DOI: 10.1590/1809-2950/19033328022021

Functionality of family of the patients with chronic obstructive lung disease

Funcionalidade da família dos pacientes com doença pulmonar obstrutiva crônica

Funcionalidad de la familia de pacientes con enfermedad pulmonar obstructiva crónica

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ABSTRACT | Background: Chronic Obstructive Pulmonary Disease (COPD) is highly limiting, both physically and socio-emotionally, causing significant difficulties in the daily lives of patients. In addition, COPD also influences the lives of family and friends, because theirs who come to the support network that patient need. **Objective:** To evaluate the family functionality in the daily life of COPD patients. **Methods:** This cross-sectional study evaluated the family functionality in COPD patients with different stages of disease and underwent Cardiorespiratory Rehabilitation Program (CRP). The Family APGAR instrument was used and it is an acronym characterized by A = (Adaptation / Adaptation), P = (Partnership / Companionship), G = (Grow / Development), A = (Affection / Affectivity), R = (Resolve / Resolving capacity), composed of 5 questions assessed in "always", "sometimes" and "never", which together result in "high family dysfunction", moderate family dysfunction "and" good family functionality". We evaluated 21 COPD patients [male gender (n = 11; 52.3%); mean age 66.3 ± 10 years], status disease between moderate to very severe. Through of the Family APGAR we identified 2 patients with high family dysfunction; 2 patients with moderate family dysfunction; 17 patients with good family functionality. Among those who reported high and moderate family dysfunction, the most compromised acromia's were "companionship", "affection" and "developments". The degree of airway obstruction was moderately and positively associated with family functionality (r = 0.697; p = 0.004). Patients with COPD who participated in CRP had good family functionality in their daily lives and the severity of the disease was associated with this functionality. Patients with high family dysfunction reported lack of "companionship", "affection" and "developments".

Keywords | Social Isolation; Family Relations; Pulmonary Disease, Chronic Obstructive; Affect; Adaptation Psychological.

RESUMO | A doença pulmonar obstrutiva crônica (DPOC) é altamente limitante, tanto nos aspectos físicos, quanto socioemocionais, causando dificuldades significativas no cotidiano dos pacientes. Além de afetar os pacientes, a DPOC também influência na vida dos familiares e amigos próximos, pois deles vem a rede de apoio de que os pacientes necessitam. O objetivo deste artigo é avaliar a funcionalidade da família no cotidiano de pacientes acometidos por DPOC. É um estudo transversal que avaliou a funcionalidade de família de pacientes com DPOC em diferentes estágios da doença e que realizam Programa Reabilitação Cardiorrespiratória (PRC). Utilizou-se o instrumento APGAR de Família, sendo este, um acrônimo caracterizado por A = (*Adaptation*/ Adaptação), P = (*Partnership*/Companheirismo), G = (*Grow*/ Desenvolvimento), A = (*Affection*/Afetividade), R = (*Resolve*/ Capacidade resolutiva), composto por 5 questões avaliadas em "sempre", "algumas vezes" e "nunca", o que somados resultam em "elevada disfunção familiar", moderada disfunção familiar" e "boa funcionalidade familiar". Foram avaliados 21 pacientes DPOC [sexo masculino (n=11; 52,3%); idade média 66,3±10 anos], com estadiamento

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entre moderado a muito severo. Através do APGAR da Família identificamos 2 pacientes com elevada disfunção familiar; 2 pacientes com moderada disfunção familiar; 17 pacientes com boa funcionalidade familiar. Dos que relataram elevada e moderada disfunção familiar, os acrômios mais comprometidos foram "companheirismo", "afetividade" e "desenvolvimentos". O grau de obstrução das vias áreas associou-se moderada e positivamente com a funcionalidade da família (r = 0,697; p = 0,004). Pacientes com DPOC participantes do PRC apresentaram boa funcionalidade familiar no seu cotidiano e a gravidade da doença esteve associada a esta funcionalidade. Pacientes que apresentaram maior disfunção familiar relataram falta de "companheirismo", "afetividade" e "desenvolvimentos".

Descritores | Isolamento Social; Relações Familiares; Doença Pulmonar Obstrutiva Crônica ; Afeto; Adaptação Psicológica.

RESUMEN | La enfermedad pulmonar obstructiva crónica (EPOC) es muy limitante, tanto en aspectos físicos como socioemocionales, causando dificultades significativas en la vida diaria de los pacientes. Además de afectar a los pacientes, la EPOC también influye en la vida de los familiares y amigos cercanos, ya que de ellos proviene la red de apoyo que los pacientes necesitan. El objetivo de este artículo es evaluar la funcionalidad de la familia en la vida cotidiana de los pacientes afectados por EPOC. Se trata de un estudio transversal que evaluó la funcionalidad familiar de pacientes con EPOC en diferentes etapas de la enfermedad y que realizan un Programa de Rehabilitación Cardiaca (PRC). Se utilizó el instrumento APGAR familiar, que es un acrónimo caracterizado por A = (*Adaptation*/Adaptación), P = (*Partnership*/Compañerismo), G = (*Grow*/Desarrollo), A = (*Affection*/Afectividad), R = (*Resolve*/Capacidad de resolución), compuesto por 5 preguntas evaluadas en "siempre", "a veces" y "nunca", que combinadas resultan en "disfunción familiar severa", "disfunción familiar moderada" y "buena funcionalidad familiar". Se evaluaron 21 pacientes con EPOC [sexo masculino (n=11; 52,3%); edad media 66,3±10 años], con una estadificación que varía de moderada a muy grave. A través del APGAR familiar identificamos 2 pacientes con severa disfunción familiar; 2 pacientes con disfunción familiar moderada; 17 pacientes con buena funcionalidad familiar. De los que relataron disfunción familiar severa y moderada, los acrónimos más comprometidos fueron "compañerismo", "afectividad" y "desarrollo". El grado de obstrucción de las vías se asoció moderada y positivamente con la funcionalidad de la familia (r=0,697; p=0,004). Los pacientes con EPOC que participaron en el PCR presentaron una buena funcionalidad familiar en su vida diaria y la gravedad de la enfermedad se asoció a esta funcionalidad. Los pacientes que presentaron mayor disfunción familiar relataron falta de "compañerismo", "afectividad" y "desarrollo".

Palabras clave | Aislamiento social; Relaciones Familiares; Enfermedad Pulmonar Obstructiva Crónica; Afecto; Adaptación Psicológica.

INTRODUCTION

There is a growing interest on the effect that psychological distress has on morbidity and mortality rates in patients with chronic diseases[1]. Studies suggest that emotional disorders, such as depression and anxiety, are common among patients with chronic obstructive pulmonary disease (COPD), since it has a damaging effect in their overall quality of life, affecting their emotional, social, and physical functions[1,2]. Depressive disorders, anxiety disorders, panic attacks, and suicidal thoughts are among the psychiatric diseases commonly found in patients with COPD[2].

COPD is a frequent and limiting pathology – both physically and psychosocially – causing significant difficulties in daily life, and even leading to social isolation, deeply affecting the patient's quality of life[3]. As a result of these changes, COPD patients suffer with lack of freedom, consequently affecting those who provide to support to them.

According to data from the Brazilian Ministry of Health's epidemiological bulletin[4], chronic respiratory diseases (CRD) corresponds to 7% of global mortality, representing 4.2 million deaths annually. In Brazil, in 2011, CRD was the third leading cause of death from the group of chronic noncommunicable diseases (NCDs). COPD is predicted to erupt in 2020, in what is estimated to be the third largest cause of death worldwide.

Psychiatric disorders in COPD patients are multifactorial and may be related to smoking, dyspnea, fear, pain, hypoxemia, limitation of daily activities, and frequent hospitalizations[2]. All these factors, combined with their symptoms, lead patients to feel physically incompetent, aggravating their depressive condition[5].

Thus, considering the severity of the disease and all the physical, social, and mental limitations of these patients combined with the need of a support network to assist in daily activities, this study aims to evaluate the functionality of the family in the daily life of patients affected by COPD.

METHODOLOGY

This cross-sectional case study, with convenience sampling, evaluated patients diagnosed with COPD, who participated in cardiorespiratory rehabilitation program (CRP). Adult patients included in the study were of both sexes – independent of marital status – with good cognitive aspects, and who signed the informed consent form. Patients with musculoskeletal disorders and/or neurological sequelae, uncontrolled metabolic disease, and confirmed clinical diagnosis of lung cancer were excluded.

Procedures

All patients were evaluated for the collection of clinical and sociodemographic data, namely: age, gender, ethnicity, body mass index (BMI), history of smoking, use of antidepressant and anxiolytic medications, schooling, and degree of kinship that patients resort to situations of personal need. Spirometric data were collected using the digital Microloop™ Spirometer, identifying the forced expiratory volume in the first second (FEV_1), the forced vital capacity (FVC), and the FEV_1/FVC ratio, by the performance of three measurements according to the guidelines of the American Thoracic Society (ATS)[6]; and the curve that presented the best performance was compared with the values predicted in the literature and described in the predicted percentage[7]. The International Global Initiative for Chronic Obstructive Lung Disease Guidelines[8] were followed in order to establish the stage of the disease.

The Family APGAR is an instrument characterized by its acronym: A = Adaptation, which represents the satisfaction of the family member with the assistance received when family resources are needed; P = Partnership, understood as the satisfaction of the family member with reciprocity in family communications and problem solving; G = Growth, which represents the satisfaction of the family member with the freedom made available by the family for change in roles and achievement of maturity or emotional development; A = Affection, which indicates the satisfaction of the family member with intimacy and emotional interactions in their family context; and R = *Resolve*, which represents the satisfaction of the family member with the time shared between them. APGAR consists of five questions, one for each letter cited, in which "always" is worth 2 points, "sometimes" 1 point and "never" 0 points, when added it will result in 0-4 high family dysfunction, 5-6 moderate family dysfunction and 7-10 good family functionality. At the end of the questionnaire, there are two subjective questions: "who do you live with?" and "Do you live alone? Please list below the people you seek most often when you need help"[9], used to evaluate the functionality of the family in the patients participating in the study .

The results were analyzed in the statistical analysis program SPSS version 24.0 and described as frequency, mean and standard deviation, median (minimum and maximum). Subjective responses were analyzed qualitatively and described as frequency. The association between the variables was analyzed by Pearson's correlation and a $p \leq 0.05$. was considered significant.

RESULTS

The study included 21 patients with COPD, mean age of 66.3±10 years, 11 (52%) males, predominantly Caucasians (n=19; 90.4%) and low education level (n=13; 62.9%) (Table 1). There was a predominance of very close degree of kinship (spouse+children=81%) in the family nucleus referred by the patient in the Family APGAR.

Table 1. Socioeconomic characteristics of patients evaluated.

Characteristic	Patients (n=21)
Age (years)	66.3±10
Female, n (%)	10 (47.7)
Male, n (%)	11 (52.3)
Race	
Caucasian, n (%)	19 (90.4)
Mixed race, n (%)	2 (9.5)
Education level	
Illiterate	1 (4.8)
Incomplete Elementary School	8 (39.1)
Elementary or Middle School	4 (19)
Incomplete High School	1 (4.8)
High School	5 (23.8)
Incomplete Higher Education	1 (4.8)
Higher Education	1 (4.8)
Degree of kinship, n (%)	
Spouse	11 (52)
Children	6 (29)
Others	4 (19)

Data expressed in±standard deviation; n: sample number; (%): frequency.

The stages of COPD varied from moderate to very severe; in nutritional status, most participants were obese (BMI: n=10; 47.7%) and former smokers (n=17; 81%) with packs/years ratio 50.4±31.7. Among the medicines used, four (19%) subjects reported regularly using antidepressants and three (14%) anxiolytics, according to medical prescription (Table 2).

Table 2. Clinical characteristics of the patients evaluated.

Characteristic	Patients (n=21)
BMI, (kg/m^2)	29±7.8
BMI classification, n (%)	
Thinness	5 (23.7)
Eutrophic	6 (28.5)
Obesity	10 (47.7)
Smoking, n (%)	
Former smoker	17 (81)
Smoker	4 (19)
Nº of cigarettes smoked, (packs/years)	50.4±31.7
Lung function	
FEV_1, (l/s)	1.2±0.4
FEV_1 (predicted %)	44.3±13.7
FEV_1/FVC	53.1±13.2
FEV_1/FVC (predicted %)	66.6±17.3
Stage of COPD*, n (%)	
Moderate	7 (33.4)
Severe	10 (47.6)
Very severe	4 (19)
Drugs for psychological disorders, n (%)	
Antidepressants	4 (19)
Anxiolytics	3 (14)
Family Apgar, (points)	8±2.1
Degree of dysfunction, n (%)	
Good family functionality	17 (80.9)
Moderate family dysfunction	2 (9.5)
Moderate family dysfunction	2 (9.5)

Data expressed in±standard deviation; n: sample number; (%): frequency; BMI. Body mass index, FEV_1: forced expiratory volume in the first second; FVC: forced vital capacity; l/s: liters per second. *GOLD, 2017 (15).

With the Family APGAR we found that 17 patients had "good family functionality" and the other patients reported moderate (n=2) and high (n=2) "family dysfunction" (Table 2). Out of those who reported moderate and high "family dysfunction," the most affected aspects (0 points) were "partnership," "affection," and "growth" (Figure 1).

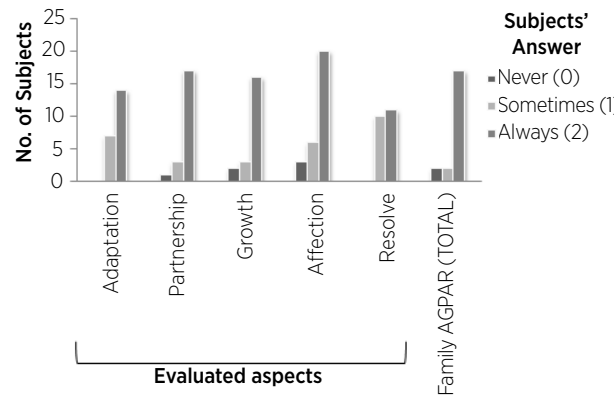

Figure 1. Family AGPAR graphic representation of the Acronyms (evaluated aspects) that compose the Family APGAR according to the patients' responses (0=never; 1=sometimes; 2=always) and total score. No.= number of subjects.

We observed a positive correlation between FEV_1 (%predicted) and the Family APGAR score only for patients with "Good family functionality" (p=0.004; r=0.697), meaning that individuals with a lower degree of airway obstruction are the ones with better family functionality (Figure 2).

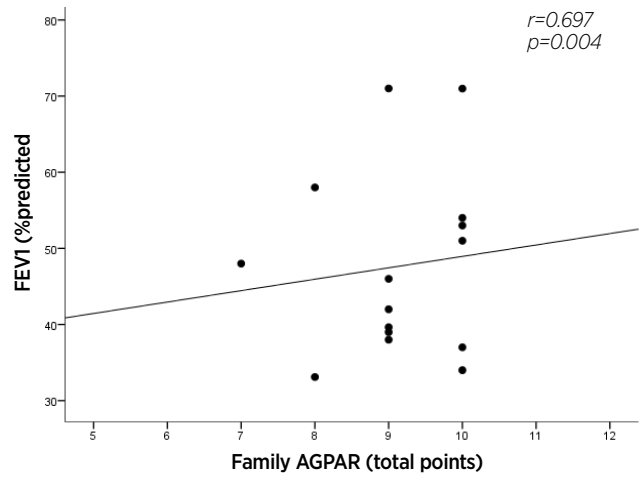

Figure 2. Association between FEV_1 and Family APGAR in patients with "Good family functionality." Correlation between the predicted percentage of Forced Expiratory Volume in the first second (FEV_1% predicted) and family APGAR score, for patients with "Good family functionality."

DISCUSSION

The main results found in this study are: (1) most patients with COPD who attend the Pulmonary Rehabilitation Program have good family functionality

assessed by the Family APGAR; (2) among patients with family dysfunction, the aspects most affected were "partnership," "affection," and "growth"; and (3) the degree of obstruction of the airways is positively associated with the functionality of the family.

Studies have shown that the Family APGAR instrument allowed the understanding of family members' functionality to be measured in an objective and systematized way, reported based on the view of subjects with COPD [10,11]. The Family APGAR offered accurate and reliable results, quickly recognizing any family dysfunction present, as well as identifying the characteristics (gender and age) and the degree of kinship of the family member [10,11].

Despite an equivalent distribution between the sexes in our study, no woman presented family dysfunction; on the other hand, four men presented moderate and high degrees of family dysfunction. The lowest scores found in our study were from the aspects of "partnership" (satisfaction with the way the family discusses the issues of interest, comments, and shares the solution of the problem), "growth' (satisfaction of the family member with the freedom made available by the family for the changes in roles and the achievement of maturity or emotional development), and "affection" (satisfaction of the family member with intimacy and emotional interactions).

Our results are in line with Gomes and Pinheira's study[12], in which older adults with chronic pain were not satisfied in the aspect of "partnership." However, in this study, a lower score was also found in the aspect of "resolve" (satisfaction with the time they spend with their families)[12]. The lack of family functionality often results in physical, emotional and social symptoms, that, when combined with chronic disease, can be even more aggravating, considering the limitations of freedom that it can cause, resulting in loneliness[12].

A study found that the level of loneliness in subjects with chronic diseases, especially in older adults , is higher when compared to subjects who do not have these diseases[12]. COPD is a disease that produces significant consequences in the patient's life, restricting it in several aspects, affirming and reinforcing their lack of freedom, often leading to feelings of abandonment by the family and by people close to them[13].

The need to supply feelings of affection, partnership, and growth is noticeable in this study, because the four patients who reported having some type of family dysfunction are the most assiduous in the CRP, reporting their contentment and well-being in participating in the program. Subjects with chronic diseases associated with advanced age can generate great challenges, since they need daily support and care[11]. Family dysfunction is directly linked to the prioritization of interests that are often only individual, not compromising or assuming their role as a support network and often blaming the sick relatives[12].

Thus, the clinical implications of this study indicate the significance of physical therapy and CRP in the lives of these patients, because in addition to increasing tolerance for exercise, it can decrease the chance of developing depression and anxiety, promoting a better quality of life in individuals with COPD. The benefits in physical and mental health can be reported even by family members, with an important role in the control and understanding of the disease[14]. This statement corroborates our findings, in which most patients who attend the CRP have "good family functionality" and few patients used medications such as antidepressants and anxiolytics.

Regarding the association between airway obstruction and Family APGAR, this is an unprecedented finding from our study and, therefore, lacks contemporary literature to discuss it. The fact is that, COPD is proven to generate a vicious circle between airway obstruction, dyspnea, decreased functional capacity, and social isolation, successively[8]. With the progression of the disease, this condition tends to worsen and increase the physical, psychological, and emotional dependence of COPD patient[3]. Thus, the pathophysiology itself is able to explain the correlation found.

This study presents some limitations, such as the non-application of the Mini Mental State Examination Questionnaire (MMSE) in all research subjects; however, we emphasize that these subjects actively participated in the CRP and their cognitive abilities were preserved. Also, the fact that all subjects attend the CRP may be a limiting factor that does not allow extrapolating the results to individuals who do not attend a CRP.

Most patients affected by COPD who attend the CRP have good family functionality in their daily lives. Despite the overall favorable context, the severity of COPD in association with the Family AGPAR makes us reflect that, with the disease progression, family functionality may deteriorate. Patients who presented "higher family dysfunction" reported lack of "partnership," "affection," and "growth." In this sense, we emphasize that, in addition to the clinical aspects that a CRP can improve, psychological aspects should be considered, as well as the support network that these patients need.

ACKNOWLEDGMENTS

To Santa Cruz Hospital; Undergraduate Research Program (PUIC) and Extension Program (PROBEX) of the University of Santa Cruz do Sul; Undergraduate Research Program of the Rio Grande do Sul Research Foundation.

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