



TREATING AND COMMUNICATING ABOUT ASTHMA:

Insights from Patients, Caregivers, and Health Care Providers



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NIH National Heart, Lung,
and Blood Institute

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Background

Understanding how asthma treatment decisions are made, how practice guidelines are used, and the communication needs of asthma patients, caregivers, and health care providers is critical to ensuring asthma patients receive the highest quality care. In fall 2019, the National Heart, Lung, and Blood Institute's (NHLBI's) *Learn More Breathe Better*SM program commissioned qualitative research on these topics with adult asthma patients, caregivers of children with asthma who are ages 12 years and younger, and health care providers who treat asthma.

Learn More Breathe Better will use the results to inform development of asthma education materials.

Ten focus groups were conducted with groups who traditionally have high rates of asthma, including English- and Spanish-speaking lower- to lower-middle income adult patients and caregivers. There were few differences in the perspectives of adults with asthma versus caregivers and English versus Spanish speakers.

In-depth interviews were conducted with 11 board-certified physicians, physician assistants and nurse practitioners in family practice and pediatrics, and an allergist/immunologist. One-fourth or more of each provider's patient population was uninsured or publicly insured. Among about one-fourth of the providers, at least one-fourth of their patients were Spanish speakers.

¹All data from the Centers for Disease Control and Prevention, Asthma Surveillance Data <https://www.cdc.gov/asthma/asthmadata.htm>. Accessed March 4, 2020.

Asthma Facts¹



1 in 13 Americans has asthma



19 million adults



6 million children



Increasing since early 1980s in all age, sex, and racial groups



Highest prevalence in lowest income households



Most prevalent among black and Puerto Rican children and adults



1/2 of people with asthma had an asthma attack in past year

Treatment Goals

Far and away the most important goal of patients and caregivers was getting **symptom relief so that patients can be more physically active**. Caregivers also wanted fewer hospital visits, and Spanish-speaking caregivers in particular sought better control of nighttime symptoms.

“She can’t do normal activities like her siblings. She always has to be near her medication.”

—Spanish-speaking mother, daughter age 9

“As I tell everyone, I only run for my life because if I run any other time, I can’t breathe.”

—English-speaking male patient

“I’m not able to improve my quality of life [exercise, go outside] if I can’t get up and do something.”—English-speaking female patient



Making Treatment Decisions

Insurance coverage affected caregivers', patients', and health care providers' decisions about treatment. Most patients and caregivers would forego uncovered treatment, though caregivers were more willing than patients to pay for uncovered medications. Other factors that may affect decision-making about asthma treatment include safety, side effects, benefits, success rates, and asthma severity. A few adult patients were concerned about developing a drug dependency or addiction (especially to pills). Patients with comorbidities also were concerned about drug interactions and contraindications, especially for oral medications.

“So I think the biggest hurdle probably that we face is getting patients the medication that they need in terms of insurance companies.”—M.D., allergist

“I would rather use whatever is more affordable as long as [insurance] covers the treatments.”—Spanish-speaking male patient

*“The percentage of kids it’s worked for. That’s a big thing for me...that was always the first thing I went to. What was the pool, the testing pool?”
—English-speaking mother, sons ages 4 & 9*

Health care providers said that poor treatment adherence, particularly once symptoms are controlled, can be a problem. Other challenges they confront include patients and caregivers who have a poor understanding of asthma, medications, device technique, and allergen management.

“Once [patients] feel that their asthma is well controlled, they automatically stop taking their inhaled corticosteroids...”

—M.D., pediatrician

“Most patients don’t know which medication does what and why they’re taking it.”

—M.D., allergist

Inhaled Versus Oral Medications

Patients and caregivers discussed various aspects of taking asthma medications. They preferred inhaled medications over pills or liquids. They said inhaled medication is easier to take or administer, faster acting, and more effective (because it is delivered directly to where it is needed).

“...the inhaler’s an instant relief so you know it’s working but I don’t know that the pills are working all of the time.”

—English-speaking male patient

“My inhaler...it’s like an extension of my body. I’ve had it since I was five.”

—English-speaking female patient

“...the inhaler is definitely the easiest route to go...he’s four. It’s hard for him to take pills, to swallow something ...and with liquid as well.” —English-speaking mother, son age 4

Number of Daily Medications

Patients and caregivers preferred one medication per day and viewed more than two to three as excessive. Caregivers were concerned with potential long-term effects of children taking more medications. They also mentioned the challenges of more frequent administration of medications at school.

“Three right now, it seems like a lot just because she is still so young...she really hasn’t started developing yet so we don’t know how that’s going to play out in the future.” —English-speaking father, daughter age 5

“[Adding medication] is a big issue when kids get to school age and schools refuse to give medication...”

—English-speaking mother, daughter age 8

Scheduled Versus As Needed

Taking medication on a set schedule versus as needed received mixed reactions. A set schedule was seen as easier to adhere to and more effective, including for preventing exacerbations in patients with severe asthma.

"I think the daily because of the routine...having a routine is what gets us through all the medications that we have to take on a daily basis."

—English-speaking mother, son, ages 4 & 9

"...but I think when we're having an asthma attack...it's actually scarring our lungs, our airways...so if there's something that'll prevent that, that's what I'd prefer."

—English-speaking male patient

"I prefer a daily medication to prevent, sometimes the rescue inhaler isn't enough. I've had to go in the ambulance with him and the rest of my kids."

—Spanish-speaking mother, son age 8

"I like it better on a schedule because I know what time to take it...I know how long it's going to last."—English-speaking male patient

In contrast, others felt taking medication as needed offers flexibility and potentially reduces side effects and dependency. This option was more appealing to those with mild to moderate asthma and Spanish-speaking caregivers.

"[For daily medication]... maybe your body get[s] addicted to it, where if you quit taking it you'd have more problems."

—English-speaking female patient

"[As needed] if it works. You hate [to] give your kids medication unless you have to."—English-speaking father, son age 10

"I want to decide the time, life is hectic. I'm not home at the same time every day."

—Spanish-speaking mother, son age 9

Using One Inhaler to Treat Asthma and Prevent Attacks

Patients and caregivers generally were receptive to using the same inhaler to both treat asthma and prevent exacerbations. However, some questioned whether one inhaler could do both effectively.

“It would be ideal. It would save time and money and I would feel prepared to combat asthma.”

—Spanish-speaking male patient

“I would have a lot of questions about how you’re going to prevent and treat the symptoms...if you’re treating the symptoms after an attack, then you didn’t prevent them.”

—English-speaking mother, daughter age 8

Allergy Shots, Allergens, and Bronchial Thermoplasty

Patients and caregivers also discussed other asthma treatment and management strategies, including allergy shots, reducing home allergens, and—for adult patients only—bronchial thermoplasty. (Biologics were not discussed).

- Awareness of allergy immunotherapy (allergy shots) was low to moderate. Some said they would consider immunotherapy if it was shown to be effective. Others were skeptical, citing concerns about pain, inconvenience, and side effects.
- Most of the caregivers and adult patients said they tried to reduce allergens in their homes. They used mattress and pillow covers, removed curtains and mold, controlled pests, and dusted and vacuumed often. They also reported keeping windows closed during pollen and wildfire season to reduce allergens and irritants. Some kept pets, but said they kept the pets outside more or vacuumed more frequently after an asthma diagnosis. Very few would stop inexpensive, easy allergen reduction efforts, even if those efforts were proven to be ineffective. Before they changed how they control allergens, they would want information on the cost and difficulty of those changes.
- Most adult patients thought bronchial thermoplasty was too risky, citing concerns about anesthesia, multiple hospital visits, having their muscle tissue heated, and possible impact on other health conditions. They wanted more information on side effects, risks, complications, success rates, and how the procedure is done. Spanish-speaking adult patients were more receptive to the procedure than their English-speaking counterparts.

Unique Challenges Facing Adolescents

Although we did not interview adolescents with asthma, their caregivers and health care providers described some of their common challenges.

<p>DENIAL</p>	<p>EMBARRASSMENT OR SHAME</p>	<p>LIMITED SELF-RELIANCE, SCHOOL ISSUES</p>	<p>SMOKING, VAPING, MARIJUANA USE</p>
<p><i>Parents often think of asthma as a handicap. So, they don't want to admit their child has asthma and therefore don't want to start or stay on meds.</i> —M.D., pediatrics</p>	<p><i>They see other kids around who don't have the same issues they do; they don't want to be different.</i> —P.A., family practice</p> <p><i>I think he was more embarrassed for his teammates to know that he had it.</i> —English-speaking mother, son age 12</p>	<p><i>Getting teens to take ownership of their asthma care as they get older and have more autonomy. I tell them 'It's your issue, not your mom's.'</i> —M.D., family practice</p> <p><i>...there was a lot of red tape to go through just to make it so she could bring her inhaler to school and keep it in her backpack...They're very strict about medications only being in the office.</i> —English-speaking mother, daughter age 13</p>	<p><i>I have quite a few adolescents who smoke... though the news is helping a lot with this, the people who vape, the hookah smokers, and the weed smokers.</i> —N.P., pediatrics</p>

Using Clinical Practice Guidelines

Most health care providers said they referred as needed to clinical practice guidelines, which they found online. Few had guidelines integrated into their electronic health record system. When evaluating whether to apply a guideline to a patient who was outside of the guideline's age range or severity, providers said they considered the patient's history, insurance coverage, and likely compliance; treatment costs; and their prior experience using the treatment and its outcomes.



Clinicians liked algorithms and decision-support tools, including the stepwise approach from the National Asthma Education and Prevention Program's Expert Panel Report 3: Guidelines on the Diagnosis and Management of Asthma (EPR-3). However, some thought EPR-3's stepwise approach was too complex. In the EPR-3 Asthma Care Quick Reference, clinicians said the most useful sections were the initial and follow-up visit sections, with the dosage section the least useful. Reactions were mixed on the sections describing key clinical activities and how to respond to patients' questions.

Health care providers suggested the following content for the Asthma Care Quick Reference: advice on verifying asthma in patients presenting as diagnosed; guidance on how to monitor/adjust the height/weight information in the parameters section of the pulmonary function test as children grow; when to refer to a specialist or consider skin testing; how to sensitively raise the risk of oral thrush; strategies for addressing patient adherence; and a flowchart or form providers can use to teach patients how to monitor their asthma, including questions to help assess what's working, what's not working, and what each medication does.



Communication Sources and Needs²



PATIENTS AND CAREGIVERS

Their most common and preferred information sources included the internet (particularly Google and WebMD), a physician (most trustworthy among caregivers), a pharmacist, and family members who work in health care.

- ✓ Many patients and caregivers wanted information about a cure and how to prevent asthma.
- ✓ **Patients** wanted more information on medication safety, efficacy, and dosing frequency.
- ✓ **Caregivers** wanted help understanding the disease; what the different classes of medications do; and guidance on device techniques, allergen management, and dosing.

Most patients and caregivers preferred web-based materials (apps, videos, websites), though a few preferred print materials to post at home. Some Spanish-speaking patients liked text messages.



HEALTH CARE PROVIDERS

Health care providers preferred receiving updates on practice guidelines in emails from professional associations and credentialing organizations. Preferred sources for asthma information included websites such as UpToDate, AAP SmartBrief, NHLBI, WebMD, and Mayo Clinic, or apps such as Lexicomp, AAP, PDR, and Medscape.

For **patients and caregivers**, health care providers wanted handouts and user-friendly websites on:

- ✓ Symptom recognition
- ✓ Functions of classes of medications
- ✓ Asthma as a **chronic**, not **acute** condition
- ✓ Guidance for teens on troubleshooting their asthma management

For **themselves**, they wanted information on:

- ✓ When to use anticholinergics and biologics
- ✓ When to refer for skin testing
- ✓ Decision supports, like EPR-3 stepwise approach

²Mention of brand names does not imply endorsement.



METHOD

Qualitative research was conducted in fall 2019. Virtual data collection methods (i.e., telephone and online platforms) were used to conduct 10 online focus groups with asthma patients and caregivers, and 11 in-depth interviews with clinicians who treat patients with asthma. Analysis used a notes- and transcript-based process.

Focus group participants were English and Spanish-speaking, lower- to lower-middle income (<\$50k annual household income) adults with asthma (n=27) and adult caregivers of children with asthma (n=26). Interviews and focus groups were 75 minutes or less to minimize burden and facilitate engagement. Health care providers were a mix of board-certified physicians, physician assistants and nurse practitioners in family practice (n=6) and pediatrics (n=4), with one allergist/immunologist. All had patient populations with one-fourth or more uninsured or publicly insured. In addition, about one-fourth had a patient load of at least one-fourth Spanish speakers.

Qualitative research techniques permit flexible exploration of topics and thus provide insights into participants' reactions and ideas that would be unattainable with structured quantitative research. However, findings are not statistically projectable to some larger group due to small sample sizes and purposeful sampling methods.

