

Childhood asthma perception in Turkey under real-life environment (CAPTURE) study

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Successful management of asthma requires good communication between patients and the healthcare team. The background and expectations of a patient inevitably influence the success of any partnership. A questionnaire-based survey was performed to obtain data on the perception of the impact of asthma in daily life among children (age-range 6–14 years) and adolescents (age-range 15–20 years). A total of 756 patients (384 children, 372 adolescents) were randomly selected from 11 Turkish cities and interviewed face-to-face. Of the total study population, 71.3% received regular follow-up and 75.9% currently took asthma medication. Almost 50% reported that asthma affected their lives significantly. Even though half of the patients had symptoms at least once a week, one-third were not receiving regular prophylactic treatment. Exercise produced asthma symptoms in 45.5% of children and 27.4% of adolescents. The finding that asthma continues to be a major health problem clearly indicates an urgent need for further management programs in Turkey.

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Bronchial asthma is one of the most common chronic diseases of childhood (1). In recent years, the prevalence of asthma has shown a steady increase, together with its social and economic impact (2,3).

Attempts to improve asthma management have included distribution of guidelines and audio-visual materials, and organization of courses, camps, and other informational activities. Successful management also requires good communication between the patient and the healthcare team, as the patient's background and expectations inevitably influence any partnership. Nevertheless, neither effective asthma-related activities nor patients' perception of the disease have been investigated extensively (4). The majority of data regarding the effect of asthma

on quality of life have been obtained in clinical settings that do not always reflect real life.

Recently, Turkey's largest asthma organizations (the National Society of Allergy and Clinical Immunology and the Turkish Thoracic Society) conducted a study to define the perceptions of asthma by patients, their relatives, and their physicians. Our observations on asthmatic children and adolescents form the basis of the present report.

Materials and methods

Study population

Asthmatic children (6–14 years of age) and adolescents (15–20 years of age) were chosen

from 11 randomly selected cities, representing different geographic regions of Turkey. The aim was to enroll ≈ 800 patients. Out-patient records of the previous 5 years from randomly selected local hospitals, clinics, and pharmacies were analysed, and 1,423 asthmatic patients were identified; these patients constituted the study pool of the present study. Three sources contributed to the pool in approximately the same proportions because of the previous observation that the spectrum of asthma severity did not differ between outpatient clinics. The study population selected randomly from the study pool and the number of patients from each city were based on the total municipal population to yield a final selected/total population ratio of $\approx 0.001\%$ for each group.

Inclusion criteria were: any diagnosis of asthma and/or allergic bronchitis; at least two of three asthma symptoms (recurrent wheezing, cough, dyspnea); and written, informed consent from the patient or a parent (or both). Because many Turkish pediatricians and general practitioners label asthma as allergic bronchitis, we used the terms synonymously and required the presence of asthma symptoms to support the diagnosis.

Questionnaire

Ten in-depth interviews were conducted to provide baseline information for the questionnaires, which were prepared by the study council of the Turkish National Society of Allergy and Clinical Immunology to reflect interview responses and Global Initiative for Asthma guidelines. The questionnaires for children and adolescents were essentially identical, except for minor clarifications of meaning appropriate for a children's instrument. The questionnaires elicited data on the patients' demographics, asthma drugs, attitude towards their physicians and treatments, physical and social effects of the disease, and degree of asthma control (see Appendix I).

Study method

Face-to-face interviews were carried out by employees of an independent research service (Procon-GFK, Istanbul, Turkey) who had at least 2 years of experience and were monitored by field supervisors during the study. To ensure consistency of the data, the interviewers received specific training for the project and were briefed about asthma by two specialists. All interviews with children were conducted in

the presence of their parents, who supplied information (initial diagnosis, initial treatment) that the patient was unable to provide. Data from the patient were used in the event of an inconsistency with information supplied from the parent. Quality control, including on-site and telephone contacts, and editing procedures were applied on completion of the field work. Data were entered by the research service and evaluated by the study council.

Statistics

Results were expressed as the percentage of responses to each question. Simple random-sample methods were used to calculate 95% confidence intervals (95% CI). To determine the patient's age at the initial asthma diagnosis and the year of initial treatment, the time interval was subtracted from the patient's current age and a numerical value was assigned as follows: asthma for <1 year = 0; 1–3 years = 2; 4–6 years = 5; 7–9 years = 8; >10 years = 10. All analyses were performed using the spss 6.0 program.

Results

The study was conducted between March and May 1999 and involved 756 patients (384 children, 372 adolescents) from 11 cities in Turkey. All centers enrolled the expected number of patients except one (Erzurum in east Anatolia), which included only 39 patients because the criterion of 'diagnosis of asthma and/or allergic bronchitis' could not be met in 23 individuals. The exact response rate was not known but was estimated to be $>95\%$, as a number of interviewers did not record refusals. However, their personal declarations and available records suggested that it was $>95\%$, and thus similar to the response rates of the studies conducted previously (5). A greater proportion of children were male, and greater number of adolescents had recurrent wheezing (both $p<0.05$) (Table 1). Adolescents were significantly older at diagnosis (12.9 vs. 6.9) and at initial asthma treatment (13.3 vs. 7.1). Exclusion of patients who reported longer than 10 years of elapsed time between these two events did not change the results (data not shown). Percentages for regular follow-up (62.4% vs. 79.9%) and current asthma drug usage (70.7% vs. 81.0%) were significantly lower ($p<0.05$) among adolescents than among children.

Table 1. Characteristics of the study population

	Children	Adolescents	Total
Number	384	372	756
Female/male ratio	0.84	0.99*	0.92
Age†	10.60±0.1	17.5±0.1*	14.0±0.2
Age at asthma diagnosis†	6.90±0.2	12.9±0.2*	9.90±0.2
Age at initial asthma treatment†	7.10±0.2	13.3±0.2*	10.2±0.2
Receiving regular follow-up (%)‡	79.9 (78.1–81.7)	62.4* (60.9–63.9)	71.3
Current drug usage (%)‡	81.0 (79.2–82.6)	70.7* (69.1–72.3)	75.9
History of recurrent wheezing (%)‡	86.5 (84.7–88.3)	94.9* (93.0–96.8)	90.9
History of recurrent cough (%)‡	93.8 (91.9–95.7)	91.4 (89.5–93.3)	92.9
History of recurrent dyspnea (%)‡	89.8 (88.0–91.8)	88.2 (86.4–90.0)	89.3

*p<0.05 vs. children.

†Year±standard error of the mean (SEM).

‡95% confidence interval (CI) in parentheses.

Regular follow-up and current asthma drug usage

Of the 756 patients enrolled, 539 (71.3%) were receiving regular follow-up, and this group was significantly younger ($p<0.05$) than those followed-up intermittently (Table 2). Boys reported regular follow-up more often than girls; age at diagnosis and at initial treatment did not differ between the two sub-groups. Current drug users represented 75.9% of the enrolled population, comprised a greater number of boys than girls, and were slightly younger than patients who took no asthma medication within the past year (Table 3). Age at diagnosis and at initial asthma treatment was not significantly different between these sub-groups.

A decrease in symptoms (27.6%), financial problems (25.4%), and physician visits only for active disease (18.4%), were the most common reasons for lack of regular follow-up (results not shown). The most frequently cited reasons for not using asthma drugs within the past year were: a decrease in symptoms (33.5%); cure of the disease (25.8%); and no need for asthma drugs (18.4%) (results not shown). Responses were similar both in children and in adolescents.

Attitudes towards the physician and treatment

Patients recorded their attitudes toward physicians and treatment on a 5-point scale (always,

often, sometimes, rarely, never). ‘Always’ and ‘often’ were considered to represent a high level of agreement, ‘never’ and ‘rarely’ a high level of disagreement. Almost 75% of the total patient population reported a high level of agreement with each of the following statements: ‘My doctor does the best for my disease’; ‘I go whenever I am called for a visit’; and ‘I use my drugs as recommended’ (Fig. 1). The children’s scores were 10–20% higher than those of the adolescents. The statements ‘I have difficulties in using asthma drugs’ and ‘I use my drugs more frequently than recommended’ achieved high disagreement ratings from 50% of all patients. Between-group differences were not significant.

Drugs

Patients who reported taking asthma drugs were questioned about the identity of their medication. Of these patients, 7.8% could not remember the drug name. More than half used an inhaled preparation: almost 40% inhaled short-acting β_2 -agonists; and 36% any inhaled prophylactic (Table 4). The use of inhaled drugs was more common in adolescents than in children. Anti-histamines, antibiotics, and expectorants represented $\approx 2\%$, 8% , and 12% , respectively, of asthma drugs.

Table 2. Patients receiving regular and intermittent follow-up

	Regular follow-up	Intermittent follow-up
n	539	217
Age*	13.50±0.2	15.2±0.2†
Age at asthma diagnosis*	9.80±0.2	10.2±0.3
Age at initial treatment*	10.10±0.2	10.0±0.4
Female/male ratio	0.84	1.1

*Year±SEM.

†p<0.05.

Table 3. Usage of asthma medication

	Current use	No current use
n	574	182
Age*	13.7±0.2	14.9±0.3†
Age at asthma diagnosis*	10.0±0.2	9.6±0.3
Age at initial treatment*	10.2±0.2	10.0±0.4
Female/male ratio	0.86	1.1

*Year ± SEM.

†p<0.05.

Efficacy

Almost 70% of patients reported improvements in cough, dyspnea, nocturnal symptoms, and asthma exacerbations following treatment. The need for medication and exercise-induced symptoms decreased in nearly 40% of the patients. Global evaluation of efficacy was divided approximately evenly between those satisfied and those dissatisfied with treatment. No significant difference was noted between children and adolescents.

Physical and social effects of asthma

Patients indicated how often they encountered asthma-related physical and social problems on a 5-point scale (always, often, sometimes, rarely, never). Most children and adolescents experienced symptoms (always, often) on exposure to household dust (82.3% and 74.3%, respectively, $p<0.05$), passive smoking (78.6% and 55.8%, $p<0.05$), and intense odours (62% and 59.9%, $p>0.05$). Both groups reported exacerbations in winter (62% and 53.2%, $p<0.05$) and autumn (45.3% and 50.3%, $p>0.05$). Significantly more children than adolescents believed that their symptoms interfered with daily activities (37.3% and 18%, $p<0.05$) and exercise (45.5% and 27.4%, $p<0.05$); however, both groups reported that their parents placed limitations on their activities more frequently than they themselves did (77.3% and 57.5%, $p<0.05$).

Interestingly, children and adolescents complained relatively infrequently of the difficulty in using inhalers (11.2% and 10.5%, respectively),

inconveniencing their friends by using inhalers (10.1% and 12.1%), forgetting to take asthma drugs (10.2 and 7.3%), and cold as an asthma trigger (15.2% and 10.8%) (none of these differences were significant between the study groups).

Assessment of asthma control

At least 40% of children continue to have cough, dyspnea, and wheezing, and almost 60% experience exercise-induced symptoms more than once per week (Fig. 2). Adolescents reported less frequent symptoms, but almost 40% had nocturnal manifestations and ≈25% had wheezing and exercise-induced symptoms more than once per week (Fig. 3). Of the patients who experienced at least one symptom more than once per week, 65% were taking regular prophylactic medication. To some extent, asthma affected the daily life of 56.5% of children and 40.4% of adolescents (Fig. 4).

Discussion

This questionnaire-based survey – the first of its kind in Turkey – provides an updated description of the perception of asthma by that country's children and adolescents. Almost 50% reported a significant effect of the disease on their lives. A similar percentage experienced symptoms at least once a week, though only two-thirds of this group took any prophylactic medication. Nearly 50% of children and >25% of adolescents became symptomatic with exercise, whereas more than

Table 4. Current drug usage

Type of drug	Children (n=311) No. (%)	Adolescents (n=263) No. (%)	Total (n=574) No. (%)
Any inhaled anti-asthmatic	152 (48.9) (47.5–50.3)	143 (54.4)* (53.0–55.8)	295 (51.4)
Inhaled short-acting β_2 -agonist	108 (34.7) (33.5–35.9)	117 (44.5)* (43.2–45.8)	225 (39.2)
Inhaled long-acting β_2 -agonist	20 (6.4) (5.9–6.9)	18 (6.8) (6.3–7.3)	38 (6.6)
Inhaled prophylactic anti-asthmatic	122 (39.2) (38.0–40.4)	86 (32.7)* (31.6–33.8)	208 (36.2)
Any theophylline preparation	13 (4.2) (3.8–4.6)	15 (5.7)* (5.2–6.2)	28 (4.9)
Any oral β_2 -agonist	86 (27.4) (26.4–28.4)	45 (17.2)* (16.4–18.0)	151 (26.3)

*p<0.05.

95% confidence intervals (CIs) are shown in parentheses beneath each category.

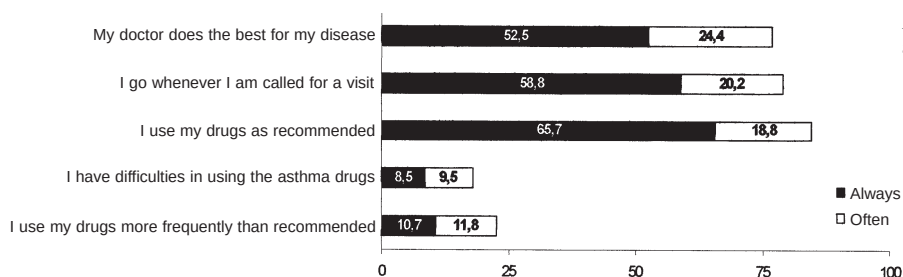


Fig. 1. Attitudes toward physicians and treatments.

60% reported parental limitations on their activities. In our study, the widespread impression that asthma remains a major health problem (1) was confirmed more strikingly among children than adolescents. Interestingly, our inability to find sufficient asthmatics in one of the 11 representative cities may reflect variations in medical practice, as no epidemiological study has documented major differences in symptom frequencies among various Turkish cities. Moreover, in a previous study (5), we obtained high rates, although rare occurrences, of infectious bronchitis among children. Therefore, it seems appropriate to postulate that in the city where an insufficient number of asthmatics were identified, many asthmatics are treated for the diagnosis of infectious bronchitis rather than for asthma. A definitive conclusion, however, must await further study of the perception of asthma by physicians, which is part of our ongoing investigation.

In our survey, adolescents differed from children in regard to reported rates of symptom frequencies and current asthma drug, and

frequency of use of inhaled drugs. Their lower reported rates of symptom frequencies and current asthma drug usage may reflect the well-known improvement in asthma symptoms with age (6). Similarly, their greater use of inhaled drugs may relate to the increased ability of older individuals to handle inhalers. Adolescents also were older at initial asthma diagnosis and initial treatment. These findings may indicate an impaired recall of past events as well as an increased awareness of asthma by physicians and the community. Adolescents appeared to have a high degree of trust in their physicians and treatments. As expected, the magnitude of trust was lower in adolescents than in children.

Of the 76% of patients who reported taking asthma drugs within the past year, only 50% were using an inhaled preparation, even though this type of medication was cited most frequently. Consumption of oral drugs, including bronchodilators, expectorants, antibiotics, and antihistamines, was high. More than 50% of the entire study population had symptoms

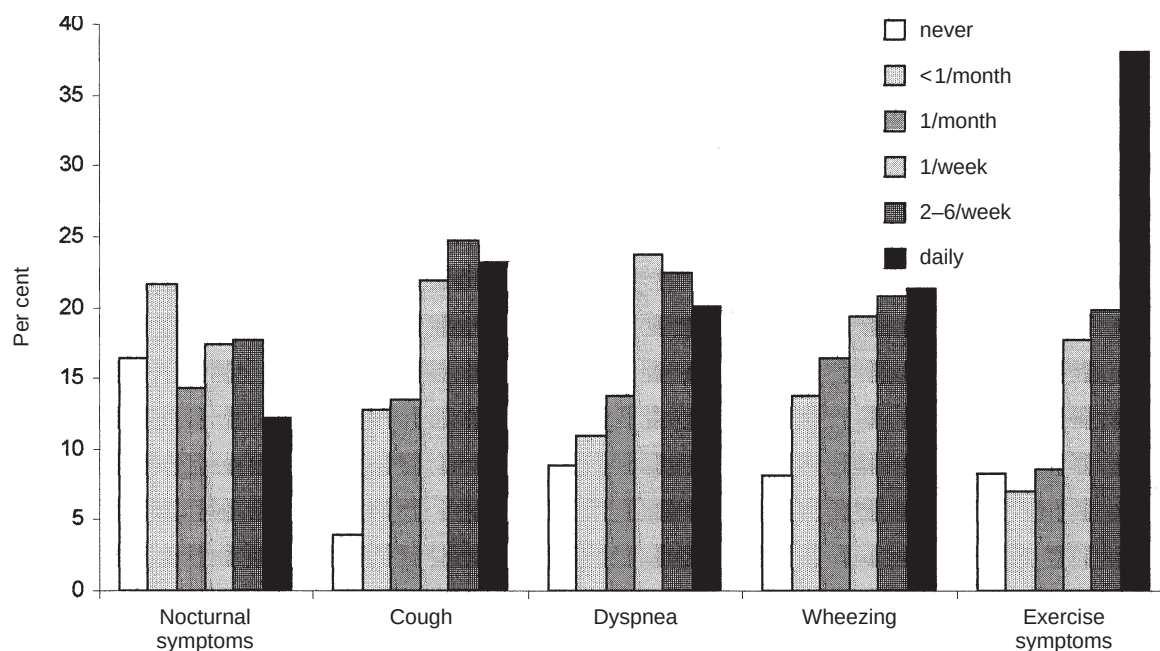


Fig. 2. Frequency of asthma-related symptoms in children.

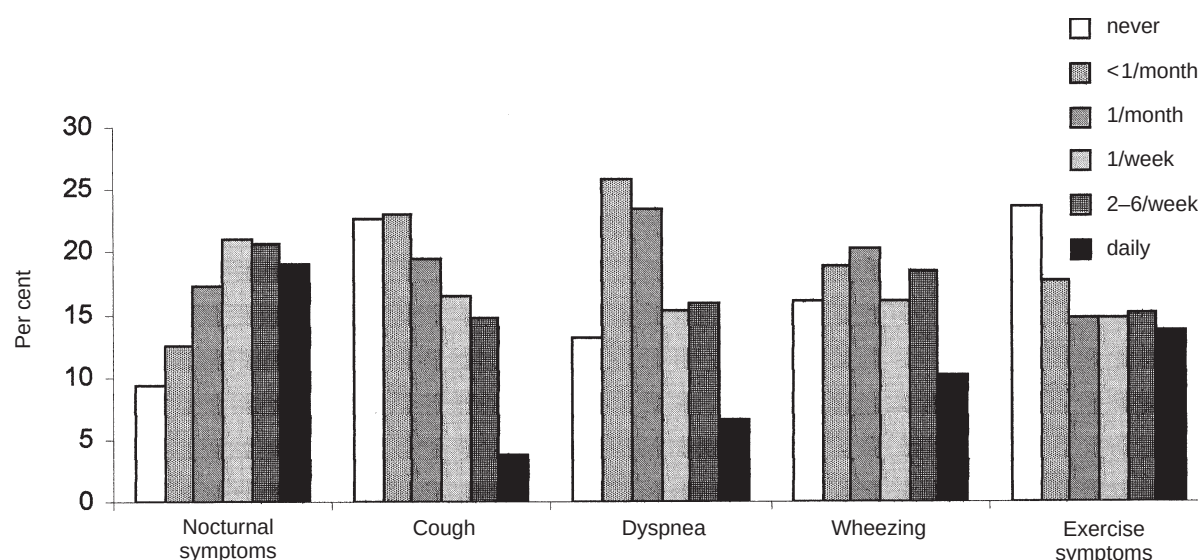


Fig. 3. Frequency of asthma-related symptoms in adolescents.

more than once per week, but only two-thirds were receiving any prophylactic treatment, as recommended by recent asthma guidelines. These figures clearly suggest frequent under-treatment and mistreatment of asthma.

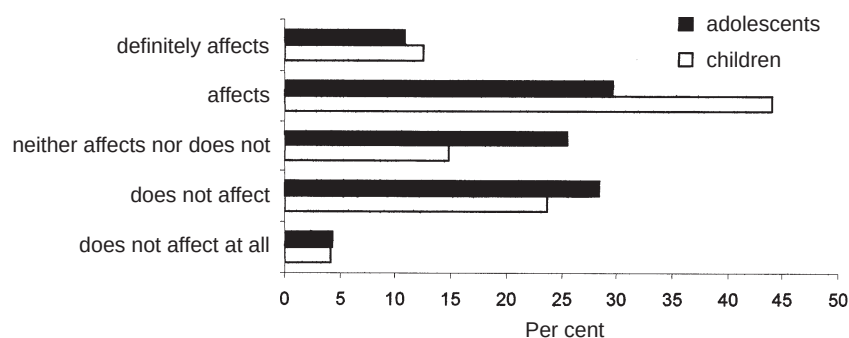
In keeping with the frequency of symptoms, almost 50% of our patients reported that asthma significantly affected their daily lives. Obtaining data from the records of hospitals, outpatient clinics, and pharmacies, however, may have resulted in the inclusion of patients with relatively severe disease. One-quarter of the total study group had not required treatment with any asthma drug during the previous year, and 50% of current drug users had symptoms less than once per week, suggesting mild disease in the majority of our patients.

Despite an increased understanding of asthma pathophysiology and the availability of many effective drugs, the frequency and severity of asthma symptoms persist in Turkey, as observed in other countries. Three factors

may explain why management of asthma often fails. First, patients are insufficiently compliant with treatments, as has been repeatedly demonstrated in studies of adults and children (7,8). Second, physicians do not follow recent guidelines because of a lack of sufficient knowledge or the impracticality of recommended treatment procedures. Third, patients and physicians may have different perceptions of asthma. This study clearly documents that asthma continues to be a major health problem, although it does not allow definitive conclusions to be reached about why that is so.

The limitations of self-reported data have been described previously and include over-estimation, probably resulting from a desire to please (9). Cultural factors may play a role, but 'being selective with the truth' is the same across countries. We believe that the high rate of compliance with treatment protocols and the low rate of difficulty in using inhaled drugs, reported by our patients, may have been affected by some degree of inaccuracy.

Fig. 4. Effect of asthma on daily life.



Conclusions

Our finding that asthma continues to be major health problem indicates an urgent need for further management programs in Turkey. Identically designed surveys conducted with relatives and physicians will illustrate differences between these groups in the perception of asthma and provide baseline information for projecting trends.

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Appendix 1

Key questions of the questionnaire

1. I will now read some statements to you concerning the drugs/treatments that your physician has given you. Please choose one of the replies written on the card.

1 – Never thought/done so 2 – Very rarely 3 – Sometimes 4 – Often 5 – Always N – Does not know

I believe my doctor does the best for my disease	
I go to my doctor whenever he calls me for a visit	
I use the drugs that my doctor has given me exactly as he told me	
I have some difficulties in using the drugs that my doctor has given me	
I have to use the drugs that my doctor has given me more frequently	

2. Looking at the card, will you please tell me how much 'asthma' affects your life
- 1-----5 N – Does not know
- Does not affect at all Definitely affects

3. Looking at the card, please tell me how much your asthma has been cured by means of the drugs that you were advised to use

1-----4 N – Does not know

Was not cured at all Was cured completely

4. Thinking of the period subsequent to starting to take asthma drugs, please answer the following sentences using one of the following expressions: 'decreased', 'increased' or 'the same'

Since I started using drugs...	Decreased	Increased	Same
Asthma attacks frequency			
Waking up at night			
Severity of my shortness of breath			
Ease of applying everyday work (walk, run, go to school/work)			
Cough			
Amount of drugs that I use			
Visits to doctor			

5. How frequently do you face the problems that I will be reading to you?
- 1 – Did never have anything like that 4 – Once a week N – Does not know
- 2 – Less than once a month 5 – 2–6 times a week
- 3 – Once a month 6 – Every day

I wake up at nights because of asthma	
I have dry cough	
I have difficulty in breathing because of asthma	
I have wheezing when I breathe	
I easily get tired because of asthma	

6. Looking at the card, please tell me how frequently you face the problems that I will be reading to you
- 1 – Never had anything like that 2 – Very rarely 3 – Sometimes 4 – Often 5 – Always

I cannot run or climb stairs because of my asthma	
I cannot play game easily like my other friends because of my asthma	
Pets like cats, dogs and birds increase my asthma problems	
My asthma problems increase in the autumn	
I have shortness of breath when people around me smoke	
I have shortness of breath because of sharp odours like paint/oily paint/pesticides	
My asthma problems increase in the winter	
My problems increase in dusty places	
The common cold increases my asthma complaints	
I have difficulty in using puffs/air	
Using puffs/air in front of others bothers me	
I forget to use my drugs	
My family does not want me to get tired	
My family does not want me to go out too much	
I/we have difficulties in buying the drugs that the doctor has prescribed	
I think there are no drugs to cure my problems	