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Parental perception and ideas about the childhood asthma

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Abstract

English:

Bronchial asthma is defined as a chronic inflammatory process of the airway that causes a simultaneous increase in airway hyperactivity that leads to recurrent attacks of noisy breathing, breathlessness, chest tightness and coughing, particularly at night or in the early morning. The survey aims to study parents', ideas and perceptions about their children's asthma. This study was conducted by direct interviewing of 150 parents of asthmatic children with a cross-sectional study on asthmatic children aged 1–14 years who were attending outpatient departments, hospital wards and private clinics from the 1 September 2019 to 1 July 2020 at Basrah city, Iraq. The questionnaire included a review of parents,' beliefs on the aetiology, naming and trigger factors of their children's asthma. Another part of the questions was regarding the usage of long-term asthma medications and phobia regarding their side effects. Findings from this study revealed that most parents could not identify asthma by its name because only 39 (26%) of them named the disease as asthma; 94 (62.7%) parents called the disease allergic bronchitis. The aetiology of childhood asthma was considered to be hereditary by most parents, i.e. 108 (72%), and the main trigger factor mentioned by parents for acute exacerbation of asthma was respiratory tract infections [115 (76.7%)]. Only 47% of the patients were using long-term asthma medications, with parents, concern on drug safety was specified by 48 (31.9%) of them as phobia regarding drug addiction [20 (13.3%)], phobia regarding palpitation by 13 (8.6%), and remaining 15 (10%) had phobia regarding growth failure effect from steroids. Most of the parents had misperceptions and inadequate information about the pathogenesis and the aetiology of childhood asthma. There were a significant number of parents who had a concern about childhood asthma drug safety.

Keywords

childhood asthma • parental perception and drug phobia • allergic bronchitis

Percepția părinților și ideile despre astmul copilăriei

Rezumat

Romanian:

Astmul bronșic este definit ca un proces inflamator cronic al căilor respiratorii care determină o creștere simultană a hiperactivității căilor respiratorii care duce la atacuri recurente de respirație zgomotoasă, dispnee, senzație de apăsare în piept și tuse în special noaptea sau dimineața devreme. Scopul sondajului este de a studia părinții, ideile și percepțiile acestora despre astmul copiilor. Acest studiu a fost realizat prin interviu direct cu 150 de părinți ai unui copil astmatic, printr-un studiu transversal pe copii astmatici cu vârste cuprinse între 1–14 ani, care frecventau ambulatoriu, secții spitalicești și clinici private de la 1 septembrie 2019 până la 1 iulie 2020 în orașul Basrah, Irak. Chestionarul a inclus o revizuire a credintelor parintilor asupra etiologiei, denumirea și factorii declanșatori ai astmului copiilor lor. O altă parte a întrebărilor a fost cu privire la utilizarea de medicamente pe termen lung pentru astm și fobia de efectele lor secundare. Rezultatele acestui studiu au arătat că majoritatea părinților nu identificau astmul după numele său, deoarece doar 39 (26%) dintre ei au numit boala ca astm, altfel 94 (62.7%) dintre părinți au numit boala bronșită alergică. Etiologia astmului bronșic din copilărie a fost considerata ereditara de majoritatea părinților 108 (72%), iar principalul factor declanșator menționat de părinți pentru exacerbarea acută a astmului bronșic au fost infecțiile căilor respiratorii la 115 (76.7%). Doar 47% dintre pacienți foloseau pe termen lung medicamente pentru astmul bronșic iar preocuparea părinților privind siguranța medicamentelor a fost specificată de 48 dintre aceștia (31,9%) fiind reprezentată de fobie față de dependența de medicamente [20 (13,3%)], fobie cu privire la palpitații (13 cazuri - 8,6%), iar restul de 15 (10%) au avut fobie privind deficiența de creștere datorată corticosteroizilor. Majoritatea părinților au avut percepții greșite și informații inadecvate cu privire la patogeneza și etiologia astmului bronșic din copilărie. Există un număr semnificativ de părinți care au avut o îngrijorare cu privire la siguranța medicamentelor pentru astm bronșic din copilărie.

Cuvinte-cheie

astm bronșic din copilărie • fobie la droguri percepția părinților • bronșită alergică

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Introduction

Bronchial asthma is defined as a chronic inflammatory process of the airway. The chronic inflammation causes a simultaneous increase in airway hyperactivity, which leads to recurrent attacks of noisy breathing, breathlessness, chest tightness and coughing, particularly at night or in the early morning. In Lebanon and other Middle East countries, the term bronchial allergy or recurrent dyspnoea is often used (1). Children with asthma depend on their parents/caregivers for their disease control. The level of education of caregivers has a great role in disease control (2). Asthma is labelled as the third important cause of hospital admission among children under the age of 15 years and a significant cause of lack of school attendance (3). A recent study showed that parents who give their children asthma medications regularly, visit the doctor regularly and do not use herbal medications have more information compared with others. In another study in the USA, 115 parents of children gave education about asthma, and a follow-up survey 6 months later showed significant improvement in their knowledge regarding asthma (3). In several countries, previous studies have shown that the majority of parents of asthmatic children do not have adequate levels of knowledge about asthma, even though these are fundamental for disease management. In Brazil, the results are the same, representing one of the causes of inadequate disease control (4). Psychopathology, family dysfunction and medication non-compliance have been associated with greater risk of severe, poorly controlled asthma (5). Difficulties with inhalation are more likely to be happen in children than in adults, and even if children can follow the appropriate technique in the clinic, they often have difficulty using inhalers properly outside of the clinic because they forget the information or try a different technique (6). All previous studies have shown a link between beliefs and clinical and behavioural outcomes in asthma (7). Evidence also indicates that 75% of hospital admissions for children with asthma could have been prevented with better primary care (8).

Educating families about controller asthma drugs and proper use is very important since focussed education can help caregivers to adhere to a preventive treatment protocol, and enhanced self-management skills in asthma are known to improve clinical outcomes (9).

A study documents the associations between family asthma management and biological processes implicated in asthma and it offers a unique focus on youth. We found that better ratings of asthma management beliefs and behaviours, in terms of greater conceptual understanding of asthma among children, belief in quicker responsiveness to symptoms among parents and better integration of asthma into daily life were all associated with decreased inflammatory profiles in children, as indicated by the reduced production of asthma-relevant cytokines, eosinophil counts and immunoglobulin E (IgE) levels (7).

Methods

A cross-sectional study was conducted on the parents of asthmatic children on the knowledge and perception about childhood asthma. The study involved children with asthma aged 1–14 years; 150 parents of asthmatic children were included; the patients were from the outpatient department, private clinic, emergency units, as well as hospitalized patients. The patients were complaining of asthma or recurrent cough and wheeze unexplained by other respiratory problems.

Parents or caregivers were interviewed regarding the age and sex of the patients, their residence (urban or rural), the aetiology and duration of the disease, the naming of the disease and their thoughts about the trigger factors of the acute exacerbation of their children's asthma. Father's educational attainment, mother's educational attainment and the family's social level were also determined. We also inquired about the presence of smokers in the family and any use of herbal medications. Parents' belief regarding the cause of disease – whether it is genetic, contagious or caused by smoking, air pollution, allergy and food allergy – was also studied. The following questions were investigated: what is name of the disease: asthma, allergic bronchitis or an unknown inflammation? What is the catalyst for the condition: inflammation, pollution, exercise or smoking. Another part of the interview involved the use of asthma medications, the phobia regarding the usage of drugs (addiction, palpitation and growth failure), usage of controller medications and their effects; can parents treat an asthma attack at home; what are the side effects of the drugs; is there fear of using inhaled medications and cortisol compounds, inhalation and its effect on decreased growth, and obesity. Other aspects that were investigated included the following: Are you afraid of using the sprayer? Do you use control medications? How many types are better? What is the number of emergency hospital admissions? What is the rate of visits to the doctor each month? Is there a change after the treatment (simple, good or no change)? Which mode is preferable for use (oral treatment, inhalation or spray)? Have you received asthma instructions? The further interview was about the

sources of parents', information about childhood asthma: whether it was from the paediatrician, general practitioner, pharmacist, medical staff or others. The study also asked parents on their belief regarding disease outcome (cure, persistence over adult life or unknown) and the type of treatment used, whether one or more than one: Beta-agonist inhaled steroid; theophylline long acting; Beta-agonist antihistamine; antihistamine leukotriene; and antagonist oral Beta-agonist (Appendix).

Data were analysed using Statistical Package for the Social Sciences (SPSS) programme for statistical analysis (version 24; SPSS Inc., Chicago, IL, USA). Quantitative results were documented as mean ± standard deviation (SD). Qualitative results were documented as frequency and percentage. Chi-square (χ^2)-test was used for comparison between two variables. A value of $P < 0.05$ was considered statistically significant.

Results

Table 1 shows the patients' characteristics. The sex of the patients was about 100 males (66.6%) to 50 female patients (33.3%) with a male:female ratio of 1.5:1. The residence of the patients was urban for 125 (83.3%) and rural for 25 (16.7%). The presence of passive smoking exposure was found in 90 (60%) children. The distribution of patients' age category was as follows: 75 (50%) were from 1 to 4 years of age , 70 (46.7%) were from 5 to 10 years of age, and only five patients (3.3%) were older than 10 years , as shown in Figure 1.

Table 2 shows the data about parent's belief for childhood asthma. Regarding the aetiology of childhood asthma, 108 (72%) parents thought that the cause is hereditary. On the other hand, the belief that allergy was a cause was reported by 33 (22%) parents, and four (2.7%) parents considered

Table 1. Patient characteristics.

Variable		No.	%
Sex	Male	100	66.7
	Female	50	33.3
Presence of passive smoking	Yes	90	60
	No	60	40
Patient's residence	Urban	125	83.3
	Rural	25	16.7
Education level of parents or caregiver	Illiterate	7	4.6
	Primary school	49	32.6
	Secondary school	66	44
	University	28	18.7
Age category	1–4 years	75	50
	5–10 years	70	46.7
	>10 years	5	3.3

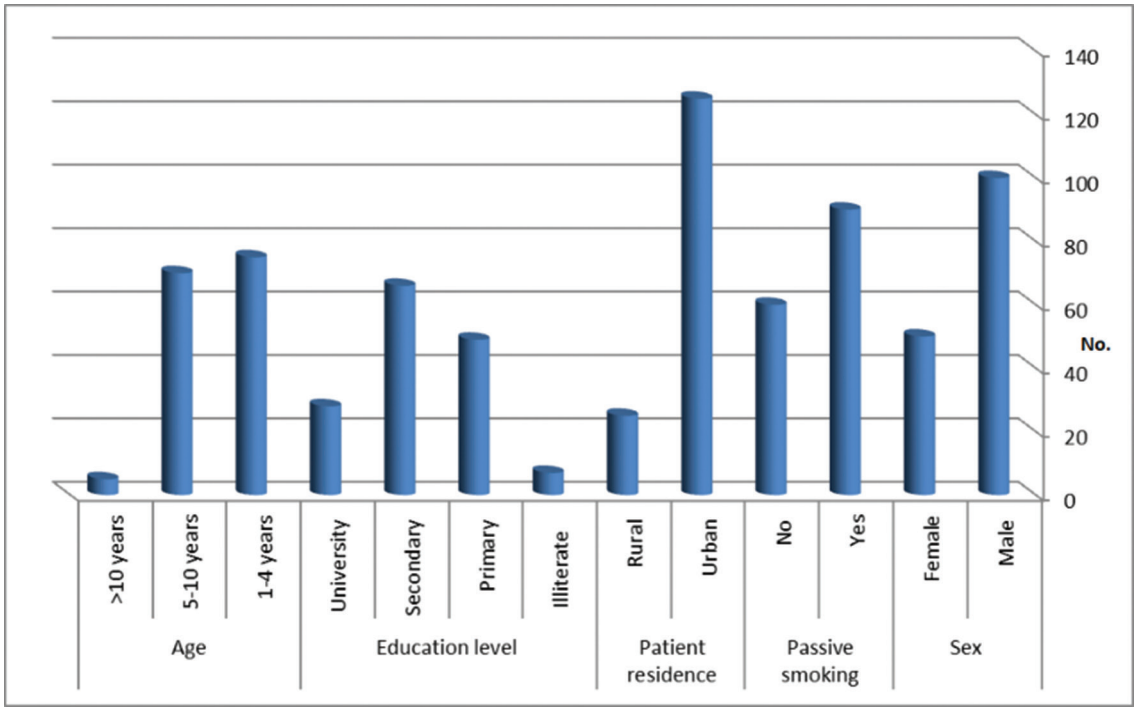


Figure 1. Patient characteristics.

the disease as contagious or infectious. Only 39 (26%) parents identified asthma by its name; otherwise, the majority (94; 62%) of parents named the disease as allergic bronchitis.

Table 2. Parents' belief in the aetiology, trigger factors, naming of the disease and prognosis.

Patient thought	Variable	No.	%
Aetiology of asthma	Hereditary	108	72
	Allergy	33	22
	Infection	4	2.6
	Air pollution	4	2.6
	Unknown	1	0.7
The naming of the disease	Bronchial asthma	39	26
	Allergic bronchitis	94	62.7
	Infection	9	6
	Unknown	8	5.3
Trigger factor	Infection	115	76.7
	Air pollution	18	12
	Exercise	6	4
	Smoking	1	0.7
	Others	10	6.7
Prognosis	Cure	49	32.7
	Continue for adult life	17	11.3
	Unknown	84	56

Another name was infection, reported by nine parents (6%). The trigger factors reported were variable between the families, as follows: respiratory tract infections were the major trigger factor for acute asthmatic exacerbation in 115 (76.7%), followed by air pollution in 18 (12%) of patients. Family idea about the prognosis of childhood asthma revealed the following results: cure of the disease reported by 49 (32.9%) parents, progress of disease to adult life was mentioned by 17 (11.4%) parents and 83 (55.7%) parents replied "unknown" when asked about the fate of the disease, as shown in Figure 2.

Table 3 illustrates the usage of long-term asthma medications, phobia regarding the drugs' side effects and parents' ability to treat acute attack at home. In this study, 79 (52.7%) patients were not using long-term asthma control medications; 27 (18%) asthmatic children were using leukotriene-modifying agents. The usage of mast cell stabiliser drugs was found in 20 (13.3%), while usage of inhaled steroid was only reported by eight (5.3%) parents. Parents of the asthmatic child were concerned about asthma drug safety; the results illustrate that 20 (13.3%) parents had phobia regarding addiction to asthma drugs. Another 15 (10%) were afraid of growth failure due to steroid use. Another group of 13 (8.6%) caregivers had understood the occurrence of palpitation. The sources of information for parents were paediatric specialists in 79 (52.7%)

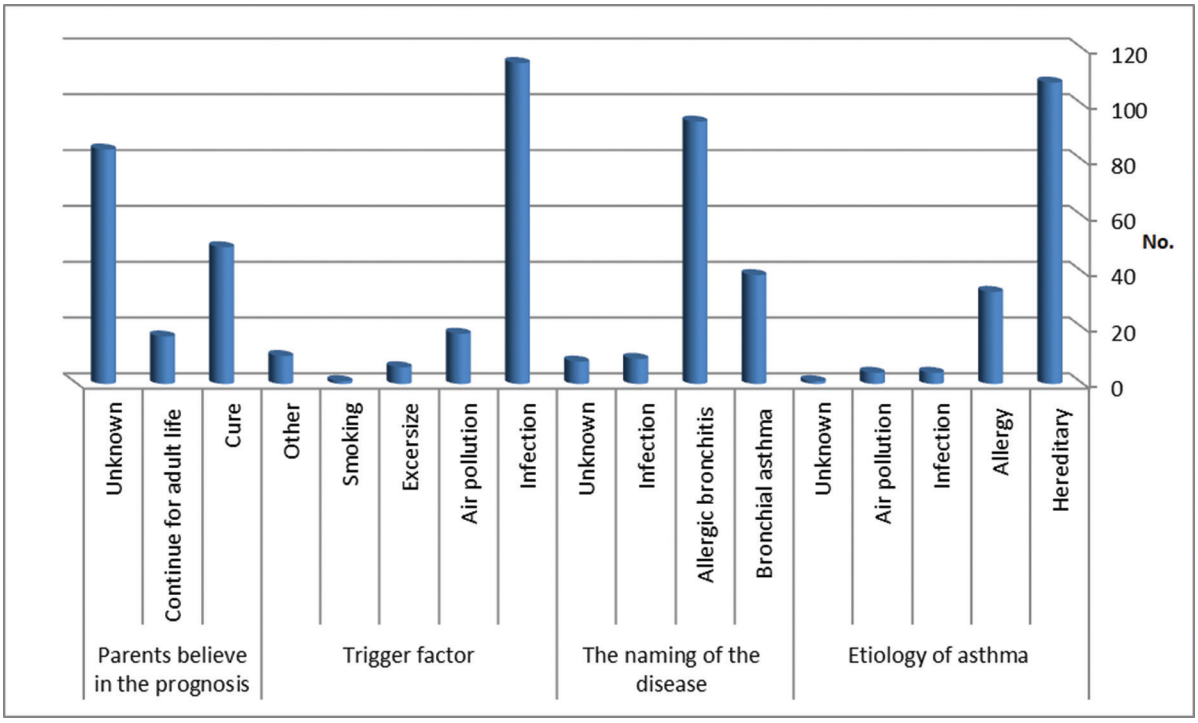


Figure 2. Parents' beliefs about asthma.

Table 3. Usage of long-term drugs in asthma and parent beliefs about their side effects.

Beliefs		No.	%
Type of drug	No usage of the drug	79	52.7
	Mast cell stabiliser	20	13.3
	Leukotriene-modifying agent	27	18
	Inhaled steroid	8	5.3
	Beta-agonist on need	12	8.7
	Antihistamine	4	2.7
No side effect		100	66.6
Fear regarding side effects of medications	Palpitation	13	8.6
	Fear regarding growth failure due to steroid use	15	10
	Addiction	20	13.3
	Other	2	1.3
Sources of information	Paediatric specialist	79	52.7
	General practitioner	35	23.3
	Medical staff	3	2
	Non-medical people	13	8
	Not receive information	19	12.7
Can treat acute attack at home	Yes	38	25.3
	No	112	74.7
Use of herbals	Yes	10	6.6
	No	140	94.4
Need hospital admission	Yes	68	45.3
	No	82	54.6

cases, whereas 19 (12.7%) parents had not received any information, as shown in Figure 3.

Discussion

Although there was a high percentage of parents who had received information from a paediatric specialist, many parents had a lot of misperception regarding asthma pathogenesis, aetiology and its treatment. This may be related to parents' belief about the disease, or there is a shortage of information given to parents by paediatricians. A large proportion of the interviewed parents could not identify asthma by its name but refereed to it as chest allergy or allergic bronchitis; the reason for this might be related to social stigma. Nevertheless, the name asthma was used much by the parents of old children with asthma. The majority of parents (108; 72%) referred to the aetiology of childhood asthma as being due to hereditary factors; this perception may be related to the occurrence of the diseases in other family members or a vary-early onset of occurrence of the disease in other patients, compared with previous studies on this perception with similar findings, as in the study conducted in Lebanon, which showed only 21% of parents identifying asthma by its name and hereditary cause as the aetiology of childhood asthma being reported by 54.2% of them (1). Up to 37% of the caregivers thought that asthma can spread from person to person. This stigma of asthma being communicable may put a considerable amount

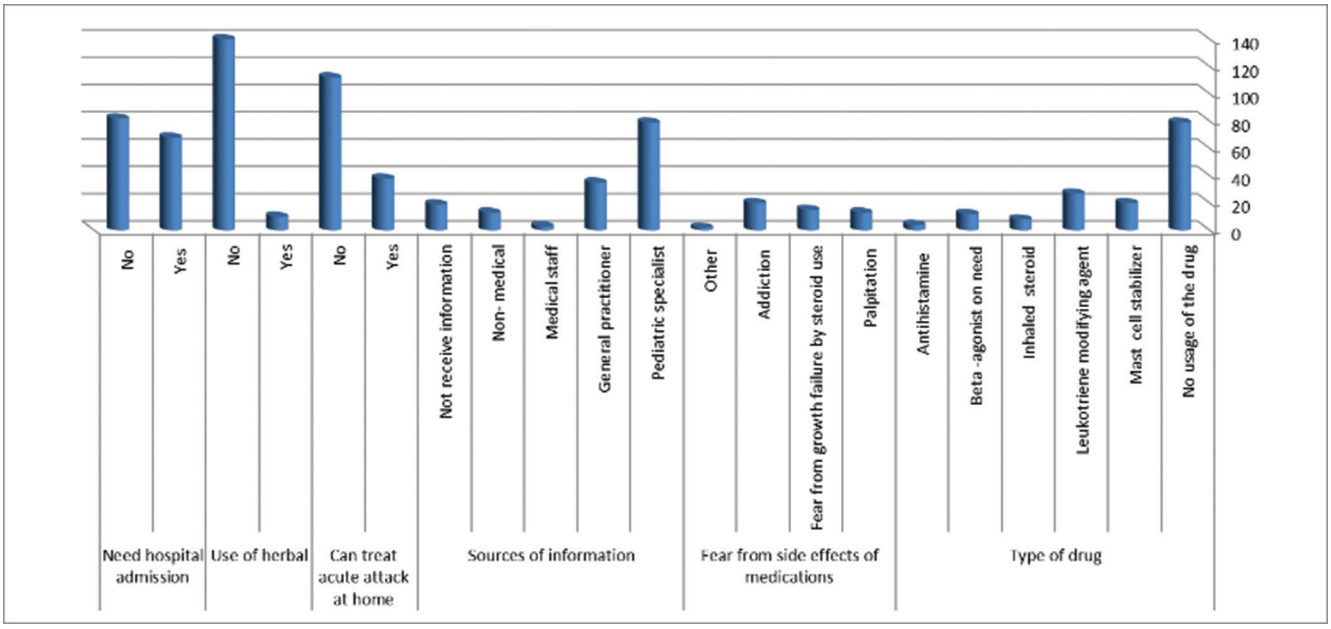


Figure 3. Usage of long-term drugs in asthma and parent beliefs about their side effects.

of social and psychological strain on the growing child, who may develop low self-esteem. Very few parents thought that heredity has anything to do with asthma; where most of the schoolteachers thought that asthma was an acquired illness. In a study from Malaysia, most of the parents were concerned about the side effects of inhaled medication, in addition to the fear of inhaler dependency (10). In this study, regarding the beliefs on the effects of the drug; a significant number of parents were concerned about the safety of childhood asthma drugs, whereby 20 (13.3%) had phobia regarding drug addiction, 13 (8.6%) had phobia regarding palpitation and 15 (10%) showed concern regarding growth failure effect of steroids. Similar results were reported by other studies, as in the study from Lebanon, which showed that the worry in parents regarding inhaled steroids causing addiction was 66.2% and worry regarding side effects of inhaled steroids in general was about 95.4% (1). Another study conducted in Egypt had reported >53% had fear of steroids' side effects, but only 1% of parents had phobia regarding growth retardation by steroids, while 9% feared addiction (11).

A study in Saudi Arabia found that the majority of participants were concerned about the side effects of inhaled steroids, and 32% of them were concerned about dependency on asthma medications. This concern was significantly more marked among less-educated parents (3).

Despite the unquestionable benefits of steroids for decreasing asthma mortality and morbidity, therapy adherence to steroids as asthma controller drugs is still poor. In a study, 24.8% (n = 124) of caregivers either made some change in their treatment regimen or stopped using the drugs due to corticosteroid phobia; medication taking in general was found to be related to parents', perception and concerns for their perceived disease severity and perceived treatment (12). In contrast with the common thought among caregivers, parental knowledge of the asthmatic child is hardly correlated with adherence or socio-demographic factors; asthma severity is of little effect in adherence to asthma medications (13). A significant familial aggregation of asthma and allergic diseases has been established. Parental asthma has been shown, in many studies, to be an important predictor of asthma in the child, as in a community-based sample of 770 children 5–9 years of age from East Boston (14).

In this study, the results revealed that only 10 (6.6%) parents used herbal treatment for childhood asthma. In another study done in San Francisco, California, they found that one in nine parents with a child with asthma reported complementary and alternative medicine (CAM) usage within the past year; the one factor that is associated with CAM use is the parent perception of control of asthma symptoms. If parents perceived that their child's asthma control is poor and the child already was taking daily asthma medications, the likelihood of CAM use for asthma is significantly increased (15). A review shows the difficulties that parents and caregivers face when dealing with a child who has asthma; attaining a definitive diagnosis of asthma can be challenging and they express uncertainty and fear due to continuing symptoms and recurrent hospitalisations. Healthcare professionals should give them a clear diagnostic strategy and treatment plan. Asthma education is very important at the onset of asthma symptoms and with the provision of accurate, easy to understand and culturally relevant information (16). However, in balancing parents' assistance in the control of the disease with children's autonomy, Western parents wish that their children and adolescents with asthma can be out of dependency on their parent's supervision. Studies show differences between Asian and Western cultures; some Asian parents feel that young children are unable to learn these guidelines and tend to protect their children more until they are at least 10 years of age (17). While inhalers have been shown to have good effects on asthma management and are advocated for by national and international guidelines, most parents perceive syrups to be better despite having good basic information on asthma. Therefore, we need to address asthma perceptions among parents/caretakers to improve control (18). The reasons why the 19 patients did not receive information are social factors, nature of Iraqi poeple, environmental causes and unusual thoughts about asthma.

Conclusions

There is clear misconception among the parents of asthmatic children regarding the aetiology, trigger factors and pathogenesis of the disease; moreover, parents had many concerns about the safety of medications used for the treatment of childhood asthma; so further information and adequate education are required to be given for those parents or caregivers to help them in dealing with their children's problems adequately.

Limitations of the study

The following are the limitations of the study:

1. Small number of patients;
2. Lack of a paediatric psychologist in the team;
3. Non-randomisation; and
4. Missing information due to social thoughts about asthma.

Patient consent

Written informed consent was obtained from the patients for publication of this case series. A copy of the written consent is available for review on request.

Conflict of interest statement

The author does not have any potential conflict of interest to disclose.

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Appendix

Patient's name:
Age:
Sex:
Residence:
Duration of illness:
Father's educational attainment:
Mother's educational attainment:
Family's social level:
Is there a smoker in the family?
Parents' belief that the cause is
Genetic: Contagious: Smoking: Air pollution: Allergy: Food allergy
The name of the disease is?
Asthma Allergic bronchitis An unknown inflammation
The catalyst for the condition: what is it?
Inflammation Pollution Exercise Smoking
Using herbs: No Yes
Has the situation improved:
Can parents treat an asthma attack at home Yes No
Negative effects of drugs?
Fear of using inhaled medications
Fear of cortisol compounds and inhalation and its effect on decreased growth
Obesity
Others
Are you afraid of using the sprayer?
Do you use control medications? No Yes
How many types are better?
Is there a change after using the treatment?
Simple Good No change
What is preferable to use?
Oral treatment Inhalation Spray
Have you received asthma instructions? Yes No
What is the source?
Doctor Specialist Health centre Pharmacist assistant Pharmacist
Nurse Non-medical source
The number of emergency hospital admissions?
The rate of visits to the doctor each month?
What is the belief of the parents in the future of asthma:
a cure…… persistence until old age……..not known?
The type of treatment used: one or more than one
Beta-agonist inhaled steroid
Theophylline long acting
Beta-agonist antihistamine
Antihistamine leukotriene
Antagonist oral Beta-agonist