

ORIGINAL RESEARCH

Concerns of patients with allergic rhinitis: the Allergic Rhinitis Care Programme in South Africa

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Abstract

Background: The major reason for treating chronic rhinitis is to improve quality of life. Although primary symptoms cause morbidity in their own right, these symptoms are significantly aggravated by the impact of cognitive dysfunction and quality of life.

Objective: The Allergic Rhinitis Care Programme was initiated by the South African Allergic Rhinitis Working Group. An important task of this programme was to document health-related quality of life impairment amongst allergic rhinitis patients in South Africa.

Methods: A questionnaire, appropriate to South Africa, was distributed to patients. The questionnaire inquired about symptoms, quality of life, complications, trigger factors, associated allergic conditions, medication preference, medication adherence and concerns about the condition.

Results: 1181 people completed the questionnaire and returned the survey. Nasal congestion was identified as a common and frequent problem, while seasonality of symptoms was uncommon. Symptoms affected sleep in 76.6% of sufferers, and in at least a third this was every night. Over 1000 respondents felt miserable due to allergic rhinitis (85.2%). 63.1% indicated that they always followed instructions for taking rhinitis medication. A variety of perceived concerns around having and being treated for allergic rhinitis were identified, suggesting multiple reasons for non-adherence.

Conclusions: We report symptom frequency and quality of life impairment for respondents who identify themselves as having allergic rhinitis. Since allergic rhinitis is, in the main, a doctor-diagnosed condition, this would suggest a significant problem with inappropriate, insufficient or incorrect therapy.

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Keywords allergic rhinitis, quality of life, nasal congestion, non-adherence**Introduction**

Rhinitis is not a life-threatening condition, and although this has perhaps trivialised its status, it places greater emphasis on patient well-being as an outcome measure. In fact, the major reason for treating chronic rhinitis is to improve quality of life.¹ As a disease, it has major ramifications in terms of associated morbidity and cost. Although primary symptoms (rhinorrhoea, nasal congestion, sneezing and itch) cause morbidity in their own right, these symptoms are significantly aggravated by associated problems of ear and sinus disease, as well as the impact of cognitive dysfunction and quality of life.²⁻⁶

The South African Allergic Rhinitis Working Group (SAARWG) was convened by interested allergists, paediatricians, Ear Nose and Throat (ENT) Surgeons, and General Practitioners (GPs). In 1996, the group met to discuss and publish guidelines for the diagnosis and management of allergic rhinitis in South Africa.⁷ International Guidelines⁸ had recently been published, but at this first meeting, and subsequently, a need was expressed to document the problems and concerns of patients with allergic rhinitis in South Africa. The Allergic Rhinitis Care Programme was born. An important task of this programme was to document

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Table 1. Symptoms of allergic rhinitis (n=1181) (%).

Symptom	More than once a week	More than once a month	Occasionally	Seasonally (eg. in spring)	Never
Nasal congestion	612 (51.8)	170 (14.4)	155 (13.1)	129 (10.9)	14 (1.2)
Runny nose	491 (41.6)	184 (15.6)	225 (19.1)	146 (12.4)	56 (4.7)
Sneezing	558 (47.3)	170 (14.4)	199 (16.9)	152 (12.9)	57 (4.8)
Itching in the nose	458 (38.8)	185 (15.7)	222 (18.8)	135 (11.4)	57 (4.8)

NB: Some responses missing hence totals not 100%

impairment in health-related quality of life amongst allergic rhinitis patients in South Africa. Subsequent to this study the SAARWG has prioritised patient education as a critical factor in the success of managing allergic rhinitis.

This study was deemed necessary to document the effects of diagnosis and pharmacological treatment on patient well-being and resolution of symptoms in patients with allergic rhinitis. The impact of these two factors alone requires documentation in devising patient education strategies. In addition, the concerns of patients with persistent allergic rhinitis needed quantification.

Methods

The members of the South African Allergic Rhinitis Working Group (Allergists, Paediatricians, Otorhinolaryngologists and GPs with an interest in allergic rhinitis) were asked to submit questions based on experience and evidence, that they felt would best uncover the concerns of patients with regard to allergic rhinitis. A 20-question questionnaire, appropriate to South Africa, was compiled. These questions were tested for their ability to demonstrate reliability in a workshop of 50 volunteers with allergic rhinitis accompanied by two expert clinicians. The questionnaire was reduced to 11 questions in this way (see Appendix 1 at www.thepcrj.org). The pilot study revealed that the language was understandable by all patients (including those with limited formal education, and patients from different racial groups) and the question results correlated well with objective observer assessment of rhinitis control. The questionnaire inquired about symptoms, quality of life, complications, trigger factors, associated allergic conditions, medication preference, medication adherence and concerns about the condition. Respondents were asked about perceived concerns around having, and being treated for, allergic rhinitis.

Patient recruitment

General Practitioners (GPs), ENT surgeons and Pharmacists (in South Africa) were randomly identified from the Medical Association database. These individuals were approached to recruit patients. Twenty of each group were identified in each of five major centres (Johannesburg, Pretoria, Durban, Cape

Table 2. Do allergic rhinitis symptoms affect the quality of your sleep? (n=1181) (%).

Affect sleep quality	904 (76.6)
- Every night	439 (37.2)
- Less than once a week	348 (29.5)
- Less than once a month	177 (15.0)

Town and Bloemfontein). They invited all their patients known to have allergic rhinitis to complete the questionnaire.

All patients had to have a clinical history of chronic nasal symptoms (nasal blockage, rhinorrhoea, sneezing or itch) together with a positive allergy test (skin prick test or RAST) to common aero-allergens. Other causes of chronic rhinitis had to be excluded in the judgement of the clinician. The questionnaire was titled 'Questionnaire for allergic rhinitis sufferers'. The survey was, however, targeted to selected patients and not a random population sample. All respondents completed written informed consent, and ethics approval (from the Medicines Control Council South Africa) was obtained for the study.

In an attempt to identify the impact of allergic rhinitis on quality of life, two questions were asked; 'Do these symptoms affect the quality of your sleep?'; and 'Does rhinitis make you feel miserable?' In an attempt to document the extent of non-adherence to chronic medication, a number of questions were posed – for example; 'Do you always follow instructions for taking rhinitis medication?'

Results

One thousand two hundred patients were approached to participate between October 2002 and September 2003. All patients were employed and had medical insurance. 1181 patients (521 male) ranging in age from 5 – 67 years (mean 32 years, SD 15.12) completed the questionnaire and returned the survey. Parents of children were asked to complete the questionnaire on behalf of children unable to do so. The number of 'proxy' responses from children was less

Table 3. Triggering factors (n=1181) (%).

Factor	Not at all	Very little	Moderately	Quite a lot	A great deal
Smoky atmosphere	84 (7.1)	118 (10.0)	228 (19.3)	280 (23.7)	327 (27.7)
Air pollution	49 (4.2)	107 (9.1)	255 (21.6)	347 (29.4)	282 (23.9)
Changes in weather	72 (6.1)	112 (9.5)	224 (19.0)	319 (27.0)	322 (27.3)
Pets	212 (18.0)	198 (16.8)	205 (17.4)	166 (14.1)	176 (14.9)
Pollen	72 (6.1)	101 (8.6)	172 (14.6)	318 (26.9)	341 (28.9)
Food	373 (31.6)	198 (16.8)	191 (16.2)	82 (6.9)	71 (6.0)
Emotional upset	370 (31.3)	179 (15.2)	179 (15.2)	112 (9.5)	81 (6.9)

NB: Some responses missing hence totals not 100%

than 20. This was a response rate of 98%. One third (34%) of questionnaires were returned from GPs, one third (31.5%) from pharmacies, and one third (34.5%) from ENT surgeons. There was no significant difference in response rate between these groups.

Table 1 documents the response of individuals to specific questions and their frequency. Nasal congestion is identified as a common and frequent problem, while seasonality of symptoms was uncommon.

Symptoms affected sleep in 76.6% of sufferers, and for at least a third this was every night (Table 2). Over one thousand respondents felt miserable due to allergic rhinitis (85.2%).

Associated conditions of sinusitis, asthma and eczema were reported frequently. The description of headaches around the nose, cheeks and/or forehead was identified as 'sinus-related headaches' in 76.2% of patients at least occasionally. Three-hundred-and-six patients (25.9%) had symptoms more than once a week, 226 (19.1%) had symptoms more than once a month, and only 135 (11.4%) never had sinus symptoms. In terms of symptoms and a possible previous doctor-diagnosis of asthma, 58.3% of respondents identified a history of asthma (coughing, wheezing and chest tightness), and 46.0% a past history of present or past eczema (itchy skin and rash).

Table 3 reflects the results of questions on triggering/exacerbating factors and their frequency. Pollen, a smokey atmosphere, air pollution and changes in weather were frequent exacerbating factors. Pet exposure was not considered a major factor.

Sixty-three percent indicated that they always followed instructions for taking medication. Reasons given for non-adherence are documented in Table 4. Table 5 attempts to document patient preference for medication.

Finally, the responses to questions about perceived

Table 4. Reasons for non-adherence (n=1181) (%).

Forget to take my medicines	351 (29.7)
Worry about side effects	551 (46.7)
Do not like the method	90 (7.6)
Take what I need	693 (58.7)
Taking medicine is admitting defeat	104 (8.8)
Cannot afford medicine	271 (23.0)
Stop taking medicine when better	737 (62.4)

Table 5. Medication preference (n=1181) (%).

Route	
Nose spray	449 (40.5)
Tablets	614 (55.4)
Both	45 (4.1)

Table 6. Concerns about rhinitis (n=1181) (%)

It may last life-long	898 (76.0)
Effects of the medicine	686 (58.1)
Passing rhinitis on to children	491 (41.6)
Feeling self-conscious	602 (51.0)
Social activities restricted	627 (53.1)

concerns around having, and being treated for, allergic rhinitis are documented in Table 6. Again, a variety of responses are noted.

Discussion

This study has a number of significant limitations. Firstly, the

questionnaire has not been validated nor translated into multiple languages. The quality of life questionnaire developed by Juniper⁹ would be a useful follow-up tool. Secondly, the questionnaire is also not specific to a quality of life study, but is an attempt to document multiple concerns of South Africans with allergic rhinitis.

This study is part of an ongoing survey of health needs of South Africans with allergic diseases, since these conditions often are considered low priority when compared to more serious infectious diseases.

Allergic rhinitis in South Africa is a common problem and is most often a persistent disease.¹⁰⁻¹² This is borne out by this study in which patients note seasonality of symptoms in only 10.9% – 12.9% of cases. Persistent disease may contribute to symptom severity and quality of life impairment. The ISAAC Study conducted in 1998 revealed a prevalence of allergic rhinitis of 16% in Cape Town school children.¹² This prevalence has increased in recent surveys.¹³

This study is important in its documentation of the problems that may be experienced by patients with allergic rhinitis. Almost half of the patients in South Africa have symptoms at least once a week, and over one third have sleep disruption every night due to allergic rhinitis. The persistence of allergic rhinitis in South Africa is due, at least in part, to the climate of the country.¹⁴ It is not surprising, therefore, that pollen is identified as a trigger factor in at least 70.4% of respondents. Using the two broad questions of sleep and 'feeling miserable' it appears that allergic rhinitis significantly affects quality of life. Despite the lack of specificity of these questions for this condition it should be remembered that these individuals identify these as problems as a consequence of their disease. This fact needs to be borne in mind by clinicians treating patients with allergic rhinitis. Bousquet *et al* reported that more than 80% of patients had impaired daily activities if they had moderate or severe allergic rhinitis, and even 40% of patients with mild disease report impairment.¹

This study also documents the reasons for non-adherence to therapy and suggests that the phenomenon of non-adherence may, as with asthma, have a differential diagnosis. Not all patients fail to adhere to their therapy for a single reason and this must be borne in mind by clinicians treating such patients. This may provide education bodies with the tools to sort out this complex problem and permit the development of questionnaires that attempt to document non-adherence in a non-punitive manner and permit patients to indicate their concerns to busy doctors.

The survey also highlights the individual preference for route of therapy administration – and with the present availability of anti-inflammatory oral anti-histamines, careful patient selection and understanding of guidelines¹⁵ is mandatory. One size definitely does not fit all in terms of

treating allergic rhinitis. Patients have many concerns about allergic rhinitis and clearly there is an opportunity now to address these issues – including the education of medical personnel, as well as education and support for patients. Ultimately, the doctor-patient interaction needs to be strengthened in order for the disease not to impact negatively on quality of life.

The finding that 63.1% of patients indicated that they always followed instructions regarding taking rhinitis medication is surprising. This may reflect the sampled group (those attending medical care). Not surprisingly, a range of responses is noted with regard to reasons for non-adherence. The denominator for non-adherence is left as the study total, since some individuals clearly indicated total adherence in one question but still answered specific questions on non-adherence.

What is particularly worrying about this survey is the symptom frequency and quality of life impairment reported by the respondents who identify themselves as having allergic rhinitis. Since allergic rhinitis is, in the main, a doctor-diagnosed condition, this would suggest a significant problem with inappropriate, insufficient or incorrect therapy. Another possibility is, of course, non-adherence to therapy for a chronic condition. Either scenario suggests a role for better doctor-patient interaction regarding the therapy of this condition. Both patient and medical intervention, through education, are urgently required.

Furthermore, this study suggests that education on diagnosis and pharmacological treatment alone are insufficient to reduce the burden of allergic rhinitis. Treatment (in the broadest sense) should be instituted to reverse the effects of allergic rhinitis, and the selection of medication is of critical importance since non-adherence and poor patient understanding may detract from a successful outcome.

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Conflict of interest declaration

The authors declare that they have no conflict of interest in connection with this study.

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Appendix 1. The Allergic Rhinitis Care Programme continued

6. Do you suffer from either of the following?

(Reply 'yes' even if you don't suffer from all these symptoms)

- a. Asthma (symptoms include coughing, wheezing, chest tightness) Yes [] No []
- b. Eczema (symptoms include itchy skin and rash) Yes [] No []

7. Which medicines are you currently taking for allergic rhinitis?

Name of medicine (brand name on pack)	Strength of medicine (shown on pack, e.g. 20 mcg, 100 mcg)	Number of puffs/tablets per day (e.g. 2,3)	For how long have you been using it? (e.g. 6 months, 1 year)
Beconase			
Clarityne			
Flixonase			
Hismanal			
Livostin			
Nasacor			
Polaratyne			
Rhinocort			
Rhinolast			
Triludan			
Triludan			
Viarox			
Zyrtec			
OTHER: Please specify			

8. Do you always follow the exact instructions for taking rhinitis medication? Yes [] No []**9. Please tick whichever of the following statements you agree with:**

I sometimes forget to take my medicine	
I worry about side effects	
I do not like the method of taking my medicine	
I take what I know I need	
I feel that taking medicine is admitting defeat	
I cannot afford to pay for my medicine	
I sometimes stop taking my medicine when I feel better	

10. Which do you prefer for your rhinitis? Nose spray [] Tablets []**11. What concerns do you have about your rhinitis?**

	Yes	No
That it may last life-long		
That you may not outgrow your rhinitis		
The effects of the medicines		
Passing rhinitis on to your children		
Feeling self-conscious about your rhinitis		
Having your social activities restricted		

Thank you for completing this questionnaire