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ORIGINAL ARTICLE

Impact of children's respiratory allergies on caregivers

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ABSTRACT: ***Impact of children's respiratory allergies on caregivers. G. Majani, I. Baiardini, A. Giardini, M. Pasquali, M. Tiozzo, M. Tosca, C. Cosentino, S. La Grutta, G.L. Marseglia, G.W. Canonica.***

Background. **Despite the great attention that has been paid to HRQoL in children with respiratory allergy, few studies have addressed this aspect in relation to caregivers. The aim of our study was to evaluate the impact of childhood respiratory allergies on caregivers by means of a new method.**

Methods. **119 parents of children suffering from allergies (75 suffering from asthma and 44 suffering from rhinitis) were recruited from three Italian Allergy Units. Parents were asked to complete the Disease Impact On Caregiver (DIOC), a new non disease specific questionnaire, validated on the Italian population. The questionnaire consists of 31 items grouped in four factors (Performance, Personal gratification, Psychophysical endurance, Socio-emotional domain) and covers the life aspects that could be affected by the assistance duties towards an ill family member.**

Results. **Child's asthma resulted to have a worse impact on many aspects of a parents' life than rhinitis. Differences resulted to be statistically significant in 19 aspects out of the 31 assessed. The worse impact of asthma versus rhinitis was confirmed in the following domains: Performance (24.0±18.2 vs 11.5±17.8), Personal gratification (26.3±20.5 vs 12.1±16.5) and Psychophysical endurance (35.0±24.8 vs 18.8±21.7). In the Socio-emotional domain no difference emerged.**

Conclusions. **Compared to parents of rhinitics, parents of asthmatic children appear to be more compromised in their resistance to stress, mood, emotional stability, amount of spare time and leisure activities. Our results suggest the need of giving the due attention to these problems both in clinical practice and in research, in order to avoid possible interferences of the caregiver's distress in the optimization of treatment outcome.**

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Keywords: Respiratory allergy, child, caregiver, disease impact.

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Introduction

Beside the conventional biomedical parameters, in the last decade Health Related Quality of Life (HRQoL) has become an important indicator of medical outcome. Within this field, a multidimensional understanding of illness burden on patient and family is nowadays gaining attention in order for appropriate and effective treatment strategies to be designed and applied [1-2].

The impact of a chronic disease on the caregiver always deserves great attention, but it becomes a central issue when dealing with paediatric patients. Illness management in this case must always be shared by parents and child.

In the last years, several questionnaires have been developed in order to explore caregivers' reactions to a child's illness [3-6].

In respiratory allergies this aspect of care has been seldom addressed providing data on HRQoL in parents of asthmatic children [7-9]. Townsend showed that the primary caregivers have stated limitations in daily activities and distress as results of their child's asthma [10]. On the basis of these results, Juniper and co-workers [11] developed the PACQLQ (Paediatric Asthma Caregiver's Quality of Life Questionnaire), a specific instrument, designed to explore the impact of paediatric asthma on parents' every day life and emotions.

Osman *et al.* [9] administered the PACQLQ to 62 parents of pre-school asthmatic children. Caregivers' age (<30) and a low socioeconomic status had a significant negative impact on QoL scores, moreover as child symptoms improved or worsened, parental PACQLQ scores changed coherently.

Studies considering the burden of allergic rhinitis on parents are not yet available.

The aim of our study was to apply a new Italian questionnaire (Disease Impact On Caregiver – DIOC) on parents of children suffering from allergic respiratory diseases, in order to compare the burden of asthma and rhinitis on parents' daily life.

Methods

Subjects and procedure

Data was collected in three Italian Allergy Units (Genoa, Pavia, Palermo). To be eligible for the study, participants had to be parents of a child suffering from intermittent allergic asthma and/or persistent allergic rhinitis. While attending the clinic, parents were assessed and informed written consent was obtained. The presence of any chronic disease (e.g. diabetes, epilepsy, major neuropsychiatric disorders) other than respiratory allergy was an exclusion criterion. Recent major events in

Table 1. - Sample characteristics

		Rhinitis group (n=44)	Asthma group (n=75)	*p*
Childrens' characteristics				
Gender	M	24 (56%)	41 (55%)	ns
	F	20 (44%)	34 (45%)	ns
Age		7.8±3.4	7.1±3.3	ns
Caregivers' characteristics				
Gender	M	9 (21%)	9 (12%)	ns
	F	35 (79%)	66 (88%)	ns
Age		38.0±5.3	36.1±6.4	ns
Marital status	Single	-	6 (8%)	ns
	Married	44 (100%)	69 (92%)	ns
Years of education	0-5	1 (3%)	4 (5%)	ns
	6-8	12 (27%)	30 (40%)	ns
	9-13	26 (59%)	35 (47%)	ns
	more than 14	5 (11%)	6 (8%)	ns
Employment status	employed	31 (70%)	40 (53%)	ns
	housewife	12 (27%)	32 (43%)	ns
	retired	1 (3%)	3 (4%)	ns

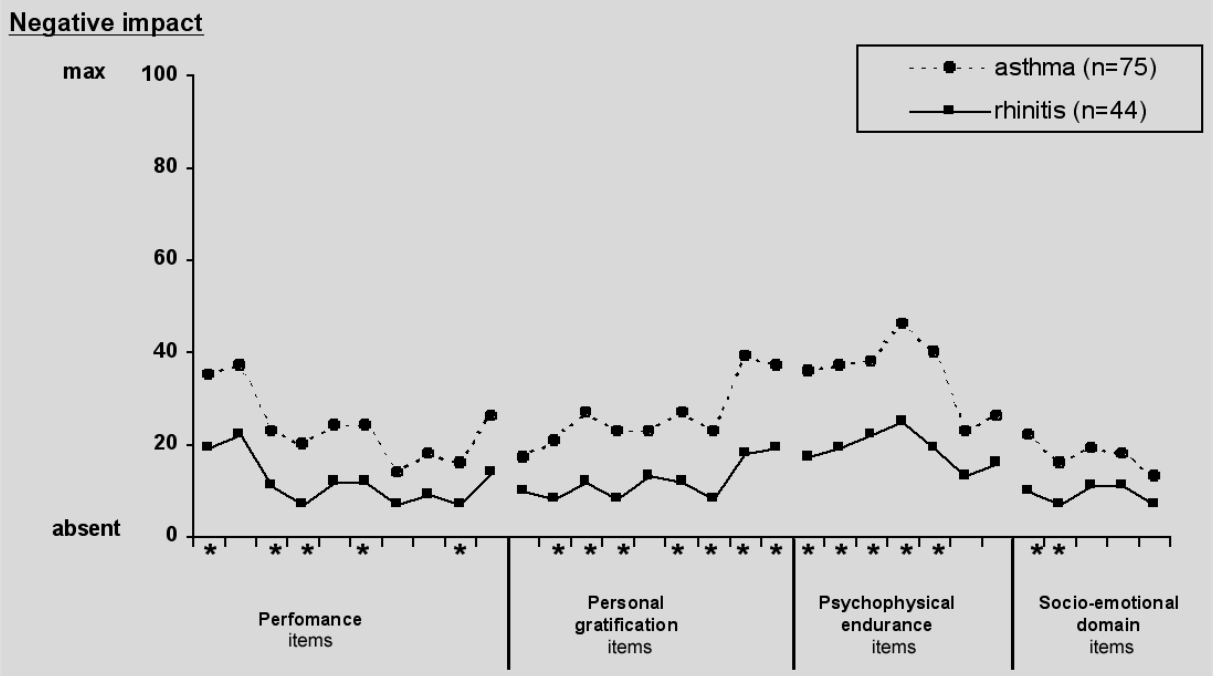

Fig. 1. - DIOC items comparison between caregivers of children with asthma and caregivers of children with rhinitis. * p<0.01

parent's or in family's life (such as divorce, death of relatives, changes in lifestyle) were exclusion criteria as well.

One hundred and twenty-five parents of these children were recruited over a three-month period, during the pollen season. The presence of a respiratory allergy was ascertained through routine diagnostic criteria: positive clinical history and skin prick test positivity to the common allergens. The prick tests were performed according to international guidelines [12] with commercial standardised extracts of the following allergens: house dust mites, grass, parietaria, cat dander, dog dander, birch, olive, hazelnut, cypress, Alternaria and Cladosporium. Tests were carried out on the forearm, using positive (histamine 1%) and negative (saline) controls for comparison. The results were expressed as the mean of the major diameter of the wheal plus it's orthogonal. Reactions greater than 3mm were considered positive.

Persistent allergic rhinitis was clinically diagnosed, following international guidelines [13]. The diagnosis of asthma was based on clinical history of recurrent attacks of shortness of breath, chest tightness, wheezing, nocturnal awakenings, cough within the past two years and/or actual dyspnea and/or wheezing at clinical examination. Pulmonary function test (PFT) showing a FEV_1 less

Table 2. - Comparison between DIOC item scores of parents of rhinitic children and DIOC item scores of parents of asthmatic children (means, standard deviations and *p* values are reported)

	Parents of rhinitic children (n=44)	**Parents of asthmatic children (n=75)**	***p***
Performance			
Amount of sleep	19.45±29.02	34.93±33.33	.01
Quality of sleep	21.82±29.26	36.52±32.94	ns
Mental efficiency	10.52±20.66	23.17±28.10	.006
Problem solving ability	7.02±15.49	19.69±23.92	.001
Type of work	12.18±24.33	23.79±30.20	ns
Organization of work	11.50±21.30	24.14±29.81	.01
Professional role	6.65±16.95	14.12±21.40	ns
Work productivity	9.39±22.46	18.01±22.92	ns
Social Image	6.68±14.81	16.40±23.63	.007
Financial situation	14.48±30.16	26.25±30.67	ns
Personal gratification			
Quality of food	10.36±20.78	17.38±23.58	ns
Eating behaviour	8.09±18.09	20.51±27.79	.004
Physical appearance	11.57±19.77	26.69±30.26	.001
Physical mobility	7.77±20.67	22.55±28.83	.002
Level of physical activity	12.66±24.49	22.79±28.95	ns
Frequency of sexual intercourse	12.11±21.58	22.11±28.60	.002
Quality of sexual intercourse	8.40±20.30	22.52±27.83	.002
Amount of spare time	18.41±26.73	38.52±34.93	.001
Leisure activities	19.34±27.92	36.71±32.58	.003
Psychophysical endurance			
Resistance to physical fatigue	16.68±26.61	35.59±34.30	.001
Physical well being	19.14±28.37	36.69±32.23	.003
Resistance to stress	22.41±29.00	37.55±31.92	.01
Mood	25.14±29.43	45.84±34.15	.001
Emotional stability	19.45±22.21	39.84±34.46	.0001
Self confidence	12.81±23.71	23.39±30.10	ns
Self control	16.43±33.48	26.37±29.34	ns
Socio-emotional domain			
Couple relationship	10.41±18.81	21.55±27.80	.01
Family role	7.27±14.14	15.99±22.66	.01
Relationship with other members of the family	11.09±21.69	18.58±26.97	ns
Relationship with friends	11.09±21.39	18.01±24.88	ns
Relationship with colleagues	7.46±14.42	13.33±22.55	ns

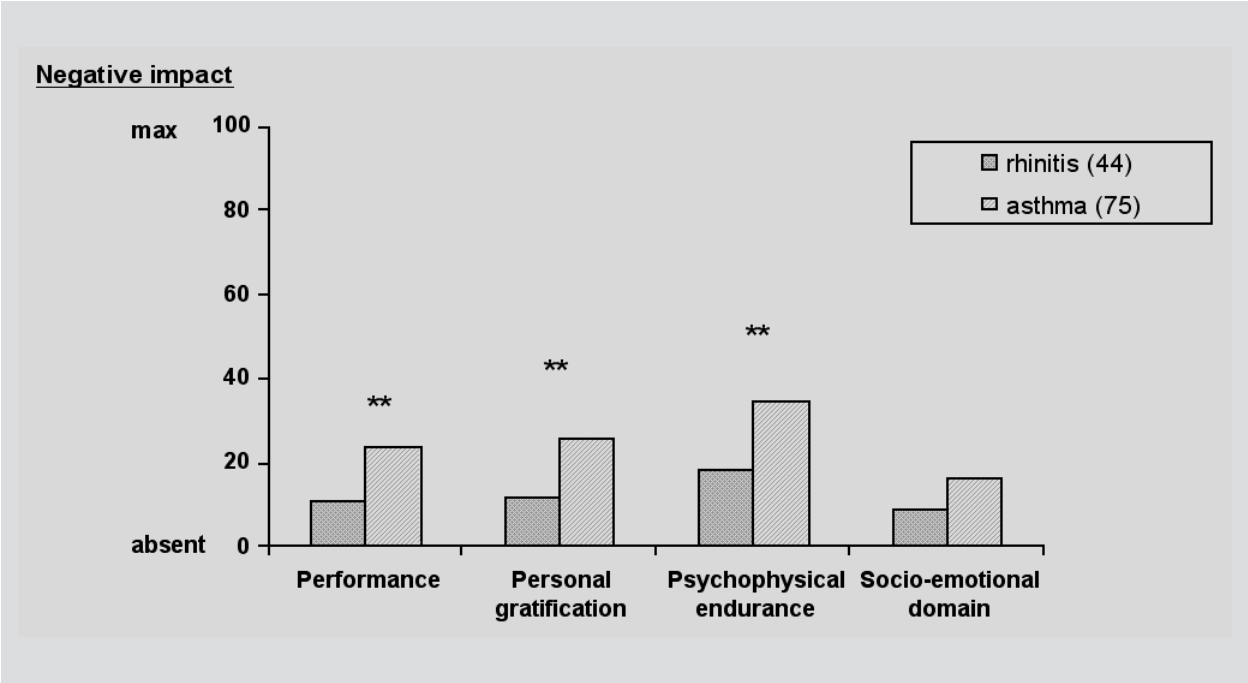

Fig. 2. - DIOC factors comparison between parents of children with asthma and parents of children with rhinitis. ** p<0.0001

than 80% of predicted value with a reversibility of at least 12% after salbutamol or a positive methacholine (MCh) challenge with a provocation dose (PD_{20}) of 1200 µg or less were also used for diagnosis.

Instrument

The Disease Impact On Caregiver (DIOC), developed by the Psychology Unit of the Scientific Institute of Montescano, is a new questionnaire recently validated on the Italian population [14-15]. The DIOC resulted in good psychometric properties (criterion and construct validity, test-retest reliability, internal reliability and responsiveness). The instrument consists of 31 items grouped by factor analysis into 4 dimensions. For each item the primary caregiver is requested to assess, on a 10cm horizontal visual analogue scale, the child disease impact on many aspects of daily life, that may be affected by the assistance duties towards an ill family member. Each score ranges from 0 (no negative impact) to 100 (maximum negative impact). The higher the scores the more negative the impact.

Statistical analyses

Descriptive analyses were conducted considering the child's demographic characteristics (sex, and age) and parent's demographic characteristics (sex, age, marital status, years of education, and employment status). After dividing the parents in two groups according to diagnosis (rhinitis alone or asthma with or without rhinitis), *t*-test for unpaired samples and Chi-square test were adopted on demographic characteristics in order to verify the homogeneity of the two samples. DIOC item and factor scores of the two groups were compared by means of *t*-test for unpaired samples. A multivariate analysis was not necessary because of group homogeneity. For all the analyses, the *p* value was set at 0.01.

The statistical analyses were performed using the SPSS 11.0 statistical software package.

Results

Out of 125 questionnaires completed by the parents, 119 questionnaires were considered for the analyses, since 6 were incorrectly completed. Parents' and children's demographic characteristics are shown in table 1. No significant statistical differences emerged in demographic characteristics between the two groups.

The comparison between DIOC item scores of rhinitics' and asthmatics' parents showed that the presence of children's asthma had a significantly heavier impact on a caregiver's life than rhinitis alone in many aspects of daily life (figure 1 and table 2).

The statistically significant worsening impact of asthma vs rhinitis was reconfirmed following the consideration of the DIOC factors: Performance (24.0±18.2 vs 11.5±17.8), Personal gratification (26.3±20.5 vs 12.1±16.5) and Psychophysical endurance (35.0±24.8 vs 18.8±21.7) (figure 2).

Discussion

The results of the present study highlight the impact of paediatric respiratory allergy on parent's every day life, as already demonstrated in recent research [7, 9, 11]. Parents of asthmatic children have to deal with demanding issues, both practical and psychological, connected to asthma manage-

ment; in our sample these aspects seem to compromise mainly their resistance to stress, mood, emotional stability, amount of spare time and leisure activities. Conversely, our results have shown that rhinitis has a lighter impact than asthma: primary caregivers of asthmatics reported higher DIOC scores in almost every item and in three out of the four dimensions.

These differences in the two groups were mainly expected and are confirmed by clinical experience. But they also provide an important clinical clue: the low scores in parents' of rhinitics may stem from a general attitude to consider rhinitis as "not more than a cold" and therefore to underestimate and minimise the possible evolution of the disease through time.

Moreover the DIOC also detected caregivers' resources: in the Socio-emotional dimension, even if the two groups' profiles did differ in two items, the item scores were substantially low. This could be read as an indicator of the presence of effective interpersonal abilities and of a strong affective network, which supports caregivers independently from the disease severity. Health care professionals can obtain useful information from the DIOC in order to better focus their psychological support.

Some limits should be underlined: a control group is not available, but theoretically, since this assessment focuses on the subjective component of disease impact, no normative data on caregivers' of healthy subjects may be collected. Further studies may investigate the correlation between the DIOC and other validated tools.

In our study disease severity and follow-up were not considered, because of sample size; further studies may be performed. Moreover, even if the *p* values underline relevant significant differences between the two groups, the high standard deviation of the scores carries a warning to be cautious when interpreting our results.

Finally, parents openly appreciated being asked about their personal difficulties and fatigue in taking care of their child. This can in turn improve the quality of communication between the primary caregiver and the medical staff, which is renowned as one of the strongest predictors of treatment adherence. The DIOC could also properly identify the caregivers' needs, thus helping clinicians in offering a focused and multidisciplinary intervention when necessary.

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