



Contents lists available at ScienceDirect

Paediatric Respiratory Reviews



Review

What do patients want from their asthma care doctors?

Bruce K. Rubin^{a,*}, Wei Zhao^a, Tonya A. Winders^b^a Children's Hospital of Richmond at Virginia Commonwealth University School of Medicine, United States^b Allergy & Asthma Network, Vienna, VA 22182, United States

Educational aims

The reader will come to appreciate:

- The discrepancy between Physicians' perceptions of what's best for patients and what patients perceive that they need.
- That patient adherence to asthma treatment plans is often based on their understating and beliefs around the value and risks of therapy.
- That better understanding patient's perspectives and active engagement with the patient in developing treatment plans may improve adherence and asthma outcomes.

ARTICLE INFO

Keywords:

Adherence

Inhaled corticosteroids

Pediatric asthma

Action plans

Survey

ABSTRACT

One of the most important causes of asthma morbidity, hospital admissions, and death is non-adherence to prescribed therapy. It is generally assumed that adherence rates can be increased with asthma education, although well conducted studies have not always supported this assumption. Education can be achieved, or can fail, in many ways and no two patients have the same needs or perceived needs. In order to better understand what children with asthma and their parents or caregivers would desire as support from their physician providers, we conducted a survey of nearly 1000 parents of asthmatic children affiliated with the Asthma and Allergy Network. Most of those who responded wanted convenient access to their doctor, more time spent in office visits with greater attention paid to the patient, help in navigating insurance and prescription costs and paperwork, and a partnership in developing care plans. Although most patients were well insured for medical coverage (not a given in the USA), half were dissatisfied with their self-reported asthma control, many were concerned about medication side effects, 60% were not cared for by an asthma specialist, and nearly half did not have an asthma action plan. These results are consistent with data from other published studies and suggest that we still can do much more to meet the needs of children for whom we provide asthma care.

© 2017 Elsevier Ltd. All rights reserved.

Introduction

In general, physicians and care providers want what is best for their patients; or what they believe to be best. We can be patronizing in our belief that if we prescribe the right therapy, and we can inspire patients to take the therapy as prescribed with the belief that they will do well. However, a wealth of data suggest that prescribing appropriate therapy and providing asthma education is

not enough for many patients. To understand how to improve the patient physician relationship and adherence to therapy, we need to understand what patients want from their doctors. To gain a better understanding of these needs, we conducted a survey of the members of the Asthma and Allergy Network in 2015 and 2016

Methods

The Asthma and Allergy Network (formerly called Mothers Against Asthma) has conducted an annual members' survey for the past 30 years. In 2015, it was decided to include 13 questions specific to the topic of what parents and patients want from their asthma care provider. These questions were piloted with a small

* Corresponding author at: Dept. of Pediatrics, Virginia Commonwealth University School of Medicine, Children's Hospital of Richmond at VCU, 1000 East Broad St, Richmond, VA 23298, United States.

E-mail address: bruce.rubin@vcuhealth.org (B.K. Rubin).

group of parents of asthmatics before they were administered by magazine and e-newsletter.

From November 2015 until March 2016, the survey was made available in the United States and Canada to members of the network and access to the survey was free for those who were not members. Approximately 2 million readers were invited to participate the survey and an additional 70,000 readers of the e-newsletter were invited to take the survey. Of this number, there were 997 responders of which 980 completed the survey in its entirety. There was no follow-up with participants for incomplete surveys nor were there objective assessment of response accuracy. All survey responses were self-reported. Demographics of respondents are shown in Table 1.

Results

Questions specific to asthma care included patient self-assessment of asthma severity, whether patients/parents had an asthma action plan, whether they had insurance coverage, whether asthma education was provided by their asthma physician, and the specialty of their primary asthma physician. These data are summarized in Table 2.

Close to half of the patients or caregivers (48%) surveyed considered themselves as having mild asthma. The number may include patients who truly have mild-intermittent asthma and

Table 1
Demographics.

<i>Age</i>	
0–12 years	15%
13–17 years	5%
18–29 years	10%
30–49 years	23%
50+ years	47%
<i>Race</i>	
Caucasian	81%
African American	15%
Other	4%
<i>Sex</i>	
Female	62%
Male	38%
<i>Highest level of education attained</i>	
High school or less	32%
Associates or trade	17%
Bachelors	31%
Masters or higher	20%

Table 2
Asthma questions.

<i>Asthma severity (patient self-assessment)</i>	
Mild	48%
Moderate	41%
Severe	11%
<i>Do you have an asthma action plan</i>	
Yes	55%
No	45%
<i>Insurance coverage</i>	
96% have coverage	
Private	77%
Government	23%
<i>Who is your primary asthma doctor?</i>	
Family doctor/Pediatrician	60%
Allergist	36%
Pulmonologist	4%
<i>Is asthma education discussed with your provider</i>	
Yes	47%
No	53%

Table 3

What patients want most from their asthma doctor.

<i>What do you want most from your asthma doctor (summary)</i>	
Access	Convenient location and office hours, more time per visit
Authenticity	Eye contact, empathy, thorough and competent in work
Shared decision making	Partnership, more listening and interaction from physician
Patient-friendly education	Support services, prescription assistance
<i>What are the most common barriers to asthma care?</i>	
Financial	38%
Side effect concerns	36%
Time concerns	30%
Lack of knowledge	29%
Overwhelmed	25%
Denial re disease	11%
<i>Overall, are you satisfied with your asthma doctor?</i>	
Yes	88%
No	12%

those who consider that asthma is under good control with or without symptoms. Forty-one percent classified themselves as moderate asthma and 11% with severe asthma, reflecting that over half of the responders were dissatisfied with their asthma control, with the effect of asthma on their life, or both. Of note, 45% of the patients reported having no asthma action plan. Most (96%) reported having either commercial (77%) or government (23%) insurance. Not surprisingly, most (60%) were cared for by their primary doctors (family doctor or pediatrician). Over a third of the patients received asthma care from allergists (36%) while few (4%) have their asthma managed by pulmonologists. Just over half of the patients (53%) reported that asthma education was not discussed with their provider.

As well, there were three questions specific to patient/parent expectations of their asthma care provider. These questions are summarized in Table 3 under the categories of what you want most from your asthma doctor, what are the greatest barriers to asthma care, and are you satisfied with your asthma physician. Those completing the survey could enter more than one response to these questions. They were also asked to elaborate providing additional information, if desired.

Responders often expressed a desire to have easier access to their asthma care such as in a convenient location and better office hours and they wanted providers to spend more time during the visit; paying closer attention to patients and showing that they are doing careful and competent assessment. Patients also want to be recognized as partners in asthma treatment decisions. Responders also asked for more support services and prescription assistance from their providers. Overall, most (88%) were satisfied with the care their doctors provide.

When patients were asked about barriers to asthma care, the most frequently mentioned barrier is the financial burden (38%). This may include direct costs of medical care and medications, as well as indirect costs associated with loss of work days and cost of housing modifications. Thirty-six percent of responders were concerned about potential side effects of medication and 30% think they don't have the time to take care of their asthma. A further 29% of them expressed the lack of knowledge of asthma and 25% felt overwhelmed. A few responders (11%) questioned their asthma diagnosis.

Discussion

In the past decade, we have seen major changes in how health-care is delivered, as well as how patients and their parents view

healthcare providers. With internet access and physician rating systems, patients are increasingly researching costs and benefits for health insurance plans to help them find a provider who best fits their perceived needs. In this new era of consumer-focused healthcare, it is imperative to understand what patients want most from their doctors.

In the current study, financial burden has been identified as the top barrier in achieving effective asthma care (38%), even though most of the patients (96%) had some form of private or government health insurance. This is consistent with the recognition that rising costs of healthcare are a concern for many patients and providers in the United States. The escalated cost of asthma care is, at least in part, due to the suboptimal control of asthma. Barnes analyzed 9 asthma cost studies from around the world and concluded that at least one third of direct costs of asthma and three quarters of total costs resulted from poorly or uncontrolled disease status [1]. Furthermore, 60% or more of hospital admissions for asthma are due to non-adherence to therapy. Common barriers to care in the asthma patients surveyed here, included lack of asthma knowledge such as understanding symptoms or following a basic treatment plan (29%), concern over a medication's side effects (36%) or feeling overwhelmed at managing the disease (25%).

Adherence to asthma control medication is also associated with low readmission rate due to asthma. In a study of 31,658 children admitted to hospital for asthma, the risk factors for hospital readmission were evaluated based on the filling of their discharge prescriptions within 3 days of discharge. While 55% filled their prescription for the short acting beta-agonist, only 37% filled the ICS prescription. The long term (90 days after discharge) risk for rehospitalization was decreased when ICS was filled, but not for the short-acting beta agonist [2].

Increasing data suggest that asthma control can be improved by better understanding patients' perspective as this could reinforce behaviors to improve adherence to medication and to ultimately achieve asthma control. Horne and Weinman who conducted a study of adherence to the use of inhaled corticosteroids (ICS) in community managed asthma patients demonstrated, that for many patients, the principle that asthma as a chronic medical condition requiring daily preventive treatment was inconsistent with the patient's perception that asthma is an episodic condition requiring only symptomatic treatment as needed. Patients with such belief were significantly less adherent to daily preventer medications as part of the treatment plan [3].

Patients' beliefs about ICS are also associated with their adherence as reported using a questionnaire based survey in conjunction with pharmacy dispensing records as a more objective measure of medication adherence. The Beliefs about Medicine Questionnaire (BMQ) was distributed to 458 adult asthma patients and completed by 238 subjects (51.1%). Self-reported adherence with data from pharmacy records correlated well with the patient's belief in the importance of using ICS and with measures of asthma control. The Beliefs about Medicines Questionnaire measured general beliefs about medicines on a 5-point Likert scale. Close to half of the patients do not believe that they needed their preventer (ICS) inhaler and 43% worried about potential adverse effects. A third of the patients believed that their doctors over prescribed their medications and 16.5% considered medications being harmful to them. Concerns about being dependent upon ICS affected a quarter of patients and 31% stated that they do not need to use their preventer medications when they do not have symptoms [4]. The Asthma Insight and Management survey of patients across Europe and Canada, screened 75,335 households with over 2000 asthma subjects were interviewed. The result suggests that patients have low expectations of their asthma management. For example, up to 81% of the patients considered their asthma to be well or completely controlled despite the presence of clinical symptoms of

poorly controlled asthma. As a result, only half of the patients were taking daily controller medication in the past year and 27% not taking controller medication at all [5].

Using the concept of Necessity-Concerns Framework, Horne and colleagues analyzed 94 studies to address the effect of Necessity Beliefs (the perception of personal need for treatment) and Concerns about potential adverse consequences on their adherences to treatment of underlying long-term conditions. Not surprisingly, a stronger perception of treatment necessity and fewer concerns about such treatment is correlated with higher adherence to prescription. The authors concluded that clinicians should take patients' necessity beliefs and concerns into account when prescribing medication to increase adherence and improve the outcome of treatment [6]. Therefore, improving asthma control through increasing patient adherence to therapy is the key to success of reducing the cost and increase the outcome of asthma care.

Many of the patients and parents who responded wanted to be involved in their care and to develop partnerships with the doctors, nurses and therapists on their healthcare team. They wished to work with their doctors to develop an Asthma Action Plan. The collaborative approach creates a mutual investment in care while taking into account the best scientific evidence available and the patient's values and preferences.

There are studies that show that individualized written action plans, taking into account symptoms and recording medication use, might reduce unscheduled visits to the doctors and days lost from work [7]. The demographics of this study was similar to what we found. 62% of their subjects were females, 20% had a university degree and 9% had a post-graduate degree. By the GINA classification, 77% had mild asthma, 12% moderate and 11% severe. The knowledge of asthma was obtained from different physician sources, with 76% seeing their primary physician for asthma management. An asthma specialist had only seen 10% of the patients, with 5.3% within the preceding year and 34% of the patients had never been seen by a specialist. Although 86% of the patients said they were able to recognize deterioration in their asthma that would require a change in therapy, and 59% had been instructed to increase their controller therapy if this occurred, only 23% reported they actually made this change.

Gibson and colleagues performed a Cochrane review of 36 trials that compared self-management education with regular medical care and found that self-management education reduced the number of hospitalizations, emergency room visits, unscheduled visits to doctors, days off work or school, nocturnal asthma and increased the quality of life. The authors concluded that in addition to monitoring peak flow and asthma symptoms, the use of written action plan improves the outcomes of patients with asthma [8].

Although adherence can be improved by the use of either action plans or asthma knowledge, some studies suggest that this may not be the case. Auger and colleagues analyzed a cohort of 601 asthma children of a tertiary care children's hospital regarding caregivers' asthma knowledge, beliefs, and medication adherence vs risk of readmission over a year follow-up period. As expected, decreased medication adherence is associated with increased readmission risk. Paradoxically, greater asthma knowledge is found to be associated with an increased risk for readmission. Data from this study argued the inpatient services should focus more on medication adherence rather than only on asthma education [9].

Written asthma action plans alone may have limited effect on improving asthma symptoms or hospitalizations at least in a subspecialty setting. A total of 407 patients with persistent asthma cared by either pulmonologists or allergists were divided into routine subspecialty-based medical care alone and with an additional written asthma action plan. Asthma symptom frequency, number of emergency visits, and asthma quality of life were compared after 12-months follow-up. Surprisingly, both groups showed equally

significant reduction in asthma symptom frequency, nocturnal symptoms, β -agonist use, number of ER visit as well as increase of asthma quality-of-life scores, indicating the benefit of subspecialty care [10]. Interestingly, 40% of asthma patients surveyed were taken care of by subspecialists. A subgroup analysis would have been informative regarding the outcome of such patients.

Patients in our survey also requested easy access and better experience, including patient-friendly education from the visit to their doctor's office. Thirty percent of the asthma survey respondents called "time concerns" a common barrier to care. Trent and her colleagues, in a questionnaire based study, identified taking time off from work being the most common barrier to asthma management due to the overlapping of their working hours with physician's office hours [11]. Patients and parents want to be able to schedule an appointment within a reasonable period of time. Most understand they need to make a well visit in advance, however when the child is ill, they want the patient to be seen as soon as possible. Fleetcroft and his colleagues performed a cross-sectional analysis of data from 7806 medical practices including over 3 million patients with asthma and concluded that patients with easier access to primary care had much lower rate of emergency room visit and hospital admission [12], underscoring the importance of patient access for asthma care.

Patient's experience during a medical visit is an integral part of their asthma care. In one study of inner-city children with asthma, parents reported a long wait, insurance, rude staff, and inability to pay for medications as barriers in optimal asthma care [13]. Each patient interaction is unique. Maintaining eye contact during a patient visit is more important than ever in an era where many providers sit in front of a computer screen during patient visits, entering data into an electronic medical record rather than engaging directly with the patient. When patients are discussing symptoms or concerns, they want to know what they say matters and that the provider is supportive, attentive and a compassionate advocate for their care. Our survey also indicates the need for patient-friendly education from the provider's office. An effective patient-health physician partnership requires knowledge of asthma by both parties and understanding of the importance and acceptance in following management plans. Optimal asthma control can be affected not only by factors such as adherence to guidelines and therapy, but also proper asthma education. Research has demonstrated that improved asthma outcome is closely associated with adequate patient education [14]. However, 53% of the patients surveyed did not receive asthma education in the provider's office. A survey on asthma education showed that younger asthma patients, males, and patients with insurance were more likely to receive asthma education, as were patients living in rural areas, having public insurance, and having longer visits [15]. Further study in children revealed the majority of the pediatric asthma patients may not receive or not recall receiving education from their doctors [16].

What seems commonplace to healthcare providers can be foreign to patients. Offering resources – with practical, patient-friendly tips on how to manage a chronic illness – can provide patients with the information and inspiration they need to adhere to their treatment plans and live better. A web-based survey in Denmark recruited 509 adult asthma patients. Participants answered questionnaire concerning asthma knowledge, adherence, and treatment. Eleven to 18% of the subjects reported having uncontrolled symptoms which included exercised induced asthma, nocturnal and daytime symptoms. These were noted in 285 participants with persistent asthma. Although 70% stated they used ICS

but only 12% of the patients had a written asthma action plan. Only 23% of the 59% of patients who were instructed to adjust their controller therapy actually did it, implying the need for change in educational strategies [17].

In summary, the difference in perspectives between patients and healthcare professionals could change behaviors of patients and impede the ultimate outcome of asthma control. Therefore, the priority in asthma care is to develop simple and effective tools in identifying the reason for poor asthma control, then to set and achieve goals for optimal outcomes. To reach such control, healthcare professionals need to have greater understanding of the patient's perspectives and to incorporate such perspectives into the care of asthma, monitoring outcomes and taking appropriate action accordingly.

Directions for future research

- How to engage strategies to improve patient engagement in asthma management (e.g. motivational interviewing).
- Developing tools to accurately connect patient needs and beliefs to therapeutic success.

References

- [1] Barnes PJ, Jonsson B, Klim JB. The costs of asthma. *Eur Respir J* 1996;9:636–42.
- [2] Kenyon CC, Rubin DM, Zorc JJ, Mohamad Z, Faerber JA, Feudtner C. Childhood asthma hospital discharge medication fills and risk of subsequent readmission. *J Pediatr* 2015;166:1121–7.
- [3] Horne R, Weinman J. Self-regulation and self-management in asthma: exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychol Heal* 2002;17:17–32.
- [4] Menckenberg TT, Bouvy ML, Bracke M, Kaptein AA, Leufkens HG, Raaijmakers JAM, et al. Beliefs about medicines predict refill adherence to inhaled corticosteroids. *J Psychosom Res* 2008;64:47–54.
- [5] Sastre J, Fabbri LM, Price D, Wahn HU, Bousquet J, Fish JE, et al. Insights, attitudes, and perceptions about asthma and its treatment: a multinational survey of patients from Europe and Canada. *World Allergy Organ J* 2016;9:13.
- [6] Horne R, Chapman SCE, Parham R, Freemantle N, Forbes A, Cooper V. Understanding patients' adherence-related Beliefs about Medicines prescribed for long-term conditions: A meta-analytic review of the Necessity-Concerns Framework. *PLoS ONE* 2013;8:e80633.
- [7] Gibson PG. Written action plans for asthma: an evidence-based review of the key components. *Thorax* 2004;59:94–9.
- [8] Gibson PG, Powell H, Wilson A, Abramson MJ, Haywood P, Bauman A, et al. Self-management education and regular practitioner review for adults with asthma. *Cochrane Database Syst Rev* 2003;1. CD001117.
- [9] Auger KA, Kahn RS, Davis MM, Simmons JM. Pediatric asthma readmission: asthma knowledge is not enough? *J Pediatr* 2015;166:101–8.
- [10] Sheares BJ, Mellins RB, Dimango E, Serebrisky D, Zhang Y, Bye MR, et al. Do patients of subspecialist physicians benefit from written asthma action plans? *Am J Respir Crit Care Med* 2015;191:1374–83.
- [11] Trent CA, Zimbro KS, Rutledge CM. Barriers in asthma care for pediatric patients in primary care. *J Pediatr Heal Care* 2015;29:70–9.
- [12] Fleetcroft R, Noble M, Martin A, Coombes E, Ford J, Steel N. Emergency hospital admissions for asthma and access to primary care: cross-sectional analysis. *Br J Gen Pract* 2016;66:e640–6.
- [13] Seid M, Sobo EJ, Gelhard LR, Varni JW. Parents' reports of barriers to care for children with special health care needs: development and validation of the barriers to care questionnaire. *Ambul Pediatr* 2004;4:323–31.
- [14] Mayo PH, Richman J, Harris HW. Results of a program to reduce admissions for adult asthma. *Ann Intern Med* 1990;112:864–71.
- [15] Shah SS, Lutfiyya MN, McCullough JE, Henley E, Zeitz HJ, Lipsky MS. Who is providing and who is getting asthma patient education: an analysis of 2001 National Ambulatory Medical Care Survey data. *Health Educ Res* 2008;23:803–13.
- [16] Orrell-Valente JK, Jones K, Manasse S, Thyne SM, Shenkin BN, Cabana MD. Children's and parents' report of asthma education received from physicians. *J Asthma* 2011;48:831–8.
- [17] Backer V, Ulrik CS, Harving H, Lange P, S  es-Petersen U, Plaschke PP. Management of asthma in adults: do the patients get what they need—and want? *Allergy Asthma Proc* 2007;28:375–81.