

Original article

The limitations of severe asthma: the results of a European survey

Background: Asthma has a major impact on patients' lives, and severe asthma is a serious health problem. The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) commissioned a telephonic survey to capture the views of people who are living with severe asthma in Europe.

Methods: A total of 1300 patients from the UK, France, Germany, Spain and Sweden who reported a previous diagnosis of asthma and reported receiving asthma medication took part in the survey.

Results: Most patients reported having limitations to their lifestyles as a consequence of the symptoms of severe asthma. Almost 70% of patients reported that physical activity was restricted, 50% were restricted from having pets, 30% from taking holidays, and many felt their job prospects were limited. In addition, 50% of this population of patients were not convinced that guideline goals were being achieved, although it is not clear as to the cause of this failing. Patients indicated that they want treatments that are fast-acting, long-lasting and have minimal side effects, and they were optimistic for the development of effective therapies over the next 5 years.

Conclusions: The results of this study provide insight into how greatly patients' lives are affected by severe asthma.

**M. Dockrell¹, M. R. Partridge²,
E. Valovirta¹**

¹The European Federation of Allergy and Airways Diseases Patients' Associations (EFA), Brussels, Belgium; ²Faculty of Medicine, Imperial College, London, UK

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Martin Dockrell
The European Federation of Allergy and Airways Diseases Patients' Associations (EFA)
35 Rue du Congrès
1000 Brussels
Belgium

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Asthma has a major impact on patients' lives, and many patients and their family members consider asthma to be a serious health problem (1). However, this need not necessarily be the case, as asthma can usually be controlled when asthma management guidelines (2, 3) are properly implemented and patients adhere to the correct treatment for their level of asthma.

In 2000, Rabe et al. published the results of the Asthma Insights and Reality in Europe (AIRE) study, which showed that many patients were unable to lead 'normal' lives because of uncontrolled asthma (4). However, not all of these patients were following the correct level of medication for their severity of asthma [as per the Global Initiative for Asthma (GINA) guidelines]; indeed, only about 30% of patients with moderate to severe persistent asthma were taking inhaled corticosteroids (ICSs) (4). Many of these patients (>80%) were overusing reliever medication. However, persisting symptoms have also been reported in patients prescribed the appropriate preventative therapy (5–7). Complete control of asthma may not always be possible in patients with the most severe asthma (2).

Patients with inadequately controlled, severe persistent asthma are at a particularly high risk of exacerbations, hospitalization and death, and often have severely impaired quality of life, as well as a pessimistic outlook towards their asthma and its management (8). Persistence of symptoms, particularly exacerbations as a result of uncontrolled asthma places a considerable economic and

resource burden on national healthcare systems (2, 9, 10), which could potentially be reduced with effective treatment and care (11, 12).

The European Federation of Allergy and Airways Diseases Patients' Associations (EFA) commissioned a report that presents the results of a telephonic survey conducted in Europe and reviews available hospital admissions and mortality data (13). Here we report on the outcomes of the telephone survey, which captures the views of people who are living with severe asthma and provides insight into how greatly their lives are affected by asthma.

Methods

Selection of subjects

The EFA survey was conducted in two phases. The first was a pilot phase conducted in 2004 by Asthma UK in severe asthma patients from the UK (14). Further research was carried out in a similar population of patients in France, Spain, Germany and Sweden in early 2005, by NOP World Health.

Patients were included in the study if they had severe asthma, as determined by having one of the three following criteria over the year prior to the study: sleep disturbance at least once a week; a wheezing attack at least once a week; or, one or more speech-limiting attacks. Patients were recruited by random-digit dialling techniques in the UK, France and Sweden. In Germany, patients were selected by field interviewers, and in Spain, by doctors and field interviewers. The field interviewers were employees of NOP World Health and they conducted interviews

with the aid of computer-assisted telephone interviewing (CATI) stations.

Questionnaire development

Prior to the UK survey, focus groups were assembled. In total there were 11 focus groups: three for the UK study and subsequently a further eight (two from each of four additional countries). Focus group meetings of people who had severe asthmatic symptoms were conducted in the capital cities of the participating countries. Participants of the focus groups were graded as having 'severe symptoms' following screening questions (sleep disturbances, wheezing, speech-limiting attacks). After the UK survey, questions on smoking and second-hand smoke were added to the questionnaire. Finally, organizations representing asthma patients in the various countries were asked to verify that the translations were appropriate and were invited to provide additional questions for their population only. The resultant structured questionnaire that was developed is shown in Table 1.

Telephonic interviews

Field interviewers, who were employees of NOP World Health (or their contractors) and native-language speakers of the respective countries, conducted interviews using the questionnaire (Table 1) and CATI stations.

Results

Patients

All patients reported a previous diagnosis of asthma from their doctor and reported receiving treatment for their asthma at the time of the study. Baseline demographics and patient characteristics were generally well matched between countries (Table 2). Of the households screened for patients meeting the criteria for severe asthma, 1300 participated in the survey.

Asthma control: current patient perspectives

As part of the screening process to determine whether or not patients had severe asthma, questions 1–3 were asked (Table 1). Two-thirds of patients reported that their sleep was disturbed at least once a week over the year prior to the survey (Fig. 1A). For about one in four patients, the severity of their night-time symptoms was more problematic, with their sleep being disturbed more often than one night a week. Wheezing attacks were also a problem for this population of patients. Two-thirds of patients experienced attacks of wheezing at least once a week (Fig. 1B). Speech-limiting attacks occurred at least once a week for one of four patients (Fig. 1C).

When asked about control of asthma, it appeared that a greater majority of patients in Sweden were closer to achieving asthma control than any other country. A comparison of the proportion of Swedish patients with the total population (data for total only shown in Fig. 2), revealed that more patients from Sweden had achieved

GINA control for each goal (data not shown). For the majority of GINA goals for asthma control, about half of the patients did not think that these goals were being achieved (Fig. 2). Only one in 10 patients felt that the goal of reducing reliever medication use to a minimum was being achieved, with almost 60% believing that this goal was not close to being achieved. Emergency visits were infrequent for the majority, but 24% of patients still felt that the goal of no emergency visits by GINA was not being achieved. Compared with 10% of patients across Europe achieving the GINA goal for reduced use of reliever medication, only 1% (2/200) in France and 3% (5/200) in Germany managed with little or no reliever. In Germany, the lowest number of patients, compared with other participating countries, achieved the GINA goal of no emergency visits [24% (47/200) of patients], but only 7% (13/200) of patients reported being free from asthma symptoms.

Asthma had a major impact on activities, and across the countries surveyed, the greatest impact was seen in the restriction on physical activities, with almost 70% of patients stating that asthma got in the way of them participating in physical activity (Table 3). In Germany, this figure was 81%, with the restriction on going out with friends receiving the next highest proportion (42%). Sweden was the only country not to record the highest percentage for a restriction in physical activity, with the ability to have and interact with pets considered by more patients as being restricted by asthma. In the UK, the restriction to having pets was not recorded and going out with friends had the second highest proportion of patients rating this as an activity affected by their asthma (44%).

Although no quantitative data were collected during the study as to the specific asthma medications taken, it was noted from the focus groups that patients in France and Spain frequently mentioned short-acting β_2 -agonists as their medication and those in Sweden commonly mentioned not only short-acting β_2 -agonists, but also controller medications [ICSs/long-acting β_2 -agonists (LABAs) combination and ICS alone]. Another general observation from the focus groups was that patients had a slight concern over long-term side effects, especially with prolonged steroid therapy where osteoporosis, cataracts and fungal infections were the main worries. However, it was not clear as to which side effects had been encountered by patients: some accepted side effects as necessary, while others avoided taking medication to reduce their exposure. A few did not worry about side effects, either because they had not experienced any or because they trusted their doctor. As part of the main analysis, half of the patients in France (as requested by the French Patients' Organisation), when asked how worried they were about asthma medication side effects, scored at least 7 (on a scale of 1 to 10), and 11% were very worried and scored 10. There was fairly strong agreement among patients, across all countries, that their

Table 1. Patient questionnaire

Number	Question
S1	Has a doctor ever diagnosed you with asthma?
S2	How many years ago were you diagnosed with asthma?
S3	Are you currently on treatment for your asthma?
Q1	In the last year, how frequently has your asthma disturbed your sleep?
Q2	In the last year, how often have you had an attack of wheezing?
Q3	In the last year, how often has your asthma been so bad that you have had difficulty speaking?
Q4	The following are some of the negative words which people with asthma have used to describe their asthma. Which, if any, of these words would you use to describe your asthma? a) Annoying; b) Burdensome; c) Stressful; d) Anxiety provoking; e) Frustrating; f) Frightening; g) Expensive; h) Time consuming; i) Embarrassing; j) Life threatening; k) None of these
Q5	People with asthma have told us they sometimes feel they miss out on things. Which, if any, of the following do you feel you have missed out on because of your asthma? a) Physical activities with friends and family; b) Pets; c) Going out with friends; d) Holidays; e) Job opportunities; f) Joining in a school or college; g) Promotion at work; h) Success at study; i) None of these; j) Don't know
Q6	When you take the medicines that the doctor has prescribed for you, what matters to you most? (minimizing side-effects, getting the longest lasting benefit, taking as little as possible, getting the quickest benefit, taking as prescribed, taking at a convenient time or place, avoiding embarrassment, none of these) a) Most important; b) Second most important; c) Third most important
Q7	When you are taking your medicines, what other things matter to you?
Q8	Thinking about your asthma medicines, on a scale of 1 to 10 where 1 = 'least important' and 10 (0) = 'most important', please tell me how important or unimportant you think each of the following are: a) How often I take it; b) Taking it in private; c) Convenience; d) Short-term side effects; e) Long-lasting side effects; f) The way I take it (inhaler, pills etc); g) How quickly it works; h) How completely it stops my symptoms; i) How much it lets me forget about my asthma
Q9	In an ideal world, how attractive are each of the following methods as a way of taking your medicine? Please use a scale of 1 to 10 where 1 = 'least attractive' and 10 (0) = 'most attractive'. a) A single inhaler once a day; b) A pill once a day; c) An injection once a day; d) An inhaler once a month; e) A pill once a month; f) An injection once a month; g) A one-off operation or implant
Q10	On a scale of 1 to 10, where 1 = 'least important' and 10 (0) = 'most important', how much do you think each of the following would improve your asthma symptoms? a) Better access to asthma specialist when I need one; b) New, more effective medicines; c) Having more influence over my asthma treatment
Q11	Thinking about your asthma now, how close would you say you are to achieving the following? a) Very few or no asthma episodes; b) Very little or no use of quick relief medicines; c) Very few or no long-term symptoms; d) Very few or no restrictions in daily activities; e) Very few or no emergency visits
Q12	And in 5 years time, how close do you expect to be to achieving the following: a) Very few or no asthma episodes; b) Very little or no use of quick relief medicines; c) Very few or no long term symptoms; d) Very few or no restrictions in daily activities; e) Very few or no emergency visits
Q13	In 5 years time, do you think that the choice of asthma drugs will be: a) Better; b) About the same; c) Worse; d) Don't know
Q14	In 5 years time, do you think that the way asthma is looked after in your national healthcare system will be: a) Better; b) About the same; c) Worse; d) Don't know
Q15	I am going to read out a number of statements. For each statement, please tell me how strongly you agree or disagree with it, on a scale of 1 to 10 where 10 (0) = 'agree strongly' and 1 = 'disagree strongly': My Asthma Doctor/Practice Nurse... a) Knows a lot about asthma; b) Involves me in making the most important decisions about my asthma; c) Gives me a choice about ways to treat my asthma; d) Gives me enough time to talk about my asthma; e) Takes time to make sure that my medicines are right for my life and my asthma; f) Calls me at least once a year to talk about my asthma.
Q16*	Some people say they are afraid of taking their asthma medication. To what extent do you agree with the following statements, using a scale of 1 to 10, where 1 = 'totally disagree' and 10 (0) = 'totally agree'? a) I'm worried about becoming dependent on my asthma medicines; b) I'm worried about the possible side effects of my asthma medicines; c) I'm worried that my asthma medicines may not be effective
Q17†	Are there any public places that you avoid because of your asthma?
Q18	Finally, if you could make the Government do one thing for people with asthma, would it be to ? a) Invest in research for new asthma treatments; b) Provide free prescriptions for people with asthma; c) Ban smoking in public places; d) Ensure immediate access to an asthma specialist when one is needed; e) Improve public awareness of what to do in an asthma attack; f) Increase public awareness of asthma in adults; g) Provide better information about treatments; h) Decrease pollution/make an effort to fight pollution; i) Other; j) Don't know

*French patients only asked this question; †Swedish patients only asked this question.

asthma practitioner gives them a choice of treatment (mean score 6.8; on a scale of 1 to 10) and checks on progress at least once a year (mean score 6.7). However, the latter had much variation across the countries with

the mean scores ranging from 2.5 (France) to 8 (Spain). The most important feature of asthma medication to 28% patients was that they get the quickest benefit from therapy. The second and third most important features of

Table 2. Patient demographics

	Country					Total
	UK	France	Germany	Spain	Sweden	
Total population, <i>n</i>	500	200	200	200	200	1300
Males, %	36	39	44	29	31	36
Mean (SD) age, years	54.4† (16.9)	41.2 (16.0)	52.1 (15.7)	40.8 (17.9)	43.0 (15.5)	48.4 (16.5)
Mean (SD) time since asthma diagnosis, years	18.7‡ (16.4)	19.2 (12.5)	17.1 (13.8)	12.2 (9.2)	15.6 (12.0)	16.7 (13.0)
Ethnic group (% White)	99	96	99	99	93	97
Employment status (%)						
Full-time employment	26	46	32	45	40	35
Retired	42	18	39	14	19	30
Part-time employment	5	12	9	14	15	9
Student	2	13	8	10	13	7
Looking after children	6	6	4	12	2	6
Disabled	10	2	4	2	–	5
Unemployed	2	4	6	4	6	4
Other	7	–	0.5	0.5	8	4
Smoking history, %*						
Smokers		27	26	23	17	
1–10 cigarettes/day		14	16	15	9	
11–20 cigarettes/day		9	10	8	6	
>20 cigarettes/day		5	2	1	3	
Exposed to secondary smoke		45	40	56	23	

*Data not collected in the UK survey.

†*n* = 491; ‡*n* = 278.

SD, standard deviation.

asthma medications were getting the longest-lasting benefit (15%) and minimizing side effects (6%), respectively.

Asthma control: patient expectations for the future

When considering symptoms of asthma now and in 5 years' time, patients' perceptions were similar for asthma episodes and long-term symptoms for the two time frames chosen (Fig. 3). France had one of the least positive outlook towards asthma now and in the future. French patients felt that the situation is not likely to improve without major investments in treatment research. However, patients were more optimistic in their outlook towards emergency visits, with about two-thirds of patients feeling that this goal is achievable (Fig. 3). Despite only 8% (15/200) of Spanish patients currently having few or no long-term symptoms of asthma, 29% (58/200) expect to achieve this goal within 5 years. Likewise in Sweden, two-thirds (136/200) of patients expect to have, or be close to having, no long-term symptoms in 5 years, and 45% (90/200) believe that by then, they will have few restrictions on their daily activities.

The optimistic outlook of Spanish and Swedish patients is continued when considering the future development of their respective healthcare systems. However, the overall view is that fewer than half (47%) of the patients expect their national healthcare systems to provide better healthcare in the future (Fig. 4), although

the majority of the patients were optimistic about new treatments being available for the management of their severe asthma (Fig. 5).

When asked what one thing the government could do for people with asthma (France, Germany, Spain and Sweden), patients considered investment in research for new asthma treatments (31%), provision of free prescriptions for people with asthma (22%), a ban on smoking in public places (14%) and ensuring immediate access to an asthma specialist when one is needed (13%) to be most important.

Discussion

The results of this survey provide an important insight into how patients with severe asthma view their asthma and its management, and how they feel these may develop in the future. It is clear from this study that most patients have limitations to their lifestyles as a consequence of the symptoms of severe asthma: physical activity is restricted in almost 70% of patients, 50% are restricted from having pets, 30% from taking holidays, and many feel their job prospects are limited. In addition, 50% of this population of patients are not convinced that guideline goals are being achieved, although it is not clear as to the cause of this failure.

Patient attitudes towards their treatment and medications play a major part in the management of asthma. As seen in this study, patients want treatments that are

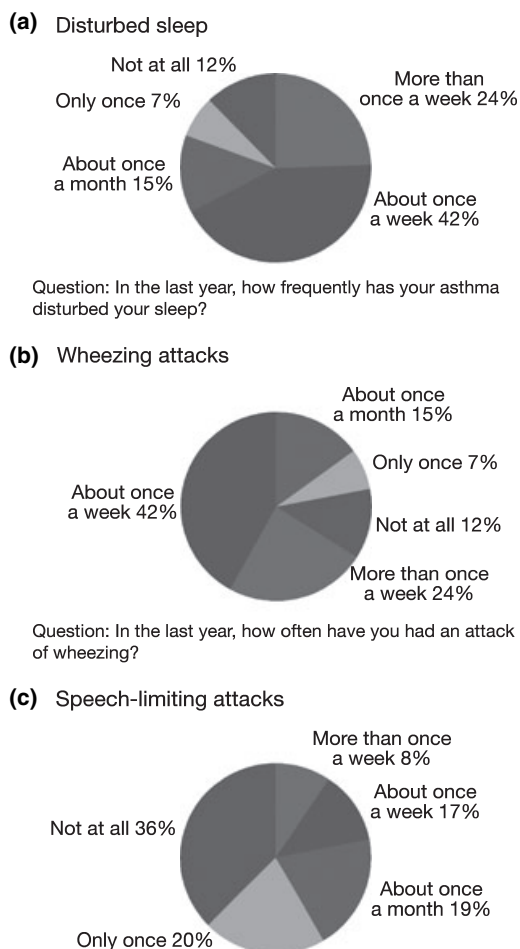


Figure 1. Frequency of symptoms experienced by European patients with severe asthma: (A) disturbed sleep; (B) wheezing attacks; (C) speech-limiting attacks ($n = 1300$).

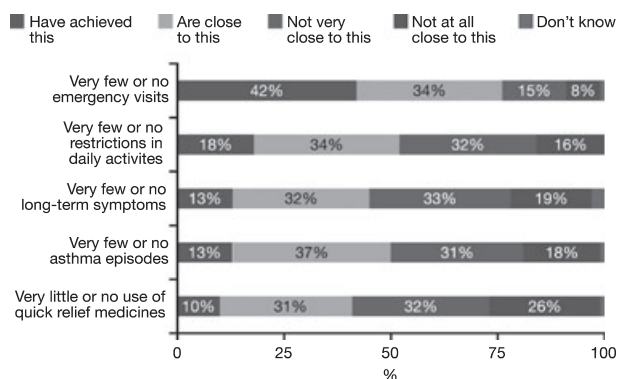


Figure 2. Percentage of patients indicating the level of achievement of the Global Initiative for Asthma (GINA) goals for asthma control (2) ($n = 1300$).

fast-acting, long-lasting and have minimal side effects. Side effects and a lack of a perceived effect of asthma medication are the major obstacles to the management of

asthma. A vast majority of patients in the International Asthma Patient Insight Research (INSPIRE) study were quite confident in the self management of their asthma, although many were concerned about taking medication when they were without symptoms (7). As patients take a more active role in the management of their asthma, better education about the treatments are needed to avoid misconceptions and to allay fears about their medications. These fears about side effects, especially of ICSs, are common among the asthma population (15). Without quantitative data on the medications taken by patients in the current study, it is difficult to draw any specific conclusions as to patients' attitudes towards their medication here. However, it is important that patients communicate their opinion and experiences, and are involved in the decision-making process. Without their insight, key information may be lacking in future essential communications such as medical information leaflets (16). Additionally, poor information and a lack of understanding about a medication's side effects can often lead to non-adherence to medication (17), which in turn will most likely lead to inadequately controlled asthma in those with severe disease.

Improving patient understanding can be facilitated by a good relationship between doctor/nurse and their patients, and many patients (and their families) value the interaction they have with their physician (18). The current survey revealed that the majority of doctors and nurses treating asthma did not always follow their patients up to check how they were progressing. This could have a major impact on the control of a patient's asthma, as patients will often try and manage troublesome symptoms themselves (7), possibly not wishing to impose on their asthma doctor/nurse. In addition, it is important to involve patients in the decision-making process. A cross-sectional survey of 230 adults with clinician-diagnosed asthma reported that 55% of patients felt that they were less involved in treatment decisions than they would prefer (19). An encouraging finding of the present survey was the high rating (approximately 7 of 10) by patients when asked whether their asthma practitioner gives them a choice of treatment.

Current management of severe asthma and patient education needs to be improved. It is clear from this survey that many patients with severe asthma are not very optimistic about the future of asthma management. It is accepted that control of asthma requires a reduction in symptoms that have such a great impact on patients' lives. The greater the severity of patients' asthma and symptoms the greater the effect on patient quality of life (20, 21), which on occasions can be so severe that patients with severe asthma live in constant fear that their next asthma attack could be fatal. In two studies, more severe symptoms of asthma in children (22) and adults (23) were assessed. Adult patients in the UK, Ireland and the Netherlands were shown in the European Community Respiratory Health Survey (ECRHS) to be more likely,

Table 3. Percentage of patients, by country, indicating how severe asthma has impacted on their lives

Activity affected by asthma, %	All (n = 1300)	UK (n = 500)	Sweden (n = 200)	Spain (n = 200)	Germany (n = 200)	France (n = 200)
Physical activity	69	63	53	70	81	77
Pets	49	–	63	45	38	50
Going out with friends	38	44	33	27	42	44
Holidays	28	26	28	16	34	37
Job prospects	21	16	33	15	22	20
Participation at school/college	14	16	22	7	9	15
Work promotion	9	8	16	4	9	10
Success at study	5	6	9	3	4	4

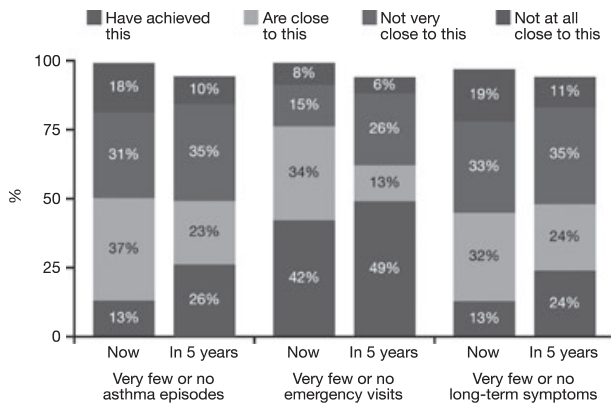
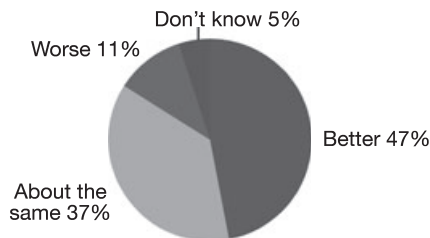


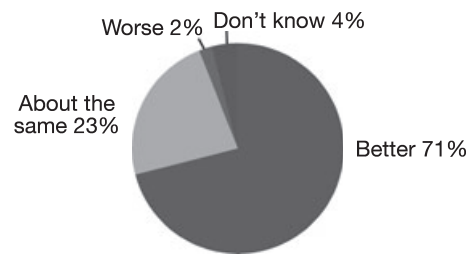
Figure 3. Comparison of patients' perceptions on asthma control now and what they expect in 5 years (n = 1300).



Question: In 5 years' time, do you think that the way asthma is looked after in your national health system will be . . . ?

Figure 4. Patient predictions on the state of national asthma care for severe asthma in the future (n = 1300).

than patients from other European countries, to have an asthma exacerbation (23). The situation in the UK in children was equally bleak, with more than twice as many children suffering episodes of wheezing, sleep disturbances and speech-limiting wheeze than children in France (9.3% vs 4.1%) (22). The results of the current survey confirm that levels of asthma control across Europe in patients with severe asthma, on the whole, are not improving. Additionally, patients with severe asthma have high levels of distress, particularly of anxiety, which manifest even between attacks (24), although severe asthma may not be the only contributing



Question: In 5 years' time, do you think that the choice of asthma drugs will be . . . ?

Figure 5. Patient prediction on the choice of asthma medication in the future (n = 1300).

factor, making diagnosis and subsequent treatment decisions difficult for most respiratory physicians. To improve future management of patients with more complex asthma, respiratory specialists with a special interest in difficult asthma will be required (25).

A potential limitation of the current study is how this population of severe asthma patients was selected. By using the method of random-digit dialling, rather than including patients by doctor-verified diagnosis, there is a risk that patients with other respiratory conditions (i.e. bronchitis and emphysema; chronic obstructive pulmonary disease) were included in the study, which would potentially skew the results in favour of more severe disease. However, the process in Spain differed from that in other countries by including doctors as interviewers. When considering the responses to questions about their asthma and symptoms (questions 1–3 and 11; Table 1), there were no major differences in the results of Spain compared with the other countries, which suggests that the populations were well matched. Interestingly, Swedish patients felt that they were closer to achieving guideline goals than the patients of other countries. This might be a consequence of better asthma management, as these patients most frequently mentioned the use of preventative medications during the focus group meetings (LABA plus ICS and ICS alone).

It is understandable that there will be differences of opinion and expectations across Europe, as governments and national healthcare systems differ; however, improved surveillance and subsequent sharing of

information would be an important step towards aligning asthma management between countries. In this survey, patients were generally pessimistic about the future, which highlights the need for an overall improvement in how their asthma is managed and controlled. However, it is not unusual to observe pessimism in patients with asthma, and negative mood should be taken into consideration when conducting surveys, as this could potentially influence data that rely on subjective opinion (26). Conversely, some studies have shown that patients tend to overestimate control of asthma, rather than underestimate it (4, 7, 15). In the INSPIRE study, 87% of patients with uncontrolled asthma (according to the Asthma Control Questionnaire) classed their asthma control as 'relatively good' (7).

Most optimistic opinion appears directed towards the development of more effective asthma treatments in the future. Several therapies are currently available that facilitate improved asthma control in patients with severe persistent asthma (2, 8, 27), which in turn will help improve patients' quality of life and allow them to live beyond their limitations. Having effective therapies is obviously a necessary component in the strategy for gaining asthma control, but other factors have been highlighted as essential measures for improving the level of care. Some patients felt that accessibility to specialist medical care might help as part of their management programme. Healthcare providers should explore other novel approaches to help bring down the asthma-related costs. Nurse-led outpatient management programmes (28), internet-based education (29) and use of mobile telephones to improve communication between patients and healthcare professionals (30, 31) might facilitate improvements in asthma control and subsequently help reduce cost.

Currently available measures, such as self-management plans, were introduced to give patients more control over how their asthma was managed and are considered a very important feature of an asthma management programme (32). Indeed, proper implementation of written action

plans may contribute to reducing the economic burden, especially in patients with severe asthma (33). However, not all patients receive these (34, 35), which could be a contributing factor towards poor asthma control.

Conclusions

Severe asthma has a major impact on patients – restricting their activities, causing embarrassment, imparting fear – and is a major burden on healthcare systems. Despite studies indicating that severe asthma is still not adequately controlled, there continue to be inefficiencies in the management of this population; consequently, guideline goals are not being achieved. Patient perceptions towards their asthma and expectations for the future management of asthma differ across Europe, and understandably, many patients are not optimistic about the future for asthma management. On a positive note, patients are optimistic about the development of new medications to help control the debilitating symptoms of severe asthma. National healthcare investment in new strategies, improving surveillance across Europe, working with patients to understand their needs and the development of new treatments to facilitate the management of severe asthma will give patients hope that they might one day live beyond the limitations of their asthma.

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