

Parent Report of Perceived Barriers to Adherence to Asthma Medication

Gowry Kulandaivel³, Genevieve Vullo², Barbara J. Howard^{1,2}, Raymond A. Sturner¹, Rebecca Sturner⁴

1. Pediatrics, Johns Hopkins U, Baltimore, MD, United States; 2. Pediatrics, The Johns Hopkins U SoM, Baltimore, MD, United States; 3. University of Maryland, School of Medicine, Baltimore, MD, United States; 4. Total Child Health, Baltimore, MD, United States; 5. Albert Einstein College of Medicine, Bronx, NY, United States.

ACKNOWLEDGEMENTS: Sande Okelo, MD; author of PACCI and collaborator: Joel Gittelsohn, PhD and Susan Liverman, RN qualitative coding. Advisors Michelle Eakin, PhD, Sandra Wilson, PhD Research reported in this publication was supported by the National Heart, Lung, and Blood Institute of the National Institutes of Health under Award Number R44HL117482. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. Howard and Sturner have a conflict of interest regarding CHADIS used in this study. Conflict was managed by the MedStar IRB.

BACKGROUND

- Pediatric asthma is highly prevalent in the US, affecting the quality of life of more than 7 million children under the age of 18 (1) and a major source of mortality.
- One contributor to uncontrolled asthma despite prescription of appropriate preventative treatment is poor adherence to the regimen; on average a child gets only 50% of their prescribed medicines (2).
- Compared to less adherent children, children more adherent to prescribed controller medication have:
 - fewer asthma attacks requiring ED visits
 - fewer acute office visits
 - fewer hospital admissions (3,4)
 - fewer prescriptions of oral corticosteroids for 3+ days (5) with their associated side effects.
- NHLBI Guidelines call for assessment of adherence and use of a Shared-Decision Making (SDM) approach,(6,7) but fewer than 10% of providers ask for such parent/child input.
- Problem Solving Counseling has been shown to improve adherence but may require more time to implement than is practical in typical pediatric practice. A practical questionnaire to elicit barriers to asthma adherence and facilitate prompt Problem Solving Counseling by healthcare providers is not available.

OBJECTIVES

- To determine the extent to which a new pre-visit parent completed questionnaire identifies the same barriers to medication adherence as those elicited from an in-depth interview.
- To determine additional barriers to adherence and/or alternative wording from parent free text and interviews to improve this questionnaire beyond those barrier selections included as the result of a literature review.
- To create a tool that will have appropriate language and brevity to support electronic moment of care decision support with enough efficiency for pediatric adoption, specifically to make problem solving counseling feasible.

METHODS

- A new questionnaire was created modeled after the open-ended interview in the Better Outcomes for Asthma Treatment (BOAT) study (8). The online questionnaire includes (1) pictures, names, and doses of all possible controller and rescue medications, and (2) a forced-choice questionnaire allowing for selection of one or two barriers to giving the daily medicine that asks:

“There are lots of reasons why it might be hard to give your child his/her medicines exactly as your doctor said to. What is the number one reason getting in the way of giving the medicines as prescribed?”

- Barriers were sought by a literature review followed by feedback from three internal researchers/clinicians and by three asthma experts.
- 65 adult caregivers of a child aged 0-19 years with a diagnosis of asthma on the problem list were recruited from two asthma specialty clinics and from two general pediatric clinics over 16 months.
- Caregivers completed the Asthma Medication questionnaire online at home or in the waiting room using the CHADIS system.
- Trained RA's conducted in-depth interviews via telephone or in-person on average 43.4 days after questionnaire completion using a script designed to promote discussion of each of the barrier options listed in the questionnaire and to probe for edifying elaborations.
- Interviews were recorded and transcribed. Qualitative codes were developed to identify remarks associated with barriers listed in the questionnaire and the interview transcripts.
- Interview transcripts were coded by three individuals blind to the questionnaire results.
- Three additional coders reviewed the transcripts and debated the final coding to reach consensus on coding disagreements.
- Interview Barriers (IBs)** were compared with the **Questionnaire Barriers (QBs)**.

RESULTS

Demographics

Adult Demographics			Child Demographics		
Age	Average	45 yrs	Age	Average	9.9 yrs
	Range	26 – 60 yrs		Range	1.3 – 19 yrs
Gender	Male	6.2 % (4)	Gender	Male	58.5% (38)
	Female	93.8% (61)		Female	41.5% (27)
Race	White/Caucasian Only	63.1% (41)	Race	White/Caucasian Only	53.8% (35)
	African American Only	26.2% (17)		African American Only	24.6% (16)
	Asian Only	0% (0)		Asian Only	1.5% (1)
	Native American Only	1.5% (1)		Native American Only	1.5% (1)
	More than One Race/Some Other Race	9.2% (6)		More than One Race/Some Other Race	18.5% (12)
Ethnicity	Hispanic	26.8% (11)	Ethnicity	Hispanic	26.8% (11)

Top Barriers to Asthma Medication Adherence

- The most frequent QBs **and** IBs were: “Forget” (16.9% of QBs, 30.8% of IBs) and “No Barriers” (63.1% of QBs, 27.7% of IBs).
- The barrier selected in the questionnaire (QB) matched one of the top two barriers noted in the interview (IB) in 32/65 cases (49%).
- Failure of the QB to match the IB (33 mismatches) occurred mainly when a QB of “Nothing” (26/33 or 76%) was selected when “what gets in the way” was asked. Of those with QB of “Nothing”, the most common secondary IB was “Forgetting” (11/33 or 42%).
- Two new top categories of barrier were revealed by interview: “Doesn’t Always Have” and “Not Sure How to Give”
- If one equates the cases of mismatched QB of “Nothing” with the cases having a secondary IB of “Forgetting (11) and combines these cases with cases of actual matched barriers (32), the QB matched the IB 66% (43/65) of the time.

Order	Top Barrier Identified in Questionnaire (QB)	n	%	Top Barrier Identified in Interview (IB)	n	%
1	Nothing (No barriers)	41	63.1	Forgets to Give Medicines	20	30.8
2	Forgets to Give	11	16.9	Nothing (No Barriers)	18	27.7
3	Has Medicines, But Child Refuses	3	4.6	Unable to Pay for Medicines or Visit	6	9.2
	Child Needs Different Medicine, Dose/Amount, or Type of Treatment	3	4.6	Doesn't Always Have Medicines	6	9.2
	Not Prescribed Any Asthma Medications	3	4.6			
4	Giving Medicines to Someone Who is Not Acting Sick Does Not Make Sense	2	3.1	Has Medicines, But Child Refuses	4	6.2
				Giving Medicine to Someone Who Is Not Acting Sick Does Not Make Sense	4	6.3
5	Unable to Pay for Medicines or Visit	1	1.5	Has Medicines, But Doesn't Give to Child	3	4.6
	Has Medicines, But Doesn't Give Them	1	1.5			
6				Not Sure How Asthma Medicine Should Be Given	2	3.1
				Medicine May Be the Wrong Way to Treat Child's Asthma	2	3.1

DISCUSSION

Does the questionnaire match interview barriers?

- Using our initial questionnaire, the questionnaire barrier matched the interview barrier 49% of the time.
- The majority of the mismatches occurred when caregivers selected “Nothing” on the questionnaire, but reported other barriers to adherence during the interview. Of those other barriers, “Forgetting” was the most common.
- Transcript review suggested that parents reporting “Nothing” but later endorsing “Forgetting” may have interpreted the questionnaire item (“What is the number one reason getting in the way of giving the medicines as prescribed”) as only referring to external factors making adherence difficult, and not considering “forgetting” as such a barrier.
- Combining cases of QB “Nothing” and IB “Forgetting” with cases of matched barriers would result in the questionnaire identifying the same barriers as interviews 66% of the time. A modified question clarifying “forgetting” as a barrier will make this questionnaire more reliable.

Were novel barriers identified by interviews?

- Medications were missed when there were changes in daily routine, such as impromptu sleepovers or while traveling.
- Many children fall asleep before the medicines can be given.
- It is common for insurance to only cover one inhaler when a child needed one at home, at another parent’s house, and at school.

Could the questionnaire create time efficiencies?

- Interviews typically took at least one hour for thorough barrier elucidation, not feasible in practice.
- The Asthma Medication questionnaire shows promise for time savings when administered pre-visit online by reliably identifying the relevant barrier to family medication adherence plus providing barrier-specific guidance via Problem Solving Counseling prompts to address the barrier and parallel handouts or Portal text.
 - If the QB is “Forgetting”**, clinicians see suggestions for family routines, charts, & electronic reminders.
 - If the QB is “Child Refuses to Take Medicines”**, clinicians are prompted to discuss reasons, flavoring, behavior modification and child responsibility.
 - If the QB is “Child Falls Asleep Before Medicines Are Given”**, clinicians are prompted to reassure parents that medicines can be given at more flexible times.
- This questionnaire is likely to provide greatest time efficiency when used in conjunction with other pre-visit data regarding adherence and severity so clinician time during the visit can be focused on goal setting and problem solving for selected patients rather than data collection for all patients. Alternative solutions to barriers can be automatically available for targeted patient education. Such a system is currently under study by our group.

CONCLUSIONS

A modified pre-visit online questionnaire can reliably identify top family barriers to asthma medication adherence as needed for Problem Solving Counseling and targeted patient education to improve asthma control in children.

KEY REFERENCES

- Akinbami LJ, Moorman JE, Bailey C, et al. Trends in Asthma Prevalence, Health Care Use, and Mortality in the United States, 2001 – 2010. CDC/NHS Data Brief. 2012; 94: 64,1458 – 1462.
- Jentzsch NS, Camargos PAM, Colosimo EA, et al. Monitoring adherence to beclomethasone in asthmatic children and adolescents through four different methods. Allergy. 2009; 64:1458 – 1462.
- Desai M and Oppenheimer JJ. Medication Adherence in the Asthmatic Child and Adolescent. Current Allergy Asthma Report. 2011; 11:454 – 464.
- McGrady ME and Hommel KA. Medication Adherence and Health Care Utilization in Pediatric Chronic Illness: A Systematic Review. Pediatrics. 2013; 132(4):730 – 740.
- Engelkes M, Janssens HM, et al. Medication adherence and the risk of severe asthma exacerbations: a systematic review. European Respiratory Journal. 2015; 45:396-407
- NHLBI. NIH, National Heart Lung and Blood Institute. Guidelines for the Diagnosis and Management of Asthma – Expert Panel Report 3. 2007.
- Institute for Clinical Systems Improvement. ICSI Shared Decision-Making Model: The Collaborative Conversation, Shared-Decision Making and the Translation of Evidence into Practice (2012, 2015)
- Wilson SR. *Farm SDM-H06: General Types of Asthma Medications* [Handout]. Better Outcomes of Asthma Treatment (BOAT) Clinical Trial. BOAT clinical trial is registered with www.clinicaltrials.gov (NCT00217945 and NCT00149526). Document from “Shared Treatment Decision Making: An Approach to Asthma Care Management - Care Manager Protocol, Care Management Resources, and Patient Handouts”.