The voice of the patients: allergic rhinitis is not a trivial disease

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Purpose of review

Patient and physician perspectives on the impact of allergic rhinitis have previously been studied in the general population. We evaluated the burden of allergic rhinitis among patients from the members of European allergy patient organizations. The Patient Voice Allergy Survey was a quantitative, self-completion survey of 3562 patients with allergic rhinitis (16 years and older). Background information on allergic rhinitis, severity of allergic rhinitis symptoms and their impact on lives, nonmedical measures for relieving of symptoms, types of medications, and concomitant conditions were evaluated.

Recent findings

Almost 50% of the responders reported symptoms lasting for more than a season. Preventive household adjustments are expensive with little perceived benefit. Sleep and emotional life are affected by allergic rhinitis. Most patients are satisfied with the current allergic rhinitis medications; at least one-fifth report dissatisfaction. Patients perceive that allergic rhinitis worsens other concomitant allergic diseases.

Summary

Future management guidelines for allergic rhinitis must take into account the results of this survey. Such guidelines must promote relief from the emotional burden of allergic rhinitis and from the negative impact on daily activities, encourage patient education, and maintain and build on the strong partnership between patients and healthcare professionals.

Keywords

allergic rhinitis, burden, comorbidities, costs

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Introduction

The increasing prevalence of allergic respiratory diseases is well documented [1,2]. Allergic rhinitis has the highest prevalence [3], affecting an average of 24% of the European population [1]. Eighty percent of asthma patients and 80% of children with atopic dermatitis [4] suffer from allergic rhinitis. Clinical trials have documented the severity of allergic rhinitis and its impact on quality of life [5]. A new classification of allergic rhinitis was proposed in the Allergic Rhinitis and its Impact on Asthma (ARIA) guidelines based on severity and duration rather than causality [6]. Complications of allergic rhinitis and concomitant diseases are well documented, such as acute and chronic sinusitis, recurrence of nasal polyps, otitis media/otitis media with effusion, hearing impairment, abnormal craniofacial development, sleep apnea, aggravation of underlying asthma, and increased propensity to develop asthma [7•]. Daytime fatigue, learning impairment, decreased overall cognitive functioning, and decreased long-term productivity have also been attributed to allergic rhinitis [8].

Allergic rhinitis, especially persistent allergic rhinitis (PER), is a serious debilitating disease. However, there is still doubt among regulatory agencies and health payers about how serious allergic rhinitis is. The use of over-the-counter drugs is common in allergy sufferers [9]. As costs are shifted away from insurers to patients, the risk of denying patients, access to effective, comprehensive, and physician-supervised disease management is growing.

Patient involvement in the management of allergic rhinitis is important. Knowledge of patients' perceptions of their disease and its consequences are scarce; so, we evaluated the impact of allergic rhinitis on the lives of allergy sufferers and assessed the success of its management. Aware that many sufferers of allergic rhinitis are undiagnosed and unaware of their disease [9], we chose to survey self-reported allergic rhinitis patients who are members of European allergy patient organizations (www.efanet.org). Thus, our survey reflects the knowledge and experience of motivated and self-conscious allergy sufferers.

The questionnaire we chose to use is patient-oriented and descriptive. There are studies and surveys using various validated health-related quality-of-life and patient-perspectives questionnaires. Most of them report

Table 1 Number of surveys and proportion of responders among the allergic rhinitis sufferers per country

Country	Number of collected surveys	Estimated AR sufferers[a] (millions)	% of AR population in PVAS	% of responses in PVAS
Belgium	331	1.7	2.4	9.2[b]
Czech Republic	272	1.7	2.4	8.0[b]
Finland	364	1.4	2.0	10.4[b]
France	302	17.0	24.4	8.1[c]
Germany	186	14.8	21.3	5.4[c]
Greece	87	1.7	2.4	2.4
Italy	294	8.0	11.5	8.4[c]
Netherlands	199	2.5	3.6	5.7[b]
Spain	561	5.4	7.8	16.1[b]
Switzerland	222	0.8	1.2	5.6[b]
UK	744	14.7	21.1	20.8
Total	3562	69.7	100	100

[a] Taken from the Decision Resources Report 2001 (www.dresources.com/stellent/groups/public/documents/abstract/dr_008812.hcsp).
[b] Down-weighted countries (see text for explanation).
[c] Up-weighted countries (see text for explanation).
AR, allergic rhinitis; PVAS, Patient Voice Allergy Survey.

findings as score numbers or percentages of score improvements which are sometimes difficult to assess and understand, and which need special interpretation [10]. Since this area remains controversial [11] we designed our own questionnaire.

Methods

The Patient Voice Allergy Survey was a quantitative, self-completion survey, initiated, co-ordinated, supervised and conducted by the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) in Belgium, Czech Republic, Finland, France, Germany, Greece, Italy, the Netherlands, Spain, Switzerland and the UK. A total of 3562 questionnaires were collected (Table 1). The following key areas were covered: (1) background information on allergic rhinitis, (2) severity of symptoms and their impact, (3) nonmedical measures, (4) medication, and (5) concomitant conditions. A description of the questions appears in Table 2. The original questionnaire was designed in English and was translated in the local languages through professional interpreters.

The local patient organizations sent the questionnaire to their members with a cover letter clarifying the purpose of the survey and an explanation of how the results would be used. The completed questionnaires were sent to a central market-research agency (Aequus Research, London, UK), which compiled a descriptive report. The report was planned to be presented both as individual results by country and as consolidated pan-European results. The latter only are presented in this paper.

Primary objectives

The aim of the this survey was to explore the impact of allergic rhinitis on the lives of sufferers across Europe. The primary objectives were to answer the following questions: (1) what is the nature of allergic rhinitis and the significance on daily life, (2) which aspects of life does allergic rhinitis affect, (3) what is the prevalence of concomitant allergic diseases, and (4) what are the costs for preventive measures and medications and are they effective?

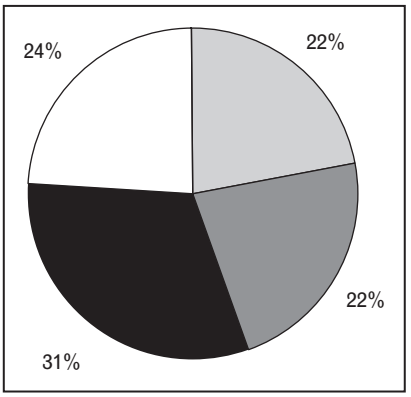
In the pan-European analysis results were weighted to account for the returned questionnaires not being in the

Table 2 A summary of the 26 survey questions

Background AR information
For how long have you had allergic rhinitis and who diagnosed it first?
During which season, for how many days per week and during how many consecutive weeks do you experience your AR symptoms?
What triggers your AR symptoms and how severe are they?
Impact of AR
How do your AR symptoms affect sleep, work, school, visiting and/or meeting friends, travelling in public transport, indoor and outdoor activities, choice of sport, choice of holiday destinations, time of holidays?
How do your nasal and ocular symptoms affect you?
How does your AR affect you emotionally?
What are the three things that bother you most about your AR?
Did you take time off work/school because of your AR, over the past year?
Have you ever been unable to concentrate at work/school, due to your AR, over the past year?
Measures taken to ease AR symptoms
Have you had to make changes to your household, for example purchasing special mattresses, pillows or duvets; special household cleaning products; a humidifiers/air cleaners; pollen screens; replaced existing furniture; removed carpets? How effective were these measures?
How much money have you spent on making your home allergy-free?
How many times a year do you visit your doctor because of your AR?
Medications taken for AR
Do you take medications to prevent or control the AR symptoms and how effective are they?
How do you obtain your medication (with or without prescription)?
AR and concomitant conditions
Do you suffer from asthma, atopic eczema, urticaria, or food allergy and if so does your AR worsen them?
Have you ever approached your doctor about your asthma/eczema/urticaria/food allergy?

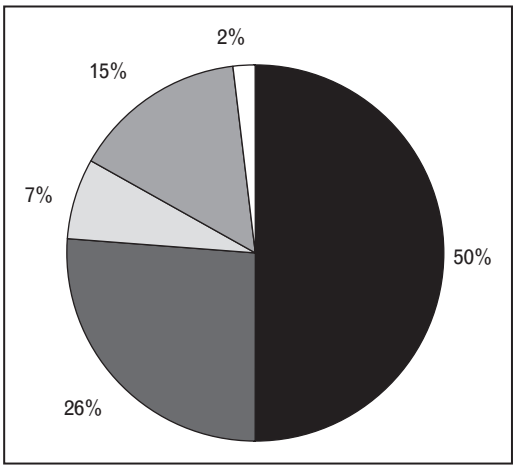
Severity was measured on a scale of 0 (none) to 3 (severe).
AR, allergic rhinitis.

Figure 1 Duration of allergic rhinitis in Europe (percentage of patients)



□ 0–5 years; ■ 6–10 years; ■ 11–20 years; □ all your life.

Figure 2 Time of year when allergic rhinitis symptoms are most bothersome (percentage of patients)



■ One season; ■ two seasons; □ three seasons; ■ four seasons; □ not stated.

same proportions as the estimated number of allergic rhinitis populations in each country.

Ethical standards

The survey was anonymous and no attempt was made to identify the patients. All survey procedures were conducted in accordance with the ESOMAR International Code of Marketing and Social Research Practice (www.esomar.org/). This code ensures the full anonymity and integrity of the participating patients and guarantees that research is carried out objectively and in accordance with established scientific principles and with national and international legislation.

Results

We collected and analysed 3562 questionnaires. Weighted results accounting for differences between countries, allergic rhinitis populations and responses achieved are presented in Table 1.

Background and severity of symptoms

Allergic rhinitis is a long-term – in 25% of patients a lifelong – condition (Fig. 1). More than 50% of patients have suffered from allergic rhinitis for 11 years or more. Almost 50% of patients experience allergic rhinitis symptoms for two seasons of the year or more (Fig. 2). Persistent allergic rhinitis (PER), defined as rhinitis of which symptoms last for ≥ 4 days/week and ≥ 4 weeks/year, was reported by 62%. More female patients reported PER (66%) than male (55%). Allergic rhinitis is triggered by a range of allergens (Fig. 3).

Patients rated the severity of nine allergic rhinitis symptoms (Table 3). Sixty-six percent experienced at least one symptom severe enough to interfere with their daily activities or sleep; 40% of those experienced at least three severe symptoms; and 57% of the patients with intermittent allergic rhinitis (IAR) reported at least one severe symptom, the number for PER being 72%. PER patients suffer significantly more than the IAR patients (Table 3).

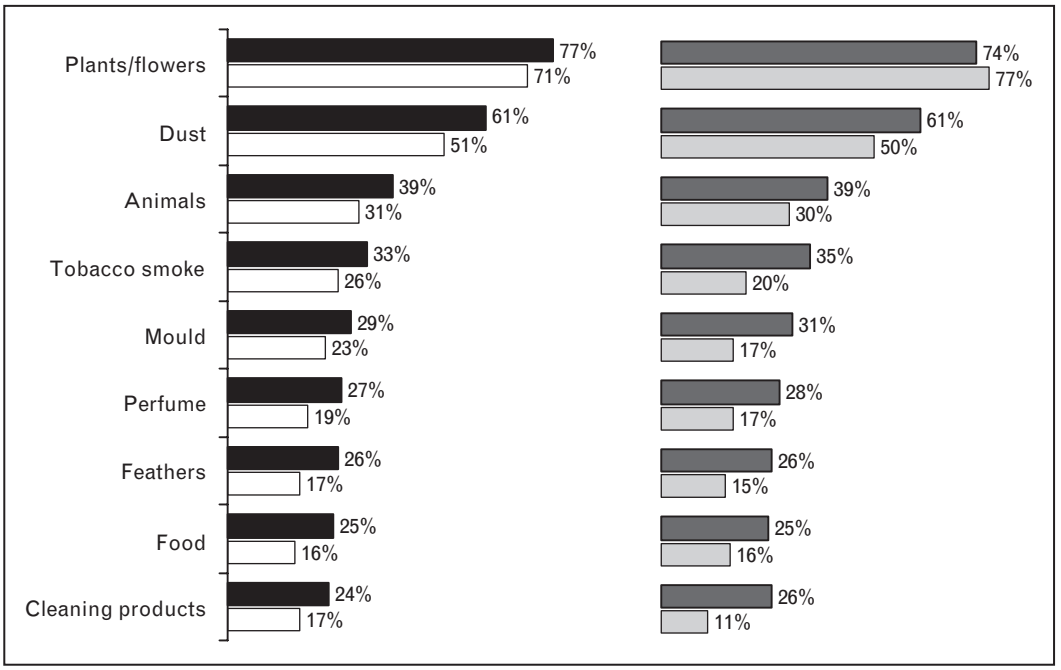
The impact on sleep is a major consideration for allergy patients. Forty-six percent of patients do not feel rested

Table 3 Allergic rhinitis symptom severity and symptom distribution over various disease types and sexes

	Severity of AR symptoms (%)				Type of AR (%)		Sex (%)	
	Absent	Mild	Moderate	Severe	PER	IAR	Male	Female
Runny nose	10	16	44	30	34	24	32	28
Sneezing	10	22	42	26	29	22	27	26
Blocked nose	19	18	34	30	34	24	32	27
Itchy/red eyes	29	21	29	21	26	13	24	16
Itchy nose	22	27	34	17	19	13	18	14
Wheezing/coughing	42	22	20	16	19	12	19	11
Watery eyes	40	24	23	12	15	9	14	9
Itchy throat	43	26	20	11	13	6	14	5
Itchy palate/ears	46	23	21	10	13	5	14	3

AR, allergic rhinitis; IAR, intermittent allergic rhinitis; PER, persistent allergic rhinitis.

Figure 3 Main triggers of allergic rhinitis



Comparisons are shown for persistent and intermittent allergic rhinitis, and for female and male patients. Percentages of patients are given. ■ Persistent ($n = 2305$); □ Intermittent ($n = 1257$); ■ Females ($n = 2287$); □ Males ($n = 1129$).

after sleep, while a further 44% wake up during the night. Thirty percent reported difficulties with getting to sleep (Fig. 4).

Impact of symptoms on patients' lives

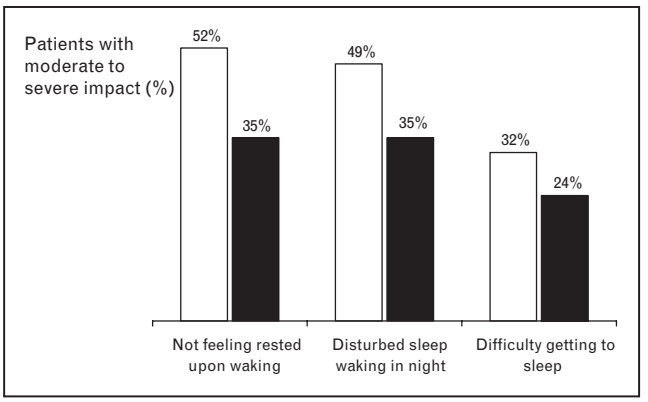
Eighty-seven percent of the PER and 79% of the IAR patients feel that their rhinitis symptoms affected moderately to severely at least one daily activity 'all the time' (Fig. 5). The impact of allergic rhinitis is most severe on work, school, outdoor activities and sleep. Forty-nine percent of the working patients ($n = 2287$) report their work affected by allergic rhinitis and 41% of patients reported affected sleep. A considerable proportion of patients also reported an affected social life (Table 4). The average proportion of the working patients ($n = 2287$) taking time off work in the past year due to their allergic rhinitis symptoms was 26%, and taking time off school ($n = 376$) was higher: 38%. Allergic rhinitis has a moderate to severe emotional impact in 77% of PER and in 66% of IAR patients (Fig. 6).

The most bothersome symptoms for all patients with allergic rhinitis are runny nose (22%), sneezing (14%), blocked nose (12%), emotional toll (11%), tiredness (11%), affected daily activities (10%) and difficulty breathing (10%). The most bothersome symptoms of PER and IAR were largely similar, with the exception of runny nose (24% for PER, 18% for IAR), tiredness (12% for PER, 8% for IAR), outdoor activities (12% for PER, 5% for IAR), itchy eyes (11% for PER, 6% for IAR), affected daily activities (8% for PER, 13% for IAR) and difficulty breathing (8% for PER, 12% for IAR).

Nonmedical measures taken to ease symptoms

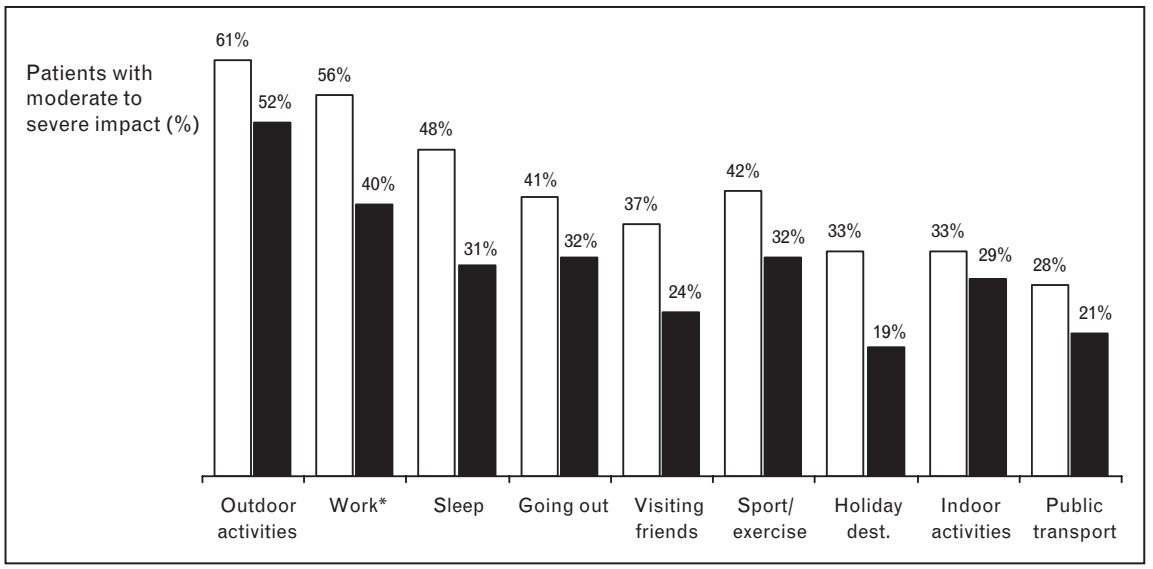
Sixty-three percent of allergic rhinitis sufferers have made changes to their homes to ease symptoms. The most common measures are buying a humidifier/air cleaner (31%), replacing furniture (30%), getting rid of soft furnishings (29%). Eight percent of sufferers stopped

Figure 4 Effect of persistent and intermittent allergic rhinitis on sleep (percentage of patients)



□ Persistent ($n = 2305$); ■ intermittent ($n = 1257$).

Figure 5 Impact of persistent and intermittent allergic rhinitis on daily activities (percentage of patients)



□ Persistent ($n = 2305$); ■ Intermittent ($n = 1257$). *Only for working patients (n = 2287).

smoking indoors, 7% removed carpets, and 7% bought special hygiene products. Only 3% bought special bedding and 2% used pollen screens. The costs for these household measures are considerable, with 22% of patients spending more than €350 a year and another 24% spending between €100 and €350 a year.

Allergic rhinitis sufferers were not happy with the effectiveness of the household changes (Fig. 7). The use of special bedding was moderately effective, but only in those with confirmed mite allergy (Fig. 7).

Type of medication taken for easing symptoms

Allergic rhinitis patients visit doctors on average three times a year. PER patients visit their doctors 3.5 times a year compared with 2.4 times for IAR patients. Almost half of the diagnoses are made by GPs (48%), and 32% by allergy and ear, nose and throat specialists. A high proportion of allergic rhinitis patients take medications to either prevent (77%) or control (88%) their symptoms. Antihistamines are the most widely used. For the control of rhinitis symptoms, 18% of patients use antihistamines alone, 11% used them in combination with nasal steroids and 11% use antihistamines together with nasal steroids and eye drops. Only 5% of patients use nasal steroids alone.

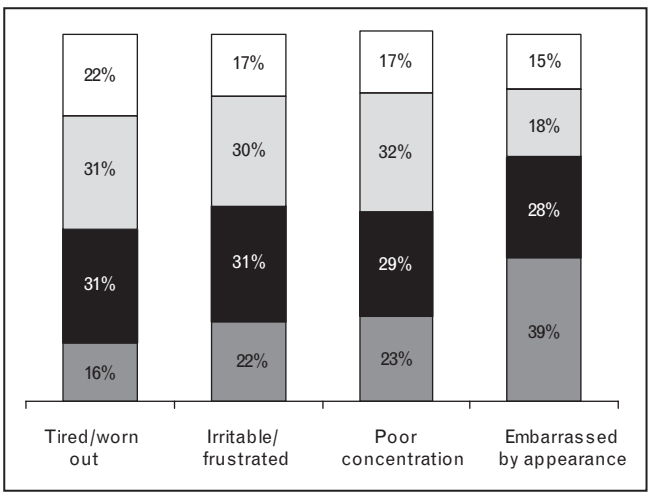
Medication use is higher among PER patients compared to those with IAR. Antihistamines are used by 75% of

Table 4 Impact of allergic rhinitis on daily activities

	Percentage of patients	
	Frequently affected (%)	Affected all the time (%)
Outdoor activities	34	24
Work[a]	36	13
Sleep	29	12
School[b]	25	9
Meeting friends in bar/restaurant	23	15
Visiting friends' houses	25	8
Choice of sport/exercise	25	13
Choice of holiday destination	17	11
Indoor activities	25	7
Travelling on public transport	19	6
Time of holiday	15	10

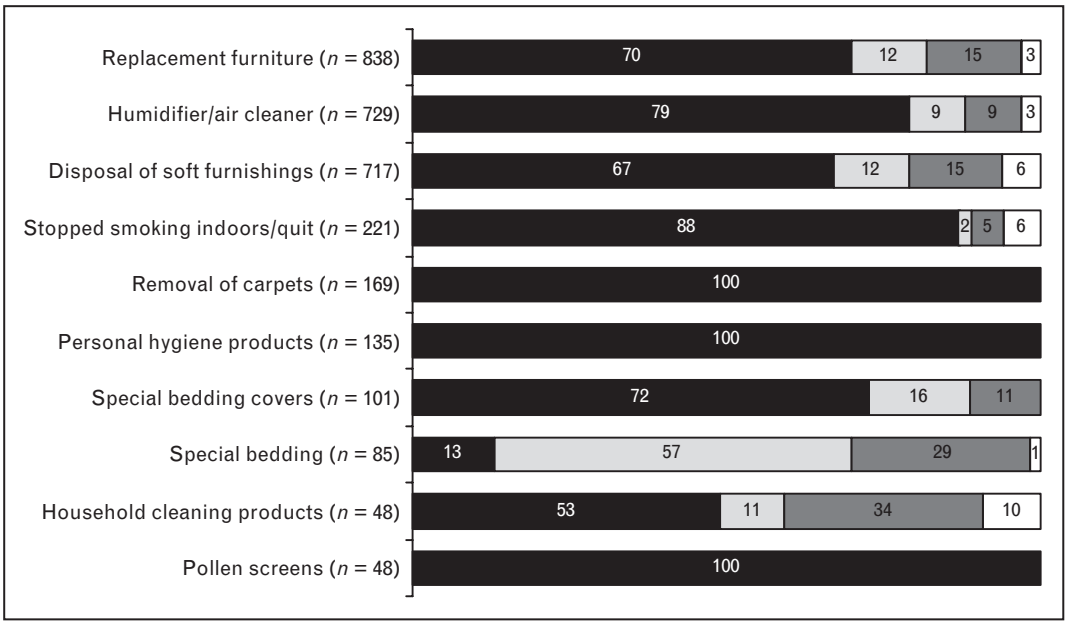
[a] Working: $n = 2287$.
[b] Studying: $n = 376$.

Figure 6 Emotional impact of allergic rhinitis across Europe (percentage of patients)



■ Absent; ■ mild; □ moderate; □ Severe.

Figure 7 Effectiveness of household changes in easing the symptoms of allergic rhinitis (percentage of patients)



■ 0 = not at all; ▒ 1 = mildly; ▒ 2 = moderately; □ 3 = completely.

PER and by 65% of IAR patients. The figures for nasal steroids are, respectively, 50 and 41%; for the eye drops 39 and 33%, respectively. Sixty-two percent of the patients who take antihistamines use them for both prevention and control, whereas 26% of the patients take antihistamines as symptom-control-only medications. The remaining 12% of antihistamines are used for prevention. Patients report antihistamines as their major medication followed by nasal steroids and eye drops (Fig. 8). The drugs are mostly obtained via prescriptions, but some patients buy their antihistamines (25%), nasal steroid sprays (17%) and eye drops (22%) without a prescription (Fig. 9).

Of all symptoms, the traditional symptoms of runny nose, sneezing and blocked nose are best controlled by the current medications, with 65% of the patients perceiving their current medication as moderately or highly effective

Figure 8 Use of medications to control symptoms of allergic rhinitis by disease duration (percentage of patients)

□ Antihistamines; ■ nasal steroid sprays; ▒ eye drops; ▒ oral steroids.

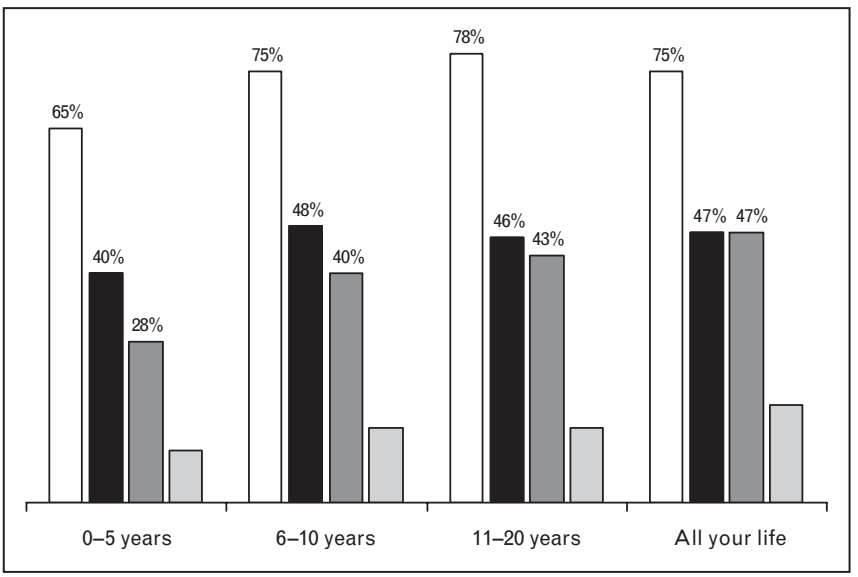
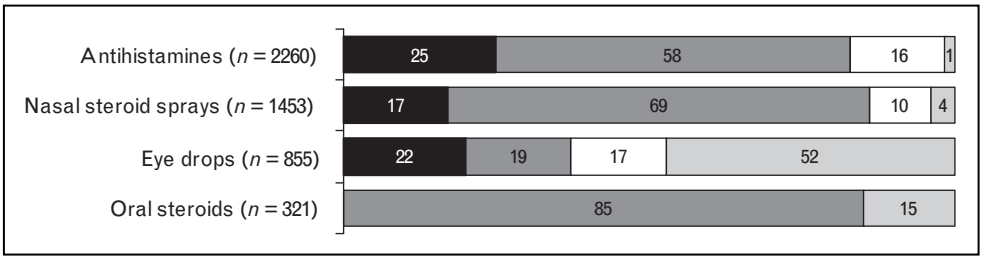


Figure 9 Source of allergic rhinitis medications: on prescription (Rx), without prescription or both (percentage of patients)



■ Buy without Rx; ■ buy with Rx; □ both; □ not stated.

in controlling runny nose. The results for sneezing and blocked nose are, respectively, 58 and 56%. Itchy throat and palate are perceived as more difficult to control with, respectively, 10 and 12% of patients reporting their current medications as not effective at all for these symptoms. Only 4, 5 and 6% of patients report that the current medications are not effective at all for, respectively, runny nose, sneezing and blocked nose.

Allergic rhinitis and concomitant conditions

Asthma, eczema, food allergy and urticaria are concomitant diseases for, respectively, 43, 32, 29 and 19% of allergic rhinitis patients; in contrast, 37% of patients reported no concomitant diseases. Generally, more patients among the older respondents (over 65 years of age) report suffering from concomitant diseases (especially asthma and food allergy) as compared with other age groups. Seventy percent of patients having asthma believe that their allergic rhinitis worsens it. The proportion of patients perceiving their allergic rhinitis as having a negative impact on their concomitant diseases is not so elevated, though significant, with 42, 40 and 37% of patients reporting allergic rhinitis to negatively affect their food allergy, eczema and urticaria, respectively. Almost all patients (94%) have discussed their concomitant asthma with a doctor, whereas the proportion for eczema, food allergy and urticaria is, respectively, 76, 74 and 64%.

Discussion

To our knowledge, this is the first survey conducted in a selected patient population with allergic rhinitis. These are patients who are members of an allergy patient organization. The survey addressed patient perceptions of the impact that allergic rhinitis has on their lives and on treatment practices.

Plants/flowers, house dust mites and animals were reported as one of the most frequent causes of allergic rhinitis symptoms. Tobacco smoke was the fourth biggest trigger. Although a recent study [12] could not establish a significant relationship between exposure to tobacco smoke and the increase in allergic sensitization and allergic rhinitis in adults; in our study, every third patient perceived tobacco smoke as a cause of suffering, in addition to moulds, perfumes, feathers and foods.

The prevalence of the seasonal allergic symptoms in our patients is only 50%, whereas the other half suffers during two or more seasons. This is in agreement with another European survey reporting 49% of allergic rhinitis patients having an established seasonal allergic rhinitis [13]. Although no big differences were observed between the triggers for the two types of rhinitis, there was a trend of more triggers being identified by PER patients. Although this could be an indication of a higher multiseasonality for PER, many perennial triggers were also perceived as being responsible for IAR symptoms.

In terms of impact on sleep, PER was clearly the more disturbing. Half of the patients suffering from PER said they did not feel rested upon waking and that their sleep was disturbed. This is important to note since there is still a lack of sufficient of understanding of how much tiredness and somnolence is caused by the antiallergic treatment and how much it is due to the disease itself. More differences between the two types of rhinitis surfaced when patients had to report their daily activities. The adverse impact of PER on work, going out, visiting friends, and choosing holiday destinations was more pronounced than the impact of IAR. Almost half of the patients perceive that their rhinitis makes them tired, worn out, irritable and frustrated.

None of the 169 patients who removed their carpets reported any beneficial impact on their rhinitis. More than 70% of the 101 patients who bought special bedding covers considered them as being not effective. Replacement of furniture or the disposal of soft furnishings, as well as buying humidifiers or air cleaners, was equally ineffective or mildly effective. This is in confirmation with other studies where despite significant reductions of house-dust-mite load, no or little evidence

was observed, proving that these reductions can translate into sustained improvements of clinical outcomes [14,15].

All of the above findings question the appropriateness of preventive household measures. Eventual household changes should be part of the overall disease-management plan discussed with healthcare professionals. These findings thus highlight the need for a regular rapport between patients and their treating physicians, for improved patient education and for accessibility to reliable information on effectiveness of household measures.

The currently utilized medications for allergic rhinitis are generally perceived as effective in relieving rhinitis symptoms. The purpose of our survey was not to distinguish between the efficacies of the various pharmacological groups but rather to evaluate the overall satisfaction with the current treatment standards. Whereas 20% of patients perceived their current treatment as highly effective, a similar proportion of patients were not satisfied with their treatment. A tendency of better satisfaction was noted for drug efficacy on nasal symptoms as compared with ocular symptoms. A reason for this could be that nasal symptoms are generally considered more bothersome and therefore their relief leads to higher satisfaction. In addition, oral antihistamines and nasal corticosteroids, whose efficacy on nasal symptoms is well documented, are the most frequently used medications by our patients. Although the use of the new nonsedating antihistamines and nasal steroids has significantly improved management of allergic rhinitis in the last decade, there is still some dissatisfaction with the treatment results. This could be partially due to noncompliance with the recommended treatment, and to the nonprescribed, self-management of patients. Another reason could be that patients do not always have access to the most potent and efficacious of the current treatments.

The relationship between rhinitis and asthma is complex and has been the topic of interest of many scientific publications [16••]. Our survey, however, reveals that this topic has come out of the academic world and is understood and perceived as a real health problem for most of the patients. Nearly all of the surveyed patients with concomitant asthma have discussed it with their doctors. Similarly, 75% of patients with other concomitant diseases have talked to their physicians about them.

Conclusion

Allergy patients in 11 European countries have voiced their experiences of a disease which is not always seen as serious enough to warrant attention from policy-makers, prescription medications, doctor's visits, and follow-up or patient education. Patients with allergic rhinitis revealed the emotional burden and restrictions to daily life. They shared satisfaction for the current treatment options, and dissatisfaction for most of the preventive measures. While being satisfied with medical treatment, patients suffer a significant impact in daily life. The results of this survey should be taken into account in future guidelines on allergic rhinitis, and should promote relief of the emotional burden of allergic rhinitis, stimulate patient education, encourage relationship between allergic rhinitis patients and healthcare professionals, and urge governments to abolish preventable triggers in public places, schools and work places.

Acknowledgements

This survey is dedicated to all European patients with allergic rhinitis, in particular those who took part in our survey. Special recognition goes to all those who have lost loved ones due to allergy, including Suzanne van Rokeghem and her family. The EFA would also like to offer special thanks to the patient organizations that carried out the survey in their countries: Allergia-ja Astmaliitto, Finland; Allergy UK; ANIKSI, Greece; Association Française pour la Prévention des Allergies, France; Astma-en-Allergiekoepel, Belgium; Astma Fonds, The Netherlands; Czech Initiative for Asthma; Dachverband Patientenorganisationen Allergie, Atemwegs-/Lungenerkrankungen und Neurodermitis, Germany; FEDERASMA, Italy; Prévention des Allergies, Belgium; Schweizerisches Zentrum für Allergie, Haut und Asthma, Switzerland; Vereniging Allergie Patienten, The Netherlands; and Amigos de la Fundación, Secretaria Técnica SEAIC, Spain. We would also like to acknowledge UCB Pharma for their educational grant to make this survey possible.

References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- • of special interest
- •• of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (p. 89).

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This important review provides evidence that rhinitis and asthma are intimately linked but some major gaps remain in our knowledge.