



Health literacy among asthma patients and treatment expectations: results of a Belgian survey

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ABSTRACT

Objectives: Non-adherence to asthma medication can lead to lower disease control and asthma exacerbations that may be fatal. This survey assessed the attitude and expectations of Belgian asthma patients towards their treatment.

Methods: This cross-sectional survey was conducted between June 2015 and February 2016 in 70 Belgian pharmacies. Participants completing the survey had to be ≥ 15 years, diagnosed with asthma, and on inhaled corticosteroid-based treatment. The analysis included 80 completed questionnaires.

Results: Participants comprehended well that controller drugs are intended to prevent the occurrence of asthma symptoms and complications, and their long-term daily use should be maintained. Twenty seven percent of participants indicated fear of side effects concerning long-term daily use of a controller inhaler. Participants had a good understanding that quick-relief drugs are intended to (quickly) relieve asthma symptoms and do not need to be used on a systematic, daily basis. Out of 73 participants on long-term controller drugs, 33 (45%) were 'non-adherent' (used less frequently than prescribed). Suboptimal adherence to maintenance treatment appeared to increase nightly awakenings and the risk of restrictions in activities due to asthma. Out of 54 participants with available quick-relief drug adherence data, 18 (33%) were non-adherent (used their quick-relief drug more frequently than prescribed).

Discussion: This survey confirms suboptimal adherence to maintenance controller therapy and overuse of short-acting reliever medications among Belgian patients, which affects asthma control and quality of life. A substantial proportion of patients expressed fear about their chronic therapy, indicating the need for patient education about their disease and its management.

KEYWORDS

Asthma; maintenance treatment; inhaled corticosteroids; long-term controller drugs; quick-relief drugs

Introduction

Asthma is a chronic inflammation of the airways. It is estimated that more than 300 million people are affected worldwide, with prevalence increasing over the last few decades [1,2]. Daily inhaled corticosteroids (ICS) remain the cornerstone of asthma management according to all guidelines [3]. ICS are, to a large extent, responsible for the observed reduction in asthma morbidity and mortality over the past two decades [4,5]. While controller medications are used for maintenance treatment, quick-relief drugs are intended to offer immediate relief [6]. Ultimately, eliminating the dependency on reliever medication remains one of the goals of asthma management.

Despite the proven efficacy of ICS therapy, adherence to daily ICS remains suboptimal at approximately 50% or lower [7,8]. Reasons for poor patient adherence to ICS include side effects, fear of side

effects, forgetfulness, or inconvenience of regular medication use [9]. Additionally, inadequate perceptions of asthma control may play a role; asthma patients, for example, may not realize the importance of using ICS on a daily basis even in the absence of symptoms. Causes commonly cited by patients for suboptimal adherence are the abatement of symptoms, forgetting to take medication, and fear of potential side effects of ICS [10–13].

Suboptimal adherence may have significant consequences for the patient, such as poor asthma control, exacerbations, hospitalizations, a decline in lung function, or a decreased quality of life [14]. Non-adherence to ICS has also been reported in a significant proportion of patients with difficult-to-control asthma [15]. It is critical to know if poor asthma control is due to non-adherence to the treatment; otherwise, a patient with uncontrolled asthma may be unnecessarily

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stepped up to other (and often more expensive) therapies. Thus, continuous efforts aimed at improving adherence, especially with ICS and inhaler treatments, are warranted. A literature review on hindering factors influencing adherence to asthma treatment among adolescents revealed that the plethora of parameters involved complicate refinement of the situation [16]. A better understanding of patients' behavior, motives, beliefs, and perceptions towards adherence to asthma treatment remains key to ultimately achieve better self-management.

Thus, the objectives of the survey were to assess the attitude of Belgian asthma patients towards their treatment and expectations concerning their medications, the adherence to controller and quick-relief therapy, and its association with limitations in activities and night awakenings.

Material and methods

Study design

This cross-sectional survey was conducted in Belgium between June 2015 and February 2016. Seventy pharmacies across the three regions (Flanders, Wallonia, and Brussels-Capital) were randomly selected from a complete list of Belgian pharmacies. Each pharmacy was asked to distribute 25 questionnaires with a target of 20 completed questionnaires. The pharmacists gave the questionnaire to the participants collecting ICS-based treatment for asthma. Participation to the survey was voluntary and pharmacies had the right to withdraw from the study at any time.

The questionnaire had to be filled in by the participant; pharmacists or other pharmacy staff could not be involved in the completion of the form. Participants could either fill in the hard copy questionnaire on site or at their convenience and return the completed form back to the pharmacy. The participants' anonymity was ensured and no personally identifiable information (such as name, address) was collected. To ensure complete data privacy, questionnaires from all sites were pooled together before encoding.

Data entry was done in duplicate and was systematically compared for accuracy. Questionnaires with incomplete data related to the objectives of the survey were excluded from the survey.

The study was approved by the central Ethics Committee of the Universitair Ziekenhuis Gent and received a favorable opinion in writing by the College of Pharmacists.

Study participants

Participants had to be 15 years of age or older, have a diagnosis of asthma, and use ICS-based treatment to

control his/her asthma symptoms, at the time of completing the survey. Potential participants had to indicate their diagnosis of asthma on the questionnaire; persons suffering from chronic obstructive pulmonary disease (COPD) were not included.

Study objectives

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Questionnaire design

The questionnaire was available in two local languages (Dutch and French) and divided in three sections to collect the following information: (1) general data: questions regarding diagnosis, gender, year of birth, and smoking status; (2) questions related to participant's attitudes towards asthma treatment (long-term controllers and quick-relief medications were assessed separately); and (3) questions related to their expectations about the asthma treatment. The questionnaire was designed following a literature research on surveys conducted (1) in Belgian patients and (2) in patients from other countries focusing on the aforementioned topics. An English translation of the questionnaire and an overview of the consulted literature are available as an online supplement.

Statistical analysis

Data were collected using quantitative measures and analyzed using descriptive statistics. Participants indicated their answer on a scale of 0 (fully disagree) to 10 (fully agree). For analysis of the questions concerning attitude towards and expectations about asthma treatment, scores of 0–3 were pooled as 'do not agree', and 7–10 as 'agree'; scores 4–6 were considered to be neutral. To assess adherence, participants who scored ≤ 3 (disagree) on the questions 'use of long-term control drug less than prescribed' or 'use of quick-relief drug more than prescribed' were considered as adherent, whereas those with a score of 4–10 were considered as non-adherent.

A post hoc statistical analysis was performed to assess a potential correlation between non-adherence to long-term controller drugs and non-adherence to quick-relief drugs, and between treatment duration (≤ 5 years vs > 5 years) and non-adherence to controller or quick-relief drugs. These correlations were assessed using Pearson Chi-square tests. After log-transformation to account for its skewed distribution, these correlations were also analyzed considering the individual treatment duration in a logistic regression

model and statistical significance was tested using the Wald chi-square test.

Results

Survey participants

The analysis included 80 completed questionnaires (Figure 1). The mean age of the participants was 48 years (standard deviation: 18, range: 16–87); 51% were male (Table 1). Overall, regional distribution of participants was balanced (59% of participants were from Wallonia). Most participants were followed up by a physician (53% by a general practitioner, 24% by a general practitioner and pneumologist, and 17% by a pneumologist only). Out of the 77 participants who indicated their smoking status, 46 (60%) were non-smokers, 18 (23%) were former smokers, and 13 (17%) current smokers (Table 1). All 80 participants reported taking a long-term controller drug, while 56 participants indicated that they were also using a quick-relief drug (40 [71%] were using a β_2 -agonist, 13 [23%] a combined anticholinergic/ β_2 -agonist, and 3 [5%] indicated that they were using a β_2 -agonist and a combined anticholinergic/ β_2 -agonist). A complete treatment overview at baseline can be found in Supplementary Table 1.

Participants' perception and knowledge of their asthma drugs

Overall, the participants had a good comprehension that controller drugs are intended to prevent the occurrence of asthma symptoms and complications,

Table 1. Patients' characteristics.

Characteristic	N	n (%) or mean (SD)
Mean age (years) at dose 1 $\pm$ SD	N = 79	48 (18.5)
Male, n (%)	N = 80	41 (51)
Time since treatment initiation, year (SD)	N = 70	18 (16.8)
Smoking habits, n (%)	N = 77	
Non-smoker		46 (60)
Ex-/Current smokers		31 (40)
Education, n (%)	N = 79	
Secondary school		19 (24)
Higher diploma		51 (65)
Other		9 (11)
Patients distribution according to region	N = 80	
Vlaanderen		33 (41.25)
Antwerpen		3 (3.75)
Vlaamse Brabant		10 (12.50)
Limburg		1 (1.25)
Bruxelles/Brussel		6 (7.50)
West Vlaanderen		7 (8.75)
Oost Vlaanderen		6 (7.50)
Wallonia		47 (59.78)
Hainaut		18 (22.50)
Brabant wallon		2 (2.50)
Liège		13 (16.25)
Luxembourg		12 (15.00)
Namur		2 (2.50)

Abbreviations: N, total number of available data; (%), number (percentage) of patients; SD, standard deviation.

and their long-term daily use should be maintained. Most participants also indicated that controller drugs can prevent asthma symptoms, are well tolerated, and easy to use (Figure 2(a)). Although 49% of participants agreed that their controller drugs are safe on long-term basis, around 20–28% indicated a fear of side effects concerning long-term daily use of a controller inhaler, regardless of whether they had been using the drug for more than, or less than, 20 years.

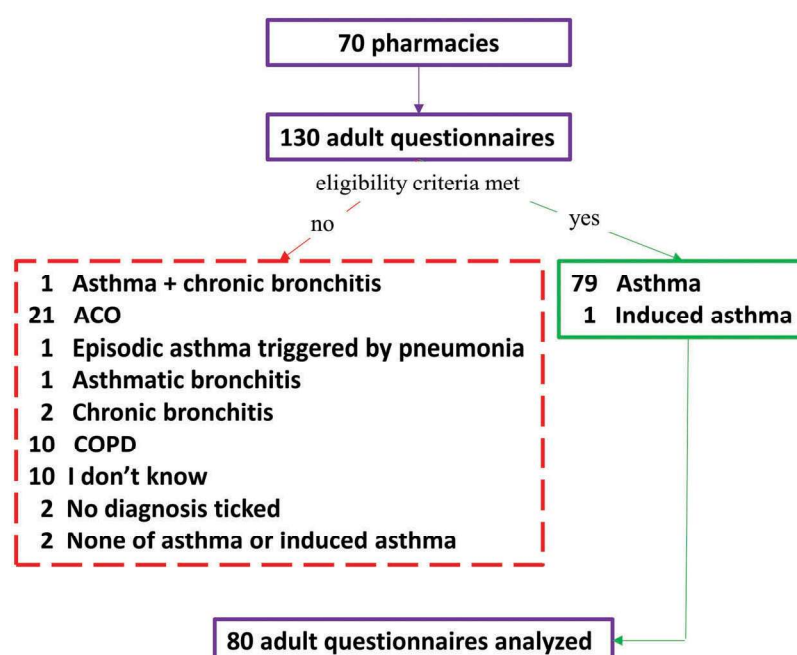


Figure 1. Participant flow chart.

Abbreviations: ACO, asthma-COPD overlap; COPD, chronic obstructive pulmonary disease.

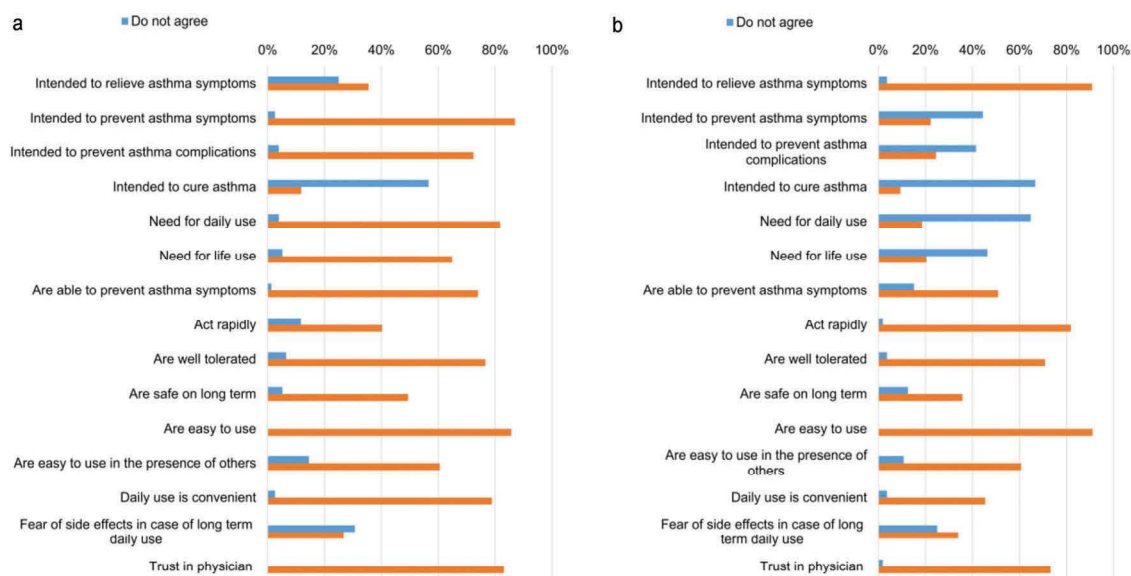


Figure 2. Participants' perception and knowledge of their controller drugs (A) and quick-relief drugs (B).

Notes: Survey scores 0–3 were grouped as 'do not agree', scores 7–10 as 'agree'. Scores 4–6 were considered to be neutral and are not shown in this graph.

Participants had a good comprehension that reliever drugs are intended to relieve asthma symptoms, act quickly on symptoms, and do not need to be used daily. The majority of participants also indicated that reliever drugs are well tolerated (71%) and easy to use (91%) (Figure 2(b)).

Around 40% of participants considered their controller drug as fast-acting, regardless of whether they were taking a fast-acting type of drug or not. More specifically, 40% of 38 participants using a formoterol-based treatment considered their controller drug as fast-acting, compared to 41% of 37 participants using another type of controller drug.

The percentage of participants who agreed that the drugs are safe when used on long-term basis tended to be lower for quick-relief drugs than for long-term controller drugs (36% vs 49%).

Adherence to therapy

Of the 73 participants with available adherence data on long-term controller drugs, 33 (45%) were considered as non-adherent as they used it less often than prescribed. Of the 54 participants with available quick-relief drug adherence data, 18 (33%) indicated that they used it more often than prescribed.

Of the 51 participants with adherence data available for both long-term and quick-relief drugs, only 21 (41%) reported being adherent to long-term drugs and using quick-relief drugs as prescribed, while 11 (22%) were non-adherent to long-term drugs and used quick-relief drugs more than prescribed (Table 2). The proportion of participants who were non-adherent to their long-term controller drugs

tended to be higher in participants using quick-relief drugs more than prescribed (11/17; 65%) than in those using quick-relief drugs as prescribed (13/34; 38%). The proportion of participants using their quick-relief drugs more often than prescribed tended to be higher in long-term drug non-adherent participants (11/24; 46%) than in long-term drug adherent participants (6/27; 22%). Thus, there was a trend towards positive correlation between non-adherence to long-term drugs and using quick-relief drugs more often than prescribed, but this trend did not reach statistical significance ($p = 0.07$).

Of the 65 patients with data available for adherence to long-term controller drugs as well as treatment duration, the proportion of non-adherence tended to be higher for those treated for more than 5 years (23/44; 52%) than for those treated for 5 years or less (8/21; 38%), but without reaching statistical significance ($p = 0.28$). In contrast, of the 48 patients with data available for both quick-relief adherence and treatment duration, the proportion of non-adherence tended to be lower in participants treated for more than 5 years (9/34; 26%) than for those treated for 5 years or less (7/14; 50%), but also without statistical significance ($p = 0.12$) (Table 2). This correlation has also been analyzed considering the individual treatment duration in a logistic regression model. The probability of long-term non-compliance tended to increase with the treatment duration, but without reaching statistical significance ($p = 0.42$, Wald chi-square test) (Supplementary Figure 1). The probability of quick-relief non-compliance tended to decrease with the treatment duration, but again without statistical significance ($p = 0.11$, Wald chi-square test) (Supplementary Figure 2).

Table 2. Adherence to therapy.

A. Correlation between adherence to quick-relief drug and to long-term controller drug (N = 51)			
	Adherent to long term: n = 27	Non-adherent to long term: n = 24	p Value
Adherent to quick-relief: n = 34	21	13	0.07
Non-adherent to quick-relief: n = 17	6	11	
<i>Pearson Chi-square</i>			
B. Correlation between treatment duration and adherence to long-term controller drug (N = 65)			
	Adherent to long term: n = 34	Non-adherent to long term: n = 31	p Value
Treatment ≤5 years: n = 21	13 (62%)	8 (38%)	0.28
Treatment >5 years: n = 44	21 (48%)	23 (52%)	
<i>Pearson Chi-square</i>			
C. Correlation between treatment duration and adherence to quick-relief drug (N = 48)			
	Adherent to quick relief: n = 32	Non-adherent to quick relief: n = 16	p Value
Treatment ≤5 years: n = 14	7 (50%)	7 (50%)	0.12
Treatment >5 years: n = 34	25 (74%)	9 (26%)	
<i>Pearson Chi-square</i>			

Notes: Adherence to quick-relief drugs was based on the question 'Do you use quick-relief drug more than prescribed?' Adherence to long-term drugs was based on the question 'Do you use long-term drug less than prescribed?' Adherent participants were those with a score ≤3 (disagree), non-adherent participants those with a score of 4–10.

Abbreviations: N, number of participants with answers available to assess the specified correlation; n, number of participants in the specified category.

We also assessed other characteristics of participants but no clear discriminating factor predicting medication adherence was observed (Table 3).

Impact of medication adherence on quality of life

Overall, 23% of participants declared to have been hospitalized due to asthma at least once, 35% declared having had at least one day with limited activities due to asthma in the past week, and 29% declared having had at least one night in the past week in which they had been awakened due to asthma. While suboptimal treatment adherence did not appear to have an impact on hospitalization due to asthma (Supplementary figure 3), the proportion of participants who had at least one day with limited activities in the past week tended to be higher for those who were non-adherent to their controller drug regimen than for the adherent participants (47% vs 24%) (Supplementary figure 4). Similarly, the

proportion of participants who were awakened due to asthma at least one night in the past week tended to be higher in non-adherent participants than in adherent participants (Supplementary figure 5).

Frequency of medication use

Of the 40 participants who indicated being adherent to their long-term controller drug (thus, not using this drug less than prescribed), 38 (95%) answered that they used their long-term drug regularly. Among the 33 non-adherent participants, 24 (73%) indicated that they used their controller drug regularly, while 6 (18%) used it only at symptoms.

Of the 54 participants using a quick-relief drug, 13 (24%) indicated using their quick-relief drug regularly, while 35 (65%) used it at symptoms, 6 (11%) at risk (e.g. pollen period, winter, sports, important or prolonged efforts), and 1 (2%) in case of stress. Of the 13 participants who indicated that they used their

Table 3. Factors assessed as potentially influencing adherence.

Clusters	N	Adherent to long-term controller drug	Non-adherent to long-term controller drug	N	Adherent to quick-relief drug	Non-adherent to quick-relief drug
All	73	40 (55%)	33 (45%)	54	36 (67%)	18 (33%)
<i>Treatment duration:</i>						
≤5 years	21	13 (62%)	8 (38%)	14	7 (50%)	7 (50%)
>5 years	44	21 (48%)	23 (52%)	34	25 (74%)	9 (27%)
<i>Education:</i>						
Secondary	49	28 (57%)	21 (43%)	34	23 (68%)	11 (32%)
Higher	23	11 (48%)	12 (52%)	20	13 (65%)	7 (35%)
<i>Smoking:</i>						
Ex-/Current smokers	28	16 (57%)	12 (43%)	20	11 (55%)	9 (45%)
Non-smoker	43	23 (54%)	20 (47%)	33	24 (73%)	9 (27%)
≤15 pack-years	10	7 (70%)	3 (30%)	8	4 (50%)	4 (50%)
>15 pack-years	17	8 (47%)	9 (53%)	12	7 (58%)	5 (42%)

Notes: A pack-year is equal to smoking 1 pack per day for 1 year.

Abbreviations: N, number of participants in the respective category.

quick-relief drug regularly, 8 (62%) had declared being adherent to their medication (thus, not using the quick-relief drug more than prescribed). The characteristics of these 13 participants were as follows: 9 (69%) were smokers, 11 (85%) had a secondary diploma as highest education level, and their mean age was 55 years (standard deviation: 16, range: 25–77). Additionally, 9 (69%) of these 13 participants were not using a fast-acting type of controller drug, 11 (85%) reported using their long-term control drug regularly, and 7 (54%) were followed up by a general practitioner only. Concerning asthma symptoms and impact on their quality of life, 4/13 (31%) declared having already been hospitalized due to asthma, 6/12 (50%) declared to have been awakened at night due to asthma in the past week, and 5/11 (46%) reported limitations in activities due to asthma.

Discussion

In the survey described in this manuscript, we aimed to understand the attitude of Belgian asthma patients towards their medication and their treatment expectations. The survey participants generally appeared positive about their long-term controller drugs; the majority agreed with statements that such therapy is able to prevent asthma symptoms (74%), is well tolerated (77%), and easy to use (86%). This seems to be an improvement when compared to a Belgian assessment performed in 1997, which reported that 48% of the patients had a negative perception about ICS, either believing that ICS lacked efficacy or being concerned about the safety of the therapy [17]. Findings of other international studies were similar to our study. When questioned about attitudes towards inhaler devices, most participants in an Italian survey tended to have positive opinions regarding safety, reliability, effectiveness, ease of use, and practicality [18]. In a survey in the US, more than 85% of patients were satisfied with the ease of use and effectiveness of their current treatment, as well as with the medication's time to onset, safety, and dosing frequency. It is not specified, however, if the treatment were inhalers [11].

Despite the generally positive opinions, approximately one-fourth of our participants indicated a fear of side effects concerning long-term daily use of a controller inhaler. In other studies, a substantial number of patients reported that they were concerned about possible side effects of regular therapy with corticosteroids, or that they disliked the idea of using an inhaled steroid [12,19–25]. The belief that constant use of respiratory drugs is unhealthy has been found to correlate with accidental as well as intentional interruption of ICS therapy, and with less frequent use of ICS upon symptom improvement [12]. Partridge et al. [26] reported that more than half of

the assessed patients from 11 countries (including Belgium) across 3 continents were concerned about taking too much controller medication at times when their symptoms were less prominent or absent. Moreover, patients preferred to increase the use of short-acting β_2 -agonists, and not of ICS, when their asthma symptoms worsened [26]. Our survey revealed that non-adherence to long-term controller drugs tended to be higher in participants who used quick-relief drugs more than prescribed, suggesting that patients over-rely on short-acting relievers in preference to their maintenance ICS. Surprisingly, medication adjustment according to symptoms was also reported by patients who agreed that their controller inhaler was necessary even when they were not having problems with their asthma [21]. In our survey, among the 33 participants who used their long-term controller drug less than prescribed, 6 indicated using the drug at symptoms instead of regularly. In further studies, it could be interesting to compare the participant's statements on actual inhalations per day and number of inhalers used per year with standard regimens in terms of adherence.

In our survey, suboptimal adherence was not associated with an increased rate of hospitalization due to asthma (which could, among others, be attributed to the small sample size), but there was a trend for increased nightly awakenings and a limitation in activities due to asthma.

Most participants had good comprehension that reliever drugs are intended to relieve asthma symptoms, act quickly on symptoms, and do not need to be used daily. For some patients, rescue medications may also be taken before a known trigger (e.g. exercise) to prevent asthma symptoms; such preventive use may have prompted certain participants to agree with statements about quick-relief drugs such as 'destined to prevent asthma complications'.

In an international survey including Belgian patients, most patients reported to be dissatisfied with the currently available therapies, particularly regarding the side-effect profiles, and believed there was a need for new treatment options. The majority of patients indicated immediate relief from symptoms as the most desirable trait of asthma medication [26]. In our survey, approximately 40% of participants considered their controller drug as being fast-acting. While most patients used their controller drug in a fixed combination with long-acting β_2 -agonist (mainly formoterol, which is characterized by a rapid onset on drug effect), the perception of long-term controller drugs as being fast-acting was not influenced by the type of treatment that the participant was using at the time of the questionnaire (i.e., actually being a fast-acting type, or not). This could be due to the fact that 'fast-acting' was not precisely defined in the questionnaires; it is possible that 1 h is

perceived as fast-acting, while this is not defined as such by medical personnel (fast-acting drugs typically have an effect within 10 min). An increasing length of time with airway problems has been reported to decrease the odds of taking the medication as prescribed [19]. Moreover, long disease duration has been associated with beliefs that disease control was driven by chance (i.e. not under their own control) [27]. In our survey, the proportion of non-adherence to long-term controller drugs tended to be higher for participants treated for more than 5 years than for those treated for 5 years or less, but without reaching statistical significance.

While the proportion of participants in our survey who did not use a quick-relief drug may appear high (21%), 10 of these 17 participants were using a fast-acting type of controller drug (e.g. ICS plus long-acting β_2 -agonist such as formoterol) and, thus, might have been advised to use that drug also as rescue therapy. The fact that some controller drugs can also be used as relief drugs (i.e. formoterol-based ICS combinations), may have influenced the participants' answer concerning controller drugs; in addition to control purposes, they may also have pointed towards the rescue use of their drug (for example, answering 'destined to relieve asthma symptoms').

Of the 13 participants who indicated regular use of their quick-relief drugs, the majority were smokers, had no higher education, and their mean age was 55 years. These characteristics resemble the profile of COPD patients, suggesting that these patients may suffer from asthma-COPD overlap rather than purely asthma. Of these 13 participants, 8 (62%) had declared not using their quick-relief drug more than prescribed and were thus considered adherent to their medication; this contradicts their statement of regular quick-relief drug use, as these drugs are not destined for regular use. These patients were more likely to have been awakened at night or have had limitations in activities due to asthma than the overall population of participants.

Limitations of this study include the small sample size, as the number of participants was considerably lower than anticipated. A potential explanation may be the fact that the questionnaire was too long to allow completion in the pharmacy; therefore, most patients took the questionnaire home and not all of them brought them back to the pharmacy. Due to the low response rate, it was not possible to separate adolescents and adults who may have other expectations and feelings about their disease and treatment. The assessment of statistical significance was only assessed post hoc for a limited number of comparisons, and the fact that none of the comparisons reached significance is likely due to the low number of survey participants and limited statistical power. Moreover, we evaluated only patients who came to

the pharmacy, and only a small subset of patients coming to the pharmacies completed and returned their questionnaire; this may have caused a bias towards more adherent patients. Using quick-relief drugs less often than prescribed has been categorized as 'adherent', while it may have limited patients in performing activities. Finally, in the survey, the diagnosis of asthma was used as mentioned by the participant on the questionnaire; thus, we had no confirmation from a healthcare provider, and we also did not have any insight in the proportion of patients with different levels of asthma severity. A large proportion of participants declared that they were not limited in activities during the day, nor had night-time symptoms, which indicates that these were rather well-controlled patients.

Conclusion

The results of our survey indicated that the majority of Belgian asthma patients had relevant knowledge and positive opinions about their long-term controller and quick-relief medications. Nevertheless, about a quarter of participants indicated a fear of side effects concerning long-term daily use of a controller inhaler. Thus, the fact that ICS are considered safe for long-term use and become more efficient with long-term daily use may need to be further stressed by healthcare providers. Education of the patients remains a challenge and should be reinforced. Adherence to both long-term controller therapy and quick-relief drugs was often found to be suboptimal – in terms of poor adherence to controller medication and overuse of reliever medication – which affected asthma control and quality of life.

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