ORIGINAL RESEARCH

Perceptions, impact and management of asthma in South Africa: a patient questionnaire study

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Abstract

Introduction: A number of studies from around the world have indicated that asthma morbidity is still unacceptably high. In the AIRE study over one-third of children and half of the adults reported daytime symptoms at least once a week. This study was conducted to understand the impact (including the impact on health-related quality of life) of asthma on South African asthmatics.

Materials and methods: General Practitioners (GPs) and pharmacists in South Africa were randomly identified from the Medical Association database. These individuals were approached and asked to recruit asthmatic patients to complete a questionnaire. The questionnaire inquired about symptoms, quality of life, complications, trigger factors, associated allergic conditions, medication used, medication preference, medication adherence and concerns about the condition.

Results: 3347 respondents returned their demographic data but only 710 met the criteria for analysis, ie. had asthma and were presently on controller medication. Symptom analysis revealed that 21.4% of respondents were coughing on most days, 25.6% were wheezing on most days, and 22.8% were experiencing night-time symptoms on most days. Symptoms were exacerbated by exercise in 56.9%, while nocturnal waking due to asthma occurred in 36.9% more than four times per week. Only 35.1% of respondents had not missed school or work in the preceding year. 45.4% of individuals worry about side effects of asthma therapy.

Conclusion: This study indicates that there is under-treatment, inappropriate treatment and/or lack of patient education for asthma patients in South Africa. The data support the notion that poor therapy and/or poor patient adherence has an enormous impact on the health-related quality of life of South Africa's asthmatics.

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See Appendix A at www.thepcrj.org for Questionnaire for asthma sufferers

Introduction

Asthma is one of the commonest chronic diseases, affecting at least 1 in 10 people. It knows no prejudice, affecting people from all social, cultural and ethnic backgrounds – unlike tuberculosis, which one would expect to encounter in less privileged societies, and coronary artery disease, which is

a disease of affluence. Therefore, no matter where the health-care giver (ie. doctor, nurse or pharmacist) practises he or she will see patients with asthma every day. This interaction with asthmatic patients is often limited – even in a medical setting – to the medical or clinical effects, and treatment, of the disease. These are very well known. Less well known, and certainly seldom discussed, are the quality of life, social, and psychological consequences of asthma as a chronic illness.

Some of these issues were highlighted in an important study from the UK in 1992; known as the Lifestyle Study,¹ it

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was one of the first large studies to focus on quality of life, which has now become an important concept in the assessment of chronic illnesses. The Lifestyle Study revealed a significant impact of asthma (even so-called "treated" asthma) on the lives of individuals with the condition. Further asthma-related quality of life studies and assessments of asthma control followed.^{2,5} They reflect a dismal picture of asthma control around the world.⁶ Such social or psychological impact goes beyond the disease itself. Poor sleep will produce a tired child who is unable to concentrate in class; this, in addition to school absence, has a dramatic impact on the academic potential of children with asthma.⁷ Two further UK studies on asthma-related school absences showed that 60% of children had taken days off due to episodes of wheeze in the past year.^{8,9} In their study of 284 children, Anderson and colleagues⁸ reported that in the 30 (12%) most severely affected children, each child lost, on average, 30 days schooling each year – giving a total of 900 days of schooling missed. The emotional impact of asthma on the child and family were likewise considerable, with fear and embarrassment common emotions when experiencing an attack. These and other emotional effects have a direct bearing on the family of the asthmatic, due to limited activity and tensions and the eventual impact on other aspects of quality of life.

In addition to these consequences of asthma, a number of studies from around the world have indicated that asthma morbidity is still unacceptably high. The Asthma Insights and Reality in Europe (AIRE) survey assessed the level of asthma control, among current asthmatics in Western Europe, from the patient's perspective.² Over one-third of children and half of the adults reported daytime symptoms at least once a week. Furthermore, 28.0% of children and 30.5% of adults experienced asthma-related sleep disturbances at least once a week. Patient perception of asthma control did not match symptom severity, since approximately 50% of those reporting severe persistent symptoms considered their asthma to be completely or well controlled. In addition, it should be remembered that this social cost of asthma, or impact on health-related quality of life, will eventually have a direct monetary cost, adding to the cost of medication and consultations. Subsequent and recent studies have revealed that between 49%¹⁰ and 53%¹¹ of asthmatics in Europe and Canada, respectively, have uncontrolled asthma.

The aim of this study, therefore, was to understand the impact (including the health-related quality of life impact) of asthma on South African asthmatics, following documentation of these parameters in South Africa's rural asthma patients.¹² There is a need to understand the complexities of asthma control in this country and to determine the burden of asthma morbidity.

Materials and methods

Questionnaire (see Appendix A at www.thepcrj.org)

A questionnaire, appropriate to South Africa, was compiled and subjected to pilot testing amongst a group of patients attending the authors' allergy clinics and practices. A list of 100 possible questions was reduced to the current questionnaire after discussion between a group of 25 asthmatics, 10 doctors and 10 pharmacists. Questions were retained if more than 80% of subjects felt the question was relevant, understandable and meaningful. In addition, the question responses had to match objective assessment of asthma control and medication usage in the patients. 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 asthma control. The questionnaire (see Appendix A at www.thepcrj.org) inquired about symptoms, quality of life, complications, trigger factors, associated allergic conditions, medication used, medication preference, medication adherence and concerns about the condition. Respondents were asked about perceived concerns around having, and being treated for, asthma.

Patient recruitment

General Practitioners (GPs) and pharmacists were randomly identified from the South African Medical Association database and were approached to recruit patients. The study was conducted between October 2002 and October 2004. Twenty of each group were identified in each of five major centres (Johannesburg, Pretoria, Durban, Cape Town and Bloemfontein). Each site was selected by a random number generator of practice numbers. The GPs and pharmacists invited patients, whom they believed had asthma, to complete the questionnaire. No attempt was made to define asthma or asthma severity in these patients. The questionnaire was entitled 'Questionnaire for asthma sufferers'. No attempt was made to select specific patients of disease type or severity. The survey was, however, targeted to patients and was 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. Despite a large number of responses to the survey, only asthmatic patients presently on controller medication were analysed.

Results

3347 patients (2340 female) ranging in age from 5 – 67 years (mean 32 years) 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 was less than 50. There was a

Table 1. Asthma symptom frequency amongst respondents [n (number out of 710), %].

Symptom	Every day		Most days		More than once a week		More than once a month		Never		Not answered	
Coughing	135	19.0	152	21.4	121	17.0	160	22.5	60	8.5	82	11.6
Wheezing	134	18.9	182	25.6	148	20.9	142	20.0	43	6.1	61	8.6
Night-time symptoms	159	22.4	162	22.8	124	17.5	159	22.4	45	6.3	61	8.6

Table 2. Asthma attacks per month [n, %].

	0-2		2-4		More than 4	
At night	218	30.7	136	19.2	262	36.9
After exercise / activity	148	20.9	118	16.6	284	40.0

response rate of 83%. Two thirds (69%) of questionnaires were returned from GPs. There was no significant difference in response rate between these groups.

3347 respondents returned their demographic data but only 710 met the criteria for analysis, ie. had asthma and were presently on controller medication. There was a fairly uniform spread across the provinces of South Africa. There were no particular trends revealed by sex or age differences. Although the individual drugs used by these patients were noted, no relationship between type, dose or duration, and the measures of asthma control questioned, was seen. Many patients were not able to recall their exact drug dosage.

Symptom analysis revealed that most patients still had symptoms of asthma; 21.4% were coughing on most days, 25.6% were wheezing on most days, and 22.8% were experiencing night-time symptoms on most days (see Table 1). Symptoms were exacerbated by exercise in 56.9% and by sport in 60.6%, probably reflecting similar patient groups.

Daily activities caused symptom exacerbation in 46.2% (with 6.5% not answering this question). Nocturnal waking due to asthma occurred frequently with 22.4% of respondents having nocturnal symptoms every day and 31.9% of respondents being woken more than four times per month due to asthma attacks (see Table 2).

Trigger factors for exacerbations and "attacks" are listed by the frequency with which they produced symptoms, in Table 3. 23.8% of respondents believed that air pollution caused symptoms every day, 28.3% on most days, and 4.4% seldom/never. Food as a trigger factor was generally reported as being uncommon, with respondents claiming a relationship (at most) more than once a month but less than once a week in 17.5%; this was the least common trigger factor reported, with a prevalence in the range of that for "emotional upset".

The vast majority of patients had associated "allergic" diseases – hay fever in 81.4%, blocked nose in 62.3% and eczema in 44.9%. 16.9% of responders did not answer the question on eczema, possibly because they didn't understand the condition.

With regard to quality of life, certain pertinent responses were received. Table 4 demonstrates the number of patients missing school or work due to disease, and the length of time off. Only 35.1% of respondents had not missed school or work in the preceding year; 26.3% had missed 1-3 days while

Table 3. Frequency with which common exposures result in symptom exacerbations [n, %].

Symptom	Every day		Most days		More than once a week		More than once a month		Never	
Smoky atmosphere	205	28.9	184	25.9	134	18.9	73	10.3	41	5.8
Air pollution	169	23.8	201	28.3	161	22.7	58	8.2	31	4.4
Weather	204	28.7	219	30.9	132	18.6	67	9.4	64	9.0
Pets	80	11.3	76	10.7	132	18.6	104	14.7	160	22.5
Pollen	116	16.3	148	20.9	118	16.6	100	14.1	81	11.4
Food	45	6.3	53	7.5%	121	17.0	124	17.5	203	28.6
Emotional upset	146	20.6	130	18.3	124	17.5	118	16.6	94	13.2

Table 4. Number of work and school days lost in the last year as a result of asthma [n, %].

No time	128	35.1
1 - 3 days off	96	26.3
4 - 7 days off	64	4.5
1 - 2 weeks off	39	10.7
2 - 4 weeks off	28	7.7
More than 5 weeks	3	0.8
Not worked - asthma	7	1.9

10.7% had missed 1-2 weeks. 15.9% of responders had been admitted to hospital in the previous year. Patients reported a doctor call-out, visit to the doctor, or visit to casualty, in 13.9%, 27.3% and 24.8% of cases, respectively.

With regard to the use of prescribed inhaled medication, a number of general questions were asked. Patient-listed reasons for non-adherence and concern about taking medication for asthma are shown in Table 5. 45.4% of individuals were worried about the side effects of asthma therapy and 321 (45.2%) of respondents admitted to stopping controller medication when feeling better.

Finally, the group was asked about home use of peak flow meters; 35.9% used one at home, and another 14.4% used their meter together with a diary card.

Discussion

This study has a number of significant limitations. Firstly, the questionnaire has not been validated nor translated into multiple languages. The complexity of some of the questions – such as that directed at symptom causation, with a matrix of symptom frequency and patient-perceived causation of symptoms (see Appendix A at www.thepcrj.org) – may have posed problems for patients in terms of their understanding and responding. For this question specifically, 73 patients (10.3%) did not answer the question on whether or not a smoky atmosphere caused symptoms. Secondly, the questionnaire is not specifically one relating to a quality of life study but is an attempt to document asthma control in South Africans. Employing other validated, international quality of life questionnaires, would be a useful follow-up tool. Thirdly, some questions were deliberately not defined in order to assess what patients understand, perceive, and do, independent of the medical label. One such example is the definition of an 'asthma attack'. Not all respondents answered every question and some results reflect missing data points – hence not all totals add up to 100%. Clearly the label of 'asthma' should be investigated and defined; however, this study reflects the real-world experience of patients who are labelled 'asthmatic' and then left to

Table 5. Patient-listed reasons for non-adherence and concern about taking medication for asthma [n, %].

	n	%
I sometimes forget to take my medicine	202	28.5
I sometimes forget how many doses I have taken	98	13.8
I worry about side effects of the medicine	322	45.4
I have difficulty using my inhaler	46	6.5
I am not sure I am getting the right amount of medicine	132	18.6
I don't know how to take my medicine properly	28	3.9
I do not like the method of taking my medicine	59	8.3
I take what I think I know I need	300	42.3
I feel that taking medicine is admitting defeat	73	10.3
I am embarrassed to take my medicine in front of other people	199	28.0
I cannot afford to pay for my medicine	203	28.6
I sometimes stop taking my medicine when I feel better	321	45.2
I prefer not to take my my medicine unless I feel it is absolutely necessary	282	39.7
I worry that feel I might be taking too much medicine	181	25.5
I am saving my medicine for bad attacks	122	17.2

experience ongoing morbidity, without either review of the diagnosis or attempts at education. Finally, this study is part of an ongoing survey of health needs of South Africans with allergic diseases; these conditions often take a back seat to more serious infectious diseases.

This study does not stratify respondents by socio-economic status and the responses may mask trends in certain populations. However, the source of data from the questionnaires was standardised – i.e. the pharmacies and doctors – and therefore it is unlikely that large "unusual" groups would skew the findings. The number of individuals who were labelled as asthmatic by their doctor who thought they had asthma but were not using anti-inflammatory therapy raises a concern. Clearly asthma diagnosis may not always be correct (and this fact was not tested nor investigated) and some of these patients may have mild persistent asthma by definition. However, the large number and significant level of ongoing symptoms in those receiving controller therapy suggests that possible under-management of asthma is a major problem.

The decision not to report drug type and dosage and to compare it to symptom control is based on two reasons; firstly, many patients could not recall their drug dosage, and secondly the drug and dosage prescribed or taken is clearly inadequate.

The primary finding of this study is the number of patients with active symptoms despite diagnosis and therapy – 21.4% coughing on most days, 25.6% wheezing on most days, and 22.8% experiencing night-time symptoms on most days. For this reason, and also given the excessively high number of patients who have symptoms triggered by either exercise or daily activity, there is a clear case to be made for there being under-treatment, inappropriate treatment, and/or lack of patient education in the asthmatic population studied. Most asthma guidelines state that a normal and physically active life is a goal of asthma management.¹³⁻¹⁵

A significant number of patients are missing school or work due to asthma. The response rate of 51% for this question reflects a large number of women who are not formally employed. As a gross estimate of quality of life, the rate of hospital admission and crisis control visits were recorded; there was an unacceptably high rate of asthma exacerbations requiring emergency care (though it is encouraging to note that peak flow usage is being introduced.) The rate of symptom exacerbation, as well as the rate of acute attacks, crisis consultations with the doctor, and/or hospitalisation rates, not only supports the notion of poor therapy – or possibly poor adherence – but also suggests an enormous impact on the health-related quality of life of South Africa's asthmatics. This cannot be solely due to poor adherence; it strongly suggests a failure on behalf of the medical fraternity to educate patients completely.

There are some interesting reflections on the well-known asthma triggers. Common factors included triggers such as smokey atmosphere, weather change, pets and environmental pollution. Food was not identified as a major trigger factor, thereby supporting a common belief.

When comparing this survey to other studies, particularly the study of asthma control in rural South Africa,¹² similar findings are seen. In that group of 35 asthmatics, 19 (31%) had wheeze at least once a week, 26 (42%) cough at least once a week and 33 (53%) were being woken by symptoms at least once a week. This latter figure of 53% is similar to the figure in this study of 62.7%. The number of South African asthmatics in this study who do report complete asthma control is remarkably similar to the average of 6% quoted for world surveys.²⁻⁶ The Lifestyle study¹ noted that 60% of children had taken days off school due to episodes of wheeze in the past year. Our study demonstrates a similar figure (64.9%) for both children and adults absent from daily activities due to asthma. As in the study by Anderson and colleagues,⁸ days lost translate into significant costs to educational needs and to the economy.

Conclusion

The limitations of this study aside, it seems obvious that the need for asthma control has been under-recognised and poorly attended to in South Africa. The National Asthma Education Programme of South Africa now has a clear mandate to upgrade education of both doctors and patients. Luckily there are moves afoot in this arena and the mere publication of asthma guidelines is now recognised as being insufficient to address this problem.

Conflict of interest declaration

No conflict of interest to declare.

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Appendix 1. The Asthma CARE Programme

Date of Birth _____
 Day Month Year

Patient Identifying Number _____

Please complete this questionnaire and return it by the date indicated in the newsletter to:

The Asthma CARE Programme, Private Bag X6, Fairland.

The answers you give will be kept fully confidential. This will help us to send you relevant information specifically designed to help your condition as you describe it. Thank you.

QUESTIONNAIRE FOR ASTHMA SUFFERERS

1. Which of the following asthma symptoms do you experience, and how often?

Symptom	Everyday	Most days	More than once a week	Never
Coughing				
Wheezing (noisy breathing)				
Night-time symptoms (experiencing coughing, wheezing or tightness of chest in bed)				

2. When and how often do you experience asthma attacks per month?

When	0-2 times	2-4 times	More than 4 times
At night			
After exercise / activity			

3. Have asthma symptoms prevented you from doing activities such as:

- a. Exercise Yes [] No []
 b. Sports Yes [] No []
 c. Daily activities (e.g. climbing stairs) Yes [] No []

4. Do you feel self-conscious about your asthma?

Yes [] No []

5. How often has your asthma prevented you from working or caused you to take time off school (Total in the past 12 months)

Lost no time off work / school	
Lost 1 – 3 days off work / school	
Lost 4 – 7 days off work / school	
Lost 1 – 2 weeks off work / school	
Lost 2 – 4 weeks off work / school	
Lost more than 5 weeks off work / school	
I have not worked because of asthma	

6. How many times in the past year have you

Been admitted to hospital with a bad attack of asthma	
Called a GP to your home because of back attack of asthma	
Attended your GP in his/her rooms because of your asthma	
Attended a hospital out-patient clinic because of your asthma	

Continued ...

Appendix 1. The Asthma CARE Programme continued

7. To what extent would you say your asthma is affected by each of the following factors?
(PLEASE TICK ONLY ONE BLOCK FOR EACH FACTOR)

Factor	Not at all	Very little	Moderately	Quite a lot	A great deal
Smoky atmosphere (e.g. in a pub)					
Being in an area affected by air pollution					
Changes in weather (e.g. cold air)					
Pets					
Pollen					
Food					
Emotional upset					
OTHER: Please specify					

8. Do you suffer from any of the following?

- a. Hayfever (symptoms include itchy eyes, runny nose, sneezing) Yes [] No []
- b. Regular blocked nose Yes [] No []
- c. Eczema (symptoms include itchy skin and rash) Yes [] No []

9. Which medicines are you currently taking for asthma?

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)
Airomir			
Atrovent			
Becloforte			
Becotide			
Becotide			
Clenil			
Duovent			
Flixotide			
Floradil			
Inflammid			
Lomudal			
Pulmicort			
Salbulin			
Seretide			
Symbicord			
Theo-Dur			
Uni-Dur			
Uniphyll			
Venteze			
Ventolin			
Zaditen			
OTHER: Please specify			

Continued ...

Appendix 1. The Asthma CARE Programme continued

10. Do you always follow the exact instructions for taking asthma medication? Yes [] No []

11. Please tick whichever of the following statements you agree with:

I sometimes forget to take my medicine	
I sometimes forget how many doses I have taken	
I worry about side effects of the medicine	
I have difficulty using my inhaler	
I am not sure that I am getting the right amount of medicine	
I do not know how to take my medicine properly	
I do not like the method of taking my medicine	
I feel that taking medicine is admitting defeat	
I am embarrassed to take my medicine in front of other people	
I cannot afford to pay for my medicine	
I sometimes stop taking my medicine when I feel better	
I prefer not to take my medicine unless I feel it is absolutely necessary	
I worry that I might be taking too much medicine	
I am saving my medicine for bad attacks	

12. Who administers your medicine?

Yourself	
Your father / mother	
Other relatives	
Your teacher	
Other	

13. What concerns do you have about asthma?

	Yes	No
That it may last life-long		
That you may not outgrow your asthma		
The choice of devices		
The effects of the medicines		
Passing asthma on to your children		

14. Have you ever used

- a. A peak flow meter Yes [] No []
- b. A peak flow diary card Yes [] No []

Thank you for completing this questionnaire