FEV₁ findings.

Caregivers were asked about the presence of comorbidities, use of medication, frequency of need of medical assistance during the preceding year, help received in taking care of the patient, number of persons in the residence, whether he or she lived with the patient and the length of time caring for the patient.

The quality of life of both patients and caregivers was evaluated with the medical outcome survey short form (SF-36). The SF-36 has been summarized into eight scales, each of which measures a health concept. The scales refer to eight different domains: *physical function* (PF), *role-physical* (RP), *bodily pain* (BP), *vitality* (VT), *role-emotional* (RE), *mental health* (MH), *social function* (SF) and *general health* (GH). Scores range from 0 to 100, with 0 (zero) as the poorest condition and 100 (one hundred) as the best condition.

The originators of the SF-36 recently developed algorithms to calculate two psychometrically-based summary measures: the physical component summary (PCS) score and the mental component summary (MCS) score.^{23,24} These have been standardized to have a mean of 50 and a standard deviation of 10. Higher scores on the scales indicate better health-related quality of life. The PCS and MCS provide greater precision, reduce the number of statistical comparisons needed, and eliminate the floor and the ceiling effects noted in several of the subscales.

The Saint George's respiratory questionnaire (SGRQ) was used to assess the quality of life of patients only. Both the SGRQ and the SF-36 have been translated, adapted and validated in Brazil.^{25,26}

To measure the subjective effect of COPD on the life of caregivers, we used the caregiver burden (CB) questionnaire, which has also been translated, adapted and

validated in Brazil.²⁷ The original questionnaire, designed by Oremark²⁸ to assess the subjective burden on caregivers of chronically ill patients, was modified by Elmstahl and coworkers in 1996.²⁹ The instrument now contains 22 questions divided into 5 domains: general strain, isolation, disappointment, emotional involvement and environment. Answers are scored from 1 to 4, corresponding to 'never', 'rarely', 'sometimes' and 'frequently'. The total score is expressed as a number between 1 (least affected) and 4 (most affected).

Each patient and respective caregiver was independently asked to rate how they perceived the caregiver/patient relationship on a 5-point Likert scale (excellent, good, reasonable, unsatisfactory, very poor).

Statistical analysis

Since the distribution of the variables differed significantly from normality, non-parametric statistics were used. The Mann–Whitney *U*-test and the Kruskal–Wallis test were used for comparison of mean scores between 2 groups and between more than 2 groups, respectively. To establish the relationship among multiple variables of the patient and caregiver with the effect measurement for carer analysis (CB scale), a multiple regression analysis was carried out. A *p*-value of less than 0.05 was considered significant. The

intercooled Stata 7.0 statistics software was used for statistical calculations.

Results

Patients were enrolled between September 2005 and March 2006. The socio-demographic characteristics of the final sample of 42 patients and caregivers are shown in Table 1. Most patients were male (71.4%), married, retired and had low income. The average age was 65.4 ± 8 years.

Most caregivers were female (85.3%) and married and 45% of them were housewives. The average age was 51.6 ± 16 years. Most caregivers were spouses (61%), followed by sons or daughters (28.5%).

The average duration of disease was 7.2 years (± 8.1), while the mean number of years smoked by the patients was 38 years (± 14). Patients' lung function was compromised with an average post-bronchodilator FEV₁ of 1.28 (± 0.64) liters per second and 52% (± 21) of the predicted value. According to the GOLD classification,²¹ 21.4% of the patients had mild disease, 21.4% were moderate, 38.1% were severe and 19% were very severe. Average findings for arterial pressure of oxygen, carbon dioxide and arterial oxygen saturation were 75 mmHg (± 9.1), 41 mmHg (± 5.1) and 95% (± 1.9), respectively. The average distance walked during the 6-min walking test was 303 meters (± 119).

Table 1 Socio-demographic data of the 42 patients with COPD and their primary caregivers.

	Patients	Caregivers	<i>p</i> *-Value
Mean age (\pm SD)	65.4 (± 08)	51.6 (± 16)	0.001
Female (%)	28.6	85.3	
Marital status (%)			
Married	78.6	85.7	
Other (widowed, separated, divorced, single)	21	14	
Occupation (%)			
Housewife	10.8	45.0	
Retired	60.8	12.6	
Other	31.0	43.3	
Level of schooling (%)			
Illiterate	23.8	4.8	
Elementary school	66.7	59.5	
High school	7.14	31	
College	2.4	4.8	
Average monthly income US\$ (SD)			
Individual	119 (± 93)	106 (± 132.6)	0.22
Type of relationship (%)			
Husband/wife		61.2	
Son/daughter		28.5	
Sister		2.3	
Sister-in-law		2.3	
Other		4.7	

SD = Standard deviation.

*Calculated using the Mann–Whitney *U*-test to compare the mean scores of 2 groups.

The vast majority (80.9%) of caregivers lived with the patient, and the average time caring for the patient was 5 years (± 3.7); however, only 2.2% received payment for their services.

The mean SGRQ scores were: symptoms 50.2, activity 63.4 and impact 49.7. The overall quality of life of patients and caregivers is shown in Table 2, according to SF-36 domain and PCS and MCS scores. The average MCS score of patients and caregivers was the same (45.6) but the average PCS score of the patients was lower than that of the caregivers (37×45.9) ($p < 0.001$). Patients scored lower than caregivers in six of the eight SF-36 domains (the exceptions being bodily pain and mental health). Differences were statistically significant for the domains of physical functioning, role-physical, general health and role-emotional.

The quality of the relationship between patients and caregivers was evaluated most positively by the former.

The global mean CB score was 1.79 ± 0.62 , with the 5 indices of the questionnaire varying from 1.63 ± 1.0 to 2.18 ± 0.72 . Mean scores were: general strain 1.75 ± 0.72 , isolation 1.63 ± 1.00 , disappointment 1.67 ± 0.67 , emotional involvement 1.96 ± 0.88 , and environment 2.18 ± 0.72 .

There were no differences in the mean global scores of the CB scale when the caregivers were stratified by gender, marital status, whether or not they lived with the patient, presence or absence of disease, COPD GOLD classification or caregiver schooling level (Table 3). A statistically significant difference was found between CB scores when the care-

givers were classified according to relationship quality, with higher scores indicating poorer relationships.

Multiple regression analysis was used to identify the independent variables used as indicators of the effect measured by the CB scale (dependent variable). Socio-demographic, clinical and quality-of-life variables were entered into separate models using the stepwise method and only those of statistical significance ($p < 0.05$) were included in the final regression model. These models were built taking into account the problems of confounding factors and co-linearity. The best predictors with standardized coefficients and corresponding significance are shown in Table 4. The model accounted for 63% ($R^2 = 0.638$) of the effect produced in the caregivers with a significance level < 0.001 . Three independent variables were statistically significant: the quality of the caregiver/patient relationship, the MCS score of the caregiver and the PCS score of the patient.

Discussion

Based on our findings, the quality of life of caregivers seems to be negatively associated with unsatisfactory and very poor caregiver/patient relationships, low MCS scores of the caregiver and low PCS scores of the patient.

About 50% of our caregivers reported co-morbidities and taking medication regularly. About 75% had sought medical

Table 2 Quality of life measurements of 42 patients with COPD and their primary caregivers.

Measurement	Patients		Caregivers		<i>p</i> *-Value
	Mean (SD)	Min.–Max.	Mean (SD)	Min.–Max.	
SF-36					
Physical functioning	45 (28.94)	0–100	72 (27.74)	10–100	0.001
Role-physical	36.3 (41.76)	0–100	68.4 (38.67)	0–100	0.001
Bodily pain	65.7 (28.32)	12–100	64.4 (29)	10–100	0.8
General health	46.6 (24.55)	5–100	61.2 (29.07)	0–100	0.02
Vitality	52.1 (28.37)	0–100	61.4 (28.48)	10–100	0.13
Social function	70.5 (31.93)	0–100	79.4 (26.45)	25–100	0.15
Role-emotional	46.8 (43.58)	0–100	67.4 (41.31)	0–100	0.03
Mental health	62 (31.51)	0–100	62 (27.08)	0–100	1
Physical component summary	37 (11.19)	17–66.7	45.9 (10.99)	19.9–66.8	<0.001
Mental component summary	45.6 (15.65)	13–72.2	46.5 (12.28)	16.2–63.2	0.8
Quality of relationship	Rated by patients (%)		Rated by caregivers (%)		
Normal to excellent	85.7		83.3		
Unsatisfactory to very poor	14.3		16.7		
SGRQ					
Total	54 (22.7)	8.5–92.8			
Symptoms	50.28 (25.6)	6.6–100			
Activity	63.45 (24.5)	6.0–100			
Impact	49.77 (25)	3.9–96.9			

SD: Standard deviation.

*Calculated using the Mann–Whitney *U*-test to compare the mean scores of the 2 groups. Min.–Max.: minimum and maximum values. SF-36: Medical outcomes study 36-Item short form health survey (normal range: 0–100). SGRQ: Saint George's respiratory questionnaire (normal range: 0–100).

Table 3 Mean CB scale in caregivers of patients with COPD.

	CB scale (SD)	<i>p</i> *-Value
Global (<i>n</i> = 42)	1.79 (0.62)	
Caregiver gender		
Male (<i>n</i> = 06)	1.51 (0.14)	0.28
Female (<i>n</i> = 36)	1.84 (0.66)	
Caregiver marital status		
Married (<i>n</i> = 36)	1.83 (0.66)	0.53
Other (<i>n</i> = 06)	1.54 (0.26)	
Living together		
Yes (<i>n</i> = 34)	1.84 (0.68)	0.67
No (<i>n</i> = 08)	1.62 (0.23)	
Caregiver schooling level		
Illiterate (<i>n</i> = 02)	1.75 (0.62)	0.88
Literate (<i>n</i> = 25)	1.84 (0.72)	
Primary school (<i>n</i> = 13)	1.76 (0.49)	
High school (<i>n</i> = 02)	1.48 (0.04)	
Presence of disease in the caregiver		
Yes (<i>n</i> = 22)	1.92 (0.71)	0.20
No (<i>n</i> = 20)	1.66 (0.50)	
COPD GOLD classification		
Mild (<i>n</i> = 09)	1.65 (0.41)	0.64
Moderate (<i>n</i> = 09)	1.67 (0.38)	
Severe (<i>n</i> = 16)	1.86 (0.78)	
Very severe (<i>n</i> = 08)	1.96 (0.73)	
Quality of relationship rated by patient		
Normal to excellent (<i>n</i> = 36)	1.65 (0.46)	0.002
Unsatisfactory to very poor (<i>n</i> = 06)	2.67 (0.81)	
Quality of relationship rated by caregiver		
Normal to excellent (<i>n</i> = 35)	1.60 (0.33)	
Unsatisfactory to very poor (<i>n</i> = 07)	2.75 (0.88)	0.001

SD: Standard deviation; GOLD: global initiative for chronic obstructive lung disease.

*Calculated using the Mann-Whitney *U*-test to compare the mean scores of 2 groups and Kruskal-Wallis test to compare the mean scores of more than 2 groups.

care during the preceding year. A study focusing on caregivers of patients with dementia or stroke showed that 71% and 69% of the caregivers, respectively, had been to the doctor at least once during the preceding week. The caregivers in that study were 74 years old on the average.³⁰ Interestingly, the caregivers in our study presented a relatively high percentage of comorbidity although they were younger (average: 51 years) than the caregivers in the study mentioned above.

Both the SF-36 caregiver PCS and MCS scores were affected. Of the eight domains of the SF-36, the lowest scores were observed for general health, vitality and mental health. A study by George and colleagues³¹ suggests that caregivers are more likely to experience psychopathologies than physical disorders, even though caregivers reported significantly more visits to the physician and poorer health than the general population. In this study both the physical and mental health were affected. Family and other caregivers also experience a significant impact on their quality of life and mental health. Other studies^{18,32,33} have shown that the type, frequency and amount of disturbance generated by caregiving tasks as well as the adequacy of informal social support were the main predictors of mental health for wives of COPD patients. The number of supervision tasks performed was an important predictor of mental health outcomes. Wives of COPD patients are affected in a number of different ways: they have to take on new roles and responsibilities and to some extent relinquish social activity and they are exposed to increased health risks.

The subjective effect of COPD on the life of caregivers as measured by the CB scale was greatest for the aspects of environment and emotional involvement. The former may be accounted for by the lack of social support for patients and caregivers and the low socioeconomic level of the population studied. COPD can reduce patients' wage-earning ability and thereby cause financial distress.³⁴ Lack of social support and unfavorable socioeconomic conditions are known to have a great influence on the quality of life of caregivers.^{6,30}

CB scores for caregivers of COPD patients should ideally be compared to scores of a matched control sample. This was not possible in the present study. Nevertheless, despite our limitations we made a comparison between the CB scores of our caregivers and those of the caregivers of rheumatoid arthritis patients studied by Medeiros and coworkers.¹⁴ The global effect was similar for the two groups of caregivers: the scores for the environment dimension of the caregivers of rheumatoid arthritis patients

Table 4 Values obtained by multiple regression analysis using the CB scale and variables of the 42 patients with COPD and their primary caregivers.

Variables	Coefficient	SE	<i>t</i>	<i>p</i>	<i>R</i>	β
Physical component summary of the patient	-0.017	0.006	-2.882	0.006	-0.424	-0.301
Mental component summary of the caregiver	-0.020	0.006	-3.468	0.001	-0.490	-0.401
Quality of relationship (caregiver/patient)	0.932	0.184	5.052	<0.001	0.634	0.563
Constant	2.278	0.500	4.555	<0.001		

p: statistical significance level; number of observations: 42; $F^{3,38} = 21.770$; $p < 0.001$; $R^2 = 0.632$; R^2 -adjusted = 0.603.

was 2.12 and the scores for the environment dimension of the caregivers of COPD was 2.18. Since the two groups were from the same location in Brazil and were both sampled from a public tertiary care hospital, they may be assumed to share the same cultural context and socioeconomic conditions.

When caregivers and patients were classified according to certain characteristics such as female gender, female spouses, living with the patient, presence of comorbidity and level of schooling of caregivers, no correlation was observed between profile and effect (Table 4). Cain and colleagues³⁵ found that the COPD caregiver burden was lower among black individuals and among family caregivers over 55 years, but found no correlation with gender, patient relationship, caregiver schooling or perceived adequacy of financial resources.

In the literature, the quality of the patient/caregiver relationship has been shown to correlate with the level of the burden. Caregivers who evaluate the relationship in a positive manner report fewer stress and depression-related effects and symptoms.^{14,36} In a study involving 193 seriously ill patients and their caregivers, the authors observed that caregivers who desired more communication with the patient had significantly higher burden scores than caregivers who did not.³⁷

It would seem that the more severe the patient's disease is, the greater the effect on the quality of life of the caregiver. However, when we classified our patients according to COPD GOLD classification, we found no significant correlation with CB scores. A possible explanation for this is that the CB scale measures the subjective effect of the disease on the quality of life of caregivers. To perceive this subjective effect, the caregiver does not take into consideration the physical (and more objective) effect but only the emotional (and more subjective) aspects of the problem.

According to theoretical stress models, the evaluation—during which the threat potential may or may not be perceived as a stress factor—depends on the assessment each individual makes of the situation. Thus, answers are determined by subjective assessment.³⁸

Patients with COPD are similar to other populations of chronically ill patients due to their high mortality, re-hospitalization risk, and post-hospital need for care. In fact, they may be seen as a challenge for caregivers since COPD is a relatively unpredictable long-term illness with evident emotional consequences. In addition, there are no identifiable systems in Brazil to provide support for COPD caregivers. Further research will have to be conducted testing interventions aimed at reducing the stress of caregivers.

Given that informal caregivers provide a service that would otherwise cost health and social services a considerable amount of money, government policies should ensure they receive adequate support to continue to fulfill their role as caregivers without damaging their own health and well being.

One of the limitations of our study relates to sample size. Since the study was cross-sectional, the sample size consisted of all patients and respective caregivers attending the hospital during the 6-month period. The sample was further limited by the difficulty of finding patients with long-

time caregivers in a socioeconomically challenged community. However, considering the scarcity of reports involving caregivers of COPD patients, this preliminary cross-sectional study represents an interesting contribution to the field.

The small sample may also have produced some confusion due to the existence of co-linearity, but we analyzed, a priori, the linear correlations between the dependent and independent variables adjusted for confounding factors and all the analyses converged towards the solution presented in the paper.

This study has contributed with potentially useful information for the planning of strategic actions towards diminishing the effect of COPD on the quality of life of caregivers. The quality of life of these caregivers was observed to be compromised, especially with regard to the domains 'emotional involvement' and 'environment'. COPD caregivers would seem to need additional support and assistance, not only from family and friends, but also from the health care system itself.

Conflict of interest

There are no conflicts of interest to report on the part of any author of this manuscript.

Acknowledgments

The work presented in the manuscript was supported in part by the Brazilian National Research Council (CNPq).

References

1. Menezes AM, Perez-Padilla R, Jardim JR, Camelier A, Rosa F, Nascimento O. Prevalence of chronic obstructive pulmonary disease and associated factors: the PLATINO study in São Paulo, Brazil. *Cad Saúde Pública* 2005;**21**(5):1565–73.
2. Yohannes AM, Roomi J, Baldwin RC, Connolly MJ. Depression in elderly outpatients with disabling chronic obstructive pulmonary disease. *Age and Aging* 1998;**27**:155–60.
3. Lacasse I, Rousseau L, Maltais F. Prevalence of depressive symptoms and depression in patients with severe oxygen-dependent chronic obstructive pulmonary disease. *J Cardio-pulm Rehabil* 2001;**20**:80–6.
4. Di Marco F, Verga M, Reggente M, et al. Anxiety and depression in COPD patients: the roles of gender and disease severity. *Resp Med* 2006;**100**:1767–74.
5. Covinsky KE, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. *JAMA* 1994;**272**:1839–44.
6. Miller B, Townsend A, Carpenter E. Social support and caregiver distress: a replication analysis. *J Gerontol B Psychol Sci Soc Sci* 2001;**56**:S249–56.
7. Pilisuk M, Parks SH. Caregiving: where families need help. *Soc Work* 1988;**33**:436–40.
8. Pearlin LI, Mullan JT, Semple SJ, et al. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;**30**:583–94.
9. Baronet AM. Factors associated with caregiver burden in mental illness: a critical review of the research literature. *Clin Psychol Rev* 1999;**19**:819–41.
10. Weitzenkamp DA, Gerhart KA, Charlifue MW, et al. Spouses of spinal cord injury survivors: the added impact of caregiving. *Arch Phys Med Rehabil* 1997;**78**:822–7.

11. Stevenson JP. Family stress related to home of Alzheimer disease patients and implications for support. *J Neurosci Nurs* 1990;**22**:179–88.
12. Given CW, Collins CE, Given BA. Sources of stress among families caring for relatives with Alzheimer disease. *Nurs Clin North Am* 1988;**23**:69–82.
13. Hayman JA, Langa KM, Kabeto MU, et al. Estimating the cost of informal caregiving for elderly patients with cancer. *J Clin Oncol* 2001;**19**:3219–25.
14. Medeiros MMC, Ferraz MB, Quaresma MR. The impact of rheumatoid arthritis on the quality of life of primary caregivers. *J Rheumat* 2000;**27**:76–83.
15. Douglas SL, Daly BJ. Caregivers of long-term ventilator patients* physical and psychological outcomes. *Chest* 2003;**123**:1073–81.
16. Ferrario SR, Zotti AM, Zaccaria S, Donner CF. Caregiver strain associated with tracheostomy in chronic respiratory failure. *Chest* 2001;**119**:1498–502.
17. Sexton DL, Munro BH. Impact of a husband's chronic illness (COPD) on the spouse's life. *Res Nurs Health* 1985;**8**:83–90.
18. Leidy NK, Traver GA. Adjustment and social behaviour in older adults with chronic obstructive pulmonary disease: the family's perspective. *J Adv Nurs* 1996;**23**:252–9.
19. Kanervisto M, Paavilainen E, Åstedt-Kurki P. Impact of chronic obstructive pulmonary disease on family functioning. *Heart Lung* 2003;**32**:360–7.
20. Keele-Card G, Foxall M, Barron C. Loneliness, depression and social support of patients with COPD and their spouses. *Public Health Nurs* 1993;**10**:245–51.
21. Workshop report global strategy for diagnosis, management and prevention of COPD—2005 update [On-line]. <<http://www.goldcopd.com/guidelineitem.asp>>. [accessed June 6, 2006].
22. ATS/ERS—standardization of lung function testing: standardization of spirometry. *Eur Respir J* 2005;**26**:319–38.
23. Ware JF, Kosinski M, Keller SD. *SF-36 physical and mental health summary scales: a user's manual*. Boston: The Health Institute. New England Medical Center; 1994.
24. Ware JF, Kosinski M, Bayliss M, Rogers WH, Raeczek A. Comparison of methods for the scoring and statistical analysis of SF-36 health profile and summary measures: summary of results from the Medical Outcomes Study. *Med Care* 1995;**4**:AS264–79.
25. Sousa TC, Jardim JR, Jones P. Validation of the Saint George's respiratory questionnaire in patients with chronic obstructive pulmonary disease. *J Pneumol* 2000;**26**:119–25.
26. Ciconelli RM, Ferraz MB, Santos W, Meinão I, Quaresma MR. Brazilian-Portuguese version of the SF-36 questionnaire: a reliable and valid quality of life outcome measure [abstract]. *Arthrit Rheum* 1997;**40**(Suppl.):S112.
27. Medeiros MMC, Ferraz MB, Quaresma MR. The caregiver burden scale. A Brazilian cultural adaptation and validation. *Braz J Rheumat* 1998;**38**:193–9.
28. Oremark I. ABS—en anhörigbelastningskala [Dependency scale]. Proceedings from the IXth Nordic congress of gerontology; Bergen, Norway, June 5, 1988. Bergen: Förlag; 1988.
29. Elmstahl S, Malmberg B, Annerstedt L. Caregiver's burden scale. *Arch Phys Med Rehabil* 1996;**77**:177–82.
30. Draper BM, Cole CJ, Poulos AD, Ehrlich F. A comparison of caregivers for elderly stroke and dementia victims. *J Am Geriatr Soc* 1992;**40**:896–901.
31. George L, Gwyther L. Caregiver well being: a multidimensional examination of family caregivers of demented adults. *Gerontologist* 1986;**26**:253–9.
32. Clough P, Harnisch L, Cebulski P, Ross D. Method for individualizing patient care for chronic obstructive pulmonary disease patients. *Health Soc Work* 1987;**12**:127–33.
33. Cossette S, Levesque L. Caregiving tasks as predictors of mental health of wife caregivers of men with chronic obstructive pulmonary disease. *Res Nurs Health* 1993;**16**:251–63.
34. American Thoracic Society Documents. Statement on home care for patients with chronic respiratory disease. *Am J Resp Crit Care Med* 2005;**171**:1443–64.
35. Cain CJ, Wicks MN. Caregiver attributes as correlates of burden in family caregivers coping with chronic obstructive pulmonary disease. *J Fam Nurs* 2000;**6**:46–68.
36. Morris RG, Morris LW, Britton PG. Factors affecting the emotional well-being of the carers of dementia sufferers. *Br J Psychiatry* 1988;**153**:147–56.
37. Fried RTR, Bradley EH, O'Leary JR, Byers AL. Unmet desire for caregiver-patient communication and increased caregiver burden. *J Am Geriatr Soc* 2005;**53**:59–62.
38. Lawton MP, Kleban MH, Moss M, Rovine M, Glicksman A. Measuring caregiving appraisal. *J Gerontol* 1989;**44**:61–71.