ALA PACE Seminar Participant Survey
Summary of Open-ended Questions

KEY FINDINGS

1. Providers lack the time to provide patient education.
2. Some providers have difficulty classifying patients, especially those that are borderline with few wheezing episodes.
3. Providers working with the homeless face additional challenges: patients do not have documentation of previous care, patients do not have insurance and patients lack the monetary resources to pay for services.
4. Some providers have difficulty getting patients to come in for a follow-up visit or to continue using medications, especially when the patient has been well.
5. Spirometry is not being used consistently.
6. Understanding medications and concerns about using steroids are barriers for families.
7. Build extra time into the seminar to practice spirometry, use spacers, discuss implementation of asthma action plans and discuss patient scenarios.

FOUR-WEEK FOLLOW-UP

BARRIERS PROVIDERS HAVE FACED, IN THE PAST MONTH, HELPING FAMILIES MANAGE ASTHMA.

- Horrible longitudina1 care documentation. Parents often don't know about meds or when to do what. I have not been able to use the spirometry yet because the clinic protocol has not yet been revised, we are working on it. Our clinic administrator says the spirometry, MDI and neb demo and group counseling codes are not consistently reimbursed along with E and U codes and that prolonged attendance is not reimbursed. She feels assigning these codes may lead to patients hardship and ill will.
- I only see adults. We have 9 clinic locations. We have placed spirometry at 2 of these (at our family clinics). I do not go to either of those sites so have not had the opportunity to try out spirometry. We hope to eventually have the spirometry at an adult site but felt that initially we wanted to have it available for use with children.
- Not enough time. Poor staff training.
- Working with the homeless if patients are not yet covered by health insurance and have mod-severe asthma. Resources are limited but essential. For adults there are copays for meds, which they often don't have. Families with children with asthma often come to MN from other locations (states) with few if any meds and limited health plans. Clinics, especially in Chicago area, are very slow to release information.
- No clinic-wide plan for asthma. <u>Time</u> constraints – most kids with cough or asthma flare only get a 7-1/2 minute appointment.
- Time.
- <u>Time restraints</u> in office setting to ensure thorough teaching, develop action plans. Spirometry not available in our office.
- Time to educate properly.
- Enough <u>time</u> to cover everything.
- Time for adequate education.
- Time, insurance reimbursements, cost of medications.
- Not enough <u>time</u> during a visit.
- Parents coming back for follow-up visits. Compliance with asthma action plans.
- Actually I've been on vacation.
- Insurance coverage.

- Time. Support staff assistance. Machine knowledge ease of use.
- Regular follow up. Misunderstanding education given. Won't use aerochamber.
- Reluctance to use chronic meds when seemingly well.
- Insurance issues – meds not covered.
- Lack of insurance.
- Compliance with prescribing plans.
- Having time to do education/go over asthma action plan/demonstrate peak flows/inhaler.
- None specific. Generally barriers are time – families not listening to the "maintenance" of asthma which is a chronic disease.
- My biggest barrier is time. We do not have adequately trained staff to do spirometry well (and I'm just learning) or to do any education. On a busy day, I have very little time with these patients, esp. education. They often do not come in for follow-up.
- Lack of insurance (uninsured and underinsured) – expense of medications and related compliance.
- I have not received spirometry training. Parents fears of using inhaled corticosteroids long term. Re-educating families that have received many information and multiple "bronchitis" diagnoses.
- Families that have no insurance are unable to pay for medication.
- We are getting a computer to use with card.
- 1) time involved and filling out asthma action plans and printed forms with files often to not lend themselves to exact plan. 2) noncompliance.
- Scheduling – follow up appts, inappropriate use meds.
- Time constraints.

BARRIERS FAMILIES HAVE FACED WHILE MANAGING ASTHMA.

- Moving state-to-state, shelter-to-shelter, no medical home, lots of ER use.
- Some patients have no medical insurance.
- Not understanding it.
- Not understanding the medications.
- Not wanting to come back when well for asthma ed.
- 1) Cost of inhalers. We stock Albuterol inhalers and have been able to give those to clients without insurance. However, we do not stock inhaled corticosteriods. Many of our clients are uninsured and now even for those with insurance (MA) there is a $1-$3 copay – a barrier for homeless individuals. 2) Use of spacers – they are large and not something that many homeless people will carry around with them in their pockets. 3) Smoking.
- Lack of understanding due to limited access to care and resources. Lack of resources due to no money.
- Still some reluctance to use inhaled steroids (concerns with growth, etc.). Too much information at one time. Families not able to take the extra time for spirometry, especially if an exercise challenge is needed.
- Pre-conception about treatment. Steroid phobia.
- Keeping up with maintenance meds (busy lives, patient willingness).
- Difficulty understanding which medicines (i.e. bronchodialation vs. steroids) for which problems.
- Most of the time the family stops using the medications once the child is better.
- Having multiple caregivers, e.g. separated parents, grandparents, school, daycare. Not understanding how to use inhalers, etc.
- Transportation to visits.
- Retained knowledge. Understanding. Both parent involvement (if 2 parent household).
- Cost of meds – no $ to pay.

- Non-compliance with meds when patients are feeling well.
- Lack of insurance.
- Incomplete knowledge of the disease and how to manage it.
- Older children not complying with management plan.
- Fear of chronic med's. Denial. Co-pays when healthy.
- Lack of insurance (uninsured and underinsured) – expense of medications and related compliance.
- Difficulty giving daily meds. Cost of aerochamber. Pharmacies giving corregated tubing rather than spacer.
- No insurance.
- Children's resistence. Incomplete understanding of plan even with several repetitions of plan.
- Access to clinic, inability to pay for meds.
- Understanding rationale for use of different classes of medication.

TOPICS MOST OFTEN STRESSED (NOTE THIS QUESTION WAS ADDED TO SURVEY MIDWAY THROUGH THE DATA COLLECITON PROCESS)

16 How to take medicines

14 How medicines work

10 Goals of therapy

8 What happens in an asthma attack?

7 Identifying and avoiding triggers

5 Responding to changes in asthma severity

3 Safety of medicines

3 Criteria of successful treatment

1 Managing asthma at school and day care

0 Referral to further education

SUGGESTIONS FOR IMPROVING THE SEMINAR.

- I felt it was very good. I don't know of any thing else to make it better – the rest is up to us. Thank you!
- More time to practice spirometry. More time trying out spacers and I also wonder if there is a source for free spacers. Maybe make it an 8 hour conference. But it was a very good training and thank you for providing it and for the excellent resource manual/articles/etc.
- Make it longer – there wasn't enough time in the current schedule for all of the speakers. Give specific ways clinics can start to implement AAP's and spirometry. Overall it was very helpful!
- Excellent seminar – perhaps patient scenarios to discuss in small groups (how to approach intervention, teaching, etc. in realistic way considering limited time).
- Very well done – nothing needed.
- Gear it more towards you audience's level of training (i.e. less basic "what is asthma if your audience is MDs).
- I still have problems with those borderline kids – who have wheezed maybe once or twice, usually with colds, and can't really be given a diagnosis of asthma (yet). Even with spirometry, there is no way to justify permanent medical treatment, as many of them will be entirely well in 4-6 months. This is actually the type of patient I see most frequently.
- Making sure that all speakers know correct time and date.
- No. Very good presentation.

- No – I thought it was great.
- None specific – it was a great course.
- I thought this seminar was excellent – probably one of the most useful I've been to. Speakers were great. The part on billing was brief and over my head, but gave me at least some preliminary info. More on spirometry – or I'll try to attend another class if available.
- No – was good!!
- More cased based scenarios. Something on dispelling myths.
- More examples of spirometry in children. Spending more time on case studies for asthma management.
- More spirometry cases, more instruction on spirometry interpretation.
- No; one of the best presentations I have attended. Thanks.

FOUR-MONTH FOLLOW-UP

BARRIERS PROVIDERS HAVE FACED, IN THE PAST MONTH, HELPING FAMILIES MANAGE ASTHMA.

- Working with the homeless, it's a challenge in that the families are in transition and often transient. We are temporary (at best) primary care providers. I still do AAP's – and treat as if they are my patients – then refer them to a community provider who they may (or may not) follow through with. We have our spirometers but haven't been able to do much with them due to lack of appropriate laptop/printer equipment.
- Cost issues, many of our clients are uninsured. For those on MA (GAMC) co-pays are a barrier. This often makes it difficult to provide spacers, to begin inhaled corticosteriods or nicotine patches for those who desire to stop smoking. We see many clients with multiple social and health issues – homelessness, mental health issues and chemical dependency issues – these complicate the treatment of asthma. It would help to have spacers to provide to clients, more samples of inhaled corticosteriods and nicotine patches on site at our clinics. (Note - this answer also applies to barriers families face.)
- Incredible difficulty at the final stages. I had to erase the hard drive of my own personal computer (an old one) in order to use it at the office. I have been requesting a room to put it in for 6 months and have resorted to plugging it in at my workstation and driving it home at night. Near total lack of organizational support.
- Access to spirometry. Poor understanding of medication uses. Poor compliance with meds.
- I am still struggling with how to classify a certain patient – otherwise other things are much better.
- Formularies not allowing Xonemex (sp?).
- Reassurance that inhaled steroids are safe. The need for maintenance meds, even when symptoms are controlled.
- Not enough time for appropriate education.
- Their acceptance of the diagnosis. Time – clinic time is limited to include all aspects of asthma care.
- Spirometry not established yet, we are working on that and training the staff.
- We still don't have our office spirometer.
- No spirometry in office
- Not enough time to go through asthma meds education and diagnosis
- Time constraints
- None.
- Scheduling concerns, patients failing appts. Patients not using ICS. We still have not received our spirometer from ALA.
- Not able to get 2 spacers for school-age kids (insurance only covers 1)

- Parents not wanting to continue inhaled corticosteroids. Children not using MDI at school – only do nebulizer.
- Time, Time, Time! We need an R.N. with experience to do the teaching. It is hard to find time in the office, especially with acute illnesses.
- Financial. No insurance and need inhaled steroids.
- Our asthma action plan forms really don't work well for all types of asthma especially mild intermittent.
- Families not accepting diagnosis of asthma esp as a chronic disease requiring chronic medication.

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BARRIERS FAMILIES HAVE FACED WHILE MANAGING ASTHMA.

- They come to us with no money, no insurance, often lack of information/ knowledge. We try to overcome all that but they are still homeless and in crisis.
- Similar to those listed above, put with multiple social and health problems, asthma may not be the #1 issue that a client is concerned about.
- They resist pay and co-pay for a follow-up when the child is well.
- Insurance coverage for meds, especially allergy meds.
- Hard to grasp the chronic nature of disease because symptoms are intermittent.
- Resistance in school to carrying inhalers.
- Some are reluctant to begin treatments (nebs, etc.) without first having their child seen in the office.
- Lack of understanding of asthma physiology and treatment.
- Their time commitments to allow proper use of meds.
- Insurance barriers. Home concerns. Allergy problems in rented facilities.
- Cost.
- Transportation
- Consistency in taking meds due to multiple homes
- Necessary frequent visits, cost of co-pay, time off work/school
- None
- Accepting/recognizing diagnosis
- Understanding of need for chronic meds.
- Lack of insurance to cover medication.
- Pharmacies dispensing accordion spacer rather than aerochamber.
- Financial.

SUGGESTIONS FOR IMPROVING THE SEMINAR.

- Excellent seminar. Thank you.
- I thought it was excellent. Perhaps specifics, like did you hire an extra nurse to do spirometry, office workflow solutions, use of multi-media to make teaching more efficient. Also, what is the evidence for daily anti-inflammatories in children 2 years and under?
- It was great.
- More hands-on PFT training.
- It was thorough, excellent – perhaps patient scenarios of ages birth through teen years.
- No – excellent.
- Less biology – we are all pediatricians – and more hands on with spirometry.
- More time on practical office management, coding, etc.
- Coding section could be shorter and more concise. Better handouts for coding. More spirometry training.
- More on spirometry re: Peds examples and how to interpret.
- Excellent seminar – may be only suggestion is to have short refresher course.