

Emotional distress in family caregivers of adolescents with bronchial asthma: analysis of its predictors

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ABSTRACT

Introduction. Adolescents with asthma face problems inherent to this stage in their development, to which the challenges of taking over control of their disease, complying with a daily treatment and regular medical follow-up are added. Any rejection generated by this may lead to treatment non-adherence and poor asthma control, which brings about problems in family dynamics, made worse by the stress or the emotional distress that this situation causes in caregivers.

Objective. Identify adjustment profiles and predictors of risk for the well-being of caregivers of pediatric patients with bronchial asthma.

Material and methods. Seventy-nine family caregivers of pediatric patients with bronchial asthma. Instruments were used to assess the emotional status (Hospital Anxiety and Depression Scale, HADS) and the perceived level of stress associated with medical care of a pediatric patient (Pediatric Inventory for Parents, PIP). We analyzed the patient's medical outcome measures and the family caregiver's psychological outcome measures regarding their emotional distress and stress.

Results. Of all caregivers studied, 34.8% exhibit anxiety symptomatology and moderate perceived stress. Emotional symptomatology correlates positively and significantly with the stress level. The models that best predict emotional distress of caregivers (40-50% of explained variance) include time since diagnosis and patient's treatment burden as stress indicators.

Conclusions. The presence of stress resulting from care, time of exposure and burden of treatments associated with the disease are identified as the main predictors of risk for the well-being of caregivers.

Key words: bronchial asthma, adolescent, family caregiver, emotional well-being.

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INTRODUCTION

Asthma is the most common chronic disease in childhood and adolescence.¹ In Spain, 5% to 14% of adolescents aged 13 to 14 years have asthma.^{2,3} Adolescence is *per se* a period of major biopsychosocial changes. Adolescents with asthma, in addition to the standard milestones in this development stage, have to see to the treatments and effects of their disease, which may be an added challenge in the construction of their own identity, assumption of responsibilities, attainment of independence from their family support system, development of their body image, maturation of their personality, and even in their peer relations.⁴

One of the problems most commonly reported by healthcare practitioners treating adolescents with asthma is the shift in attitude that adolescents exhibit toward the disease, from an affable, more dependent, collaborative posture to a more hostile, defensive or negative one. This may condition its management and self-control, and threaten the good course of the disease.⁵ Treatment non-compliance may be due to poor knowledge about the disease and the importance of treatment adherence and the consequences of non-adherence, as well as unintentionally forgetting to take medication, active rejection of medical prescriptions, underestimation of the need for treatment during symptom-free periods, downplaying of possible side effects.⁶

Scientific literature underscores the importance of family support for proper adjustment to the disease process in this type of patients, which

constitutes a stressful challenge for the entire family system. Family caregivers of adolescents requiring long-term medical follow-up tend to develop anxiety^{7,8} and clinical depression⁹⁻¹¹ symptoms more commonly and at higher levels than those reported by the parents of healthy adolescents.^{12,13} On the other hand, parents with poor parental supervision experience more complications and worse disease management.¹⁴

Our study is aimed to identify profiles of adjustment and risk for the emotional well-being of caregivers of pediatric patients with bronchial asthma.

MATERIAL AND METHODS

Participants

Sample made up of principal family caregivers of pediatric patients (aged 9 to 18 years) in treatment follow-up during 2016 at the Pediatric Pulmonology Unit of the Hospital Clínico Universitario de Valencia (HUCV), who had signed the informed consent to participate in the study.

The inclusion criteria were principal family caregiver (the person who would be most responsible for regular and hospital caregiving to the patient, at least 15 hours per week) of 9 to 18 year-old patients with bronchial asthma diagnosed at least 6 months before and controlled under treatment in the last 6 months. Asthma diagnosis and management were established according to the Spanish Guidelines for Asthma Management (Guía Española de Manejo del Asma, GEMA).²

The study exclusion criteria were patient caregivers with any of the following underlying diseases: a) pediatric cerebral palsy, b) brain tumor, c) psychological diagnosis prior to the onset of the respiratory condition.

Instruments used

Pediatric Inventory for Parents (PIP),^{15,16} a 42-item self-report questionnaire designed to assess the levels of stress perceived by caregivers in relation to caring for a child with a chronic illness. It is based on the Lazarus and Folkman's transactional model,¹⁷ which considers stress to be a process that is triggered when the person perceives an external situation as challenging and exceeding his or her coping resources. On occasions, this may demand an excessive effort that may affect personal balance.¹⁷ Each item addresses a situation of care where the following is taken into consideration: 1) frequency of occurrence

(from never to very common) and 2) the degree of psychological effort required as perceived by the caregiver (from none at all to extremely). The questionnaire provides two total scores relating to the two overall stress indicators, in addition to furnishing information relative to four factors: medical care, communication, emotional stress and family role. In different investigations, the PIP has demonstrated adequate psychometric qualities.¹⁵

The *Hospital Anxiety and Depression Scale (HADS)*,¹⁸ a screening instrument developed for detecting symptoms of depression and anxiety, particularly in their cognitive aspects, in the non-psychiatric hospital setting or in primary care. The exclusion from this measure of somatic symptoms (insomnia, fatigue, loss of appetite, etc.) is very important, as it avoids attribution errors in persons with some type of disease, due to the possible overlap of medical and psychological symptoms in these cases. The depression subscale is centered on the concept of anhedonia as the core symptom of this clinical picture, and which basically differentiates anxiety from depression.¹⁹ It is divided into two scales assessing the main elements of affective clinic: presence of symptoms of anxiety (7 items) and depression (7 items). It further provides a global measure of emotional distress. Studies conducted about its psychometric properties in the Spanish population have shown adequate values.²⁰

Procedure

Cross-sectional design, single questionnaire administration at one point in time, on the date of the patient's Pediatric Pulmonology follow-up visit. A trained psychologist explained the characteristics and purposes of the study to the family caregiver, obtained his or her consent to participate and signature of the informed consent form to assure confidentiality. The questionnaire was self-reported by the caregiver.

The results were analyzed in relation to the following clinical parameters: disease chronicity (at least 6 months since diagnosis), asthma severity and control status (as per GEMA criteria), presence –or not– of other respiratory diseases (especially allergy as secondary diagnosis). The daily treatment used was recorded (number of inhaler [aerosol] doses, nebulized therapy, oral medication and/or immunotherapy) to assess the burden that treatment might be imposing on caregivers.

The study was approved by the ethics committees of the institutions participating in the survey (Universitat de València and INCLIVA

– Instituto de Investigación Sanitaria of the Hospital Clínico Universitario de Valencia–).

Data were analyzed with the SPSS 22.0 statistical software.

RESULTS

A total of 79 principal family caregivers of patients with asthma were evaluated; 77.2% were mothers (n= 61) and 22.8%, fathers (n= 18), aged 35 to 54 years in average (mean= 44.66; standard deviation [SD]= 4.68; median= 45).

Patients' medical outcome measures

All patients had bronchial asthma clinically controlled for at least the last 6 months, regardless of the medical treatment received. Patients were classified according to the GEMA severity criteria at the time of inclusion (Table 1). Even then, 17.7% (n= 14) had uncontrolled eosinophilic inflammation (exhaled nitric oxide [eNO] \geq 30 ppb). Comorbidities were also analyzed (Table 1), with a prevalence of inhalant allergy (69.6%), clinically controlled in the majority of cases (75.4%). With regard to malacias (tracheomalacia, bronchomalacia, laryngomalacia), they only showed comorbidity with asthma (3.8%) but not with other medical diagnoses.

The mean time of disease chronicity since diagnosis was approximately 5 years (Table 2) and the mean treatment doses received were 1.86/day (more detailed data about medical treatment and frequency of visits are shown in Table 3).

Descriptive analysis of caregiver clinical outcomes

One third (33.3%) of family caregivers exhibited anxiety symptoms (feelings of anguish/

fear, sustained concern and hyperactivity); 14.1% had a possible anxiety disorder diagnosis. Around 13% presented depression symptoms (anhedonia, negative self-concept, loss of interest in their image) and, in 3.8% of them, such symptoms were striking enough to suggest the presence of a mood disorder (Table 4). As far as overall emotional distress is concerned, 5.1% exhibited indicators of an emotional disorder diagnosis.

As shown in Table 5, family caregivers evidence moderate stress in the different PIP subscales, where scores in the frequency of occurrence of situations of care stand out. Among the most stressful situations of care, those in the emotional stress scale (regarding emotional distress, uncertainty and concern over the disease, both in caregivers themselves and their children) are particularly important.

Analysis of correlation and prediction of variables

As it can be seen from Table 6, anxiety, depression, and overall emotional distress correlate positively with the stress experienced by caregivers. Thus, in the two overall stress indicators –1) frequency of occurrence of situations of care and 2) psychological effort associated with them– the highest scores in stress are associated with greater values in the three emotional clinic indicators (anxiety, depression and overall emotional distress).

In particular, it is worth pointing out that anxiety and overall emotional distress are especially associated with the high frequency of occurrence of situations of care in the emotional distress scale.

We further analyzed the relationship existing between the medical outcome measures (time of chronicity, number of daily doses used,

TABLE 1. Severity of asthma according to the Spanish Guidelines for Asthma Management and comorbidities with other diagnoses

| Severity of asthma | n | % |
|---|----|------|
| Episodic-occasional | 2 | 2.5 |
| Episodic-common | 14 | 17.7 |
| Persistent-moderate | 62 | 78.5 |
| Persistent-severe | 1 | 1.3 |
| Comorbidities | n | % |
| Bronchial asthma | 17 | 21.5 |
| Bronchial asthma plus another diagnosis | 53 | 67.1 |
| Bronchial asthma plus two diagnoses | 6 | 7.6 |
| Bronchial asthma plus three diagnoses | 2 | 2.5 |
| Bronchial asthma plus four diagnoses | 1 | 1.3 |

n: frequency of cases; %: total percentage of cases in a given category.

TABLE 2. Time of chronicity and daily doses

| | | Time since diagnosis (in months) | Total daily dose |
|--------|-------|----------------------------------|------------------|
| n | Valid | 70 | 79 |
| | Lost | 9 | 0 |
| X | | 70.63 | 1.86 |
| Median | | 57.00 | 2.00 |
| SD | | 57.378 | 1.195 |
| Mín. | | 6 | 0 |
| Máx. | | 204 | 6 |

n: frequency of cases; X: mean; SD: standard deviation.

comorbidities, severity of asthma and allergy control) and the emotional clinic outcome measures (anxiety, depression and overall emotional distress). After the analysis, in our data there appear no statistically significant associations between both groups of variables.

Finally, three multiple linear regression analyses were performed to determine what variables might help us predict the best scores in the three indicators of emotional status (anxiety, depression, overall emotional distress). Initially, the following were identified as possible predictor variables: a) both overall stress indicators and b) the medical outcome measures studied.

The model that best helps us to predict the

“level of overall emotional distress experienced by the family caregiver” includes as predictor variables the “number of daily doses of medical treatment received” and the two overall stress indicators: 1) frequency of occurrence of the situations of care and 2) the psychological effort associated with them. This model explains 37.3% of variance. After performing a clustered regression analysis, it was found that the type of situations that best predicted the stress levels associated with the frequency of occurrence of situations of care would be the one included in the emotional stress factors (emotional distress, uncertainty and concern over the disease) and medical care (undergoing medical tests, changes in treatment

TABLE 3. *Type of medical treatment used and frequency of visits of adolescents with asthma*

| Type of treatment | n | % |
|---|----|------|
| Inhaled therapy with aerosol or dry powder | 43 | 54.4 |
| Inhaled therapy with aerosol or dry powder and oral medication | 26 | 32.9 |
| Inhaled therapy with aerosol or dry powder and immunotherapy | 7 | 8.9 |
| Inhaled therapy with aerosol or dry powder. oral medication and immunotherapy | 3 | 3.8 |
| Frequency of visits | n | % |
| Annual | 57 | 72.2 |
| Every 6 months | 26 | 32.9 |
| Every 4 months | 5 | 6.3 |
| Every 3 months | 1 | 1.3 |

n: frequency of cases; %: total percentage of cases in a given category.

TABLE 4. *Indicators of emotional distress: clinical anxiety-depression*

| | Normal-absence | | Probable case | | Clinical problem | |
|----------------------------|----------------|------|---------------|------|------------------|------|
| | n | % | n | % | n | % |
| Anxiety | 52 | 66.7 | 15 | 19.2 | 11 | 14.1 |
| Depression | 68 | 87.2 | 7 | 9 | 3 | 3.8 |
| Overall emotional distress | 74 | 94.9 | - | - | 4 | 5.1 |

n: frequency of cases; %: total percentage of cases in a given category.

TABLE 5. *Indicators of perceived stress in relation to caring for a patient with asthma*

| | M | SD | Mín. | Máy. | Scale score range |
|---------------------------------|--------|-------|------|------|-------------------|
| 1. Communication frequency | 20.65 | 4.06 | 12 | 31 | 9-45 |
| 1. Communication effort | 16.61 | 5.45 | 9 | 36 | 9-45 |
| 2. Medical care frequency | 24.29 | 5.23 | 11 | 36 | 8-40 |
| 2. Medical care effort | 14.49 | 5.60 | 8 | 32 | 8-40 |
| 3. Emotional distress frequency | 35.51 | 8.02 | 20 | 67 | 15-75 |
| 3. Emotional distress effort | 37.13 | 11.35 | 16 | 70 | 15-75 |
| 4. Family role frequency | 21.34 | 5.53 | 10 | 41 | 10-50 |
| 4. Family role effort | 21.46 | 7.05 | 10 | 45 | 10-50 |
| 5. Total frequency | 101.34 | 19.1 | 57 | 90 | 42-210 |
| 6. Total effort | 89.56 | 25.64 | 44 | 183 | 42-210 |

M: median; SD: standard deviation; Mín.: minimum possible score in questionnaire; Max.: maximum possible score in questionnaire.

and decision-making on medical issues). As for the level of stress associated with care-related psychological effort, the analysis revealed that the situations included in the family role factor (family, work, or social role changes) were the ones that mainly impinged on the type of stress experienced by caregivers.

The model that best predicts the “family caregiver’s level of anxiety” includes as predictor variables the “level of depression in the caregiver”, the “overall stress indicator associated with the frequency of occurrence of the situations of care” and the “time of chronicity”, which explains 47.8% of variance. In the clustered regression analysis performed, it was found that the type of situations that best predicted the levels of stress associated with the frequency of occurrence of care-related situations would be the ones included in the emotional distress factor.

Finally, the model that best explains the “level of depression experienced by the family caregiver” is the one that includes the predictor variable “caregiver’s anxiety level”, “overall stress indicator associated with the psychological effort in relation to the situations of care” and “daily dose of medical treatments received”, which explains 48.6% of variance. As for the level of stress associated with care-related psychological effort, the situations included in the medical care and family role factors (family, work, or social role changes) might be the ones mainly impacting on the type of stress experienced by caregivers.

DISCUSSION

Results indicate that a large number of caregivers of adolescents with asthma (even with clinically controlled asthma) show significant levels of stress and anxious-depressive symptomatology that impact negatively on their well-being and increase the risk for emotional disorder.

In the studies, similar results have been observed in caregivers of pediatric patients with short stature⁷ or with diabetes,⁸ in whom moderate stress levels were detected, with the highest scores found in the medical care and emotional distress scales. Thus, the family system of a pediatric patient with asthma must cope, in addition to the stressors common to any family with adolescent children, with those resulting from the presence of the disease. These additional stressors include aspects such as the following: ^{15,16} a) the disease itself and the novelty and uncertainty about its course and progress; b) coming to grips with the information provided by healthcare providers, explanations about the disease received by the adolescent and his or her closest support system; c) economic difficulties, as a part of the household budget has to be spent on treating the disease (which impinges on other needs such as leisure, recreation or sharing experiences); d) psychoemotional management of aspects relating to the medical care needed and e) tensions with partners and family, and role conflicts.

TABLE 6. Associations between patient’s medical outcome measures and caregiver’s clinical outcome measures

| HADS (clinical anxiety-depression) | | Anxiety scale | Depression scale | Overall distress scale |
|---|-------------------------------|---------------|------------------|------------------------|
| PIP (perceived stress) | | | | |
| Frequency of occurrence of situations of care | Communication | + | | + |
| | Medical care | | | |
| | Emotional distress | + | + | + |
| | Family role | + | + | + |
| | Total stress due to frequency | + | + | + |
| Psychological effort associated with situations of care | Communication | + | + | + |
| | Medical care | | + | + |
| | Emotional distress | + | + | + |
| | Family role | + | + | + |
| | Total stress due to frequency | + | + | + |

Moderate association: white-colored; high or strong association: gray-colored.
 HADS: Hospital Anxiety and Depression Scale; PIP: Pediatric Inventory for Parents.

In our study, a high percentage of caregivers of patients with asthma exhibited anxiety and depression symptomatology, a finding further reported in studies carried out in children with short stature,⁷ type 1 diabetes mellitus or cancer,¹⁰ where, in an important proportion of cases, patients had a clinical problem requiring psychological care.

Our research has some limitations such as the fact that the vast majority of caregivers were women, as mothers are the ones who most commonly assume care for their children. It might be interesting to observe the possible differences in adjustment to disease between mothers and fathers of ill patients. In addition, for purposes of sample homogenization, our study focused solely on patients with clinically controlled bronchial asthma. Future research might assess the association existing between the degree of asthma control and the emotional repercussion on principal caregivers, as well as other medical outcome measures, such as the number of hospitalizations and length of stay, or exacerbations.

A multidisciplinary approach to bronchial asthma in adolescence might allow us to go beyond the medical condition and learn about other aspects likely to interfere with adequate disease control-evolution. This might result in the implementation of concrete action intended to prevent psychopathology in the family system as a whole, thereby improving its quality of life.

CONCLUSIONS

Of caregivers studied, 33.3% showed symptoms of anxiety, and 13%, of depression. The levels of stress in family caregivers associated with care behaviors together with the time since diagnosis of pediatric patients and the treatment burden these must bear on a daily basis were identified as main predictors of risk for emotional distress. ■

REFERENCES

1. Organización Mundial de la Salud. Enfermedades respiratorias crónicas. 2016. [Accessed on: June 1st, 2017]. Available at: <http://www.who.int/respiratory/asthma/es/>.
2. GEMA. Guía Española para el Manejo del Asma. 2016. [Accessed on: April 15th, 2017]. Available at: www.gemasma.com.
3. European Respiratory Society European Lung White Book: Respiratory Health and Disease in Europe. 2013. [Accessed on: June 1st, 2017]. Available at: <http://www.erswhitebook.org/>.
4. Pellegrini-Belinchón J, de Arriba Méndez S. El asma en el adolescente. *Adolescere* 2013;1(3):7-27.
5. Alonso Lebrero E. Asma en situaciones especiales. In García-Marcos Álvarez L, Garde J, Escribano Montaner A, et al. *Asma en pediatría*. Barcelona: Edipharma; 2002. Pp.187-217.
6. Martín Martín R. Estudio de las variables psicológicas, calidad de vida e intervención psicoeducativa en el asma bronquial infantil [Tesis]. Salamanca: Universidad de Salamanca; 2008.
7. Casaña-Granell S, Lacomba-Trejo L, Montoya-Castilla I, et al. Malestar emocional y estrés en cuidadores principales de pacientes pediátricos con talla baja. *Calid Vida Salud* 2016;9(2):93-103.
8. Lacomba-Trejo L, Casaña-Granell S, Pérez-Marín M, et al. Estrés, Ansiedad y Depresión en cuidadores principales de pacientes pediátricos con Diabetes Mellitus Tipo 1. *Calid Vida Salud* 2017;10(1):10-22.
9. Pak L, Allen PJ. The impact of maternal depression on children with asthma. *Pediatr Nurs* 2012;38(1):11-30.
10. Rodríguez E, Dunn M, Zuckerman T, et al. Cancer-related sources of stress for children with cancer and their parents. *J Pediatr Psychol* 2012;37(2):185-97.
11. Blanco Ávila DM. Habilidad de cuidado de los cuidadores principales de niños en situación de enfermedad crónica que consultan en la Clínica Colsanitas. *Av Enferm* 2007;25(1):19-32.
12. Bazán Riverón GE. Evaluación del impacto familiar del asma bronquial infantil en población mexicana. [Dissertation]. Barcelona: Universidad Autónoma de Barcelona; 2009.
13. González-Barcala JF, García-Couceiro N, Facal D. Educación en asma. *Arch Bronconeumol* 2016;52(11):543-4.
14. Mann NM. Compliance among adolescents with asthma. [Dissertation]. Utah: Universidad de Utah, 2000.
15. Streisand R, Braniecki S, Teryack K, et al. Childhood Illness-Related Parenting Stress: The Pediatric Inventory for Parents. *J Pediatr Psychol* 2001;26(3):155-62.
16. Del Rincón C, Remor E, Arranz P. Estudio psicométrico preliminar de la versión española del Pediatric Inventory for Parents (PIP). *Int J Clin Health Psychol* 2007;7(2):435-52.
17. Lazarus RS, Folkman S. Estrés y procesos cognitivos. Barcelona: Martínez Roca; 1986.
18. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67(6):361-70.
19. American Psychiatric Association. DSM-5. Diagnostic and Statistical Manual of Mental Disorders. 5.^a ed. Arlington, VA: American Psychiatric Publishing; 2014.
20. Gabalda IC, Ibañez E. La escala hospitalaria de ansiedad y depresión. *Bol Psicol* 1992;36:43-69.