Published in final edited form as:
J Asthma. 2011 December ; 48(10): 1022–1031. doi:10.3109/02770903.2011.626482.

Child and caregiver involvement and shared decision-making during asthma pediatric visits

Betsy Sleath, PhD[*]**[George H Cocolas Distinguished Professor]**,
University of North Carolina Eshelman School of Pharmacy & Research Associate, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill; CB # 7590, Chapel Hill, NC 27599-7590; Office: 919/966-8969, Fax: 919-966-1634

Delesha M. Carpenter, PhD, MSPH[Research Assistant Professor],
University of North Carolina Eshelman School of Pharmacy, University of North Carolina at Chapel Hill

Robyn Sayner[PharmD Candidate],
University of North Carolina Eshelman School of Pharmacy, University of North Carolina at Chapel Hill

Guadalupe X. Ayala, PhD, MPH[Professor],
Division of Health Promotion and Behavioral Science, Graduate School of Public Health, San Diego State University

Dennis Williams, PharmD[Associate Professor],
University of North Carolina Eshelman School of Pharmacy, University of North Carolina at Chapel Hill

Stephanie Davis, MD[Associate Professor in Pediatrics],
University of North Carolina School of Medicine, University of North Carolina at Chapel Hill

Gail Tudor, PhD[Professor], and
Department of Science and Mathematics, Husson University, Bangor, Maine

Karin Yeatts, PhD[Research Assistant Professor]
University of North Carolina Department of Epidemiology, University of North Carolina at Chapel Hill

Betsy Sleath: betsy_sleath@unc.edu

Abstract

Objective—The purpose of this study was to examine: (a) the extent to which caregivers and children asked asthma management questions during pediatric asthma visits, (b) the extent to which providers engaged in shared decision-making with these caregivers and children, and (c) the factors associated with question-asking and shared decision-making.

Methods—Children ages 8 through 16 with mild, moderate, or severe persistent asthma and their caregivers were recruited at five pediatric practices in non-urban areas of North Carolina. All of the medical visits were audio-tape recorded. Generalized estimating equations were used to analyze the data.

[*]Correspondence should be addressed to Betsy Sleath, betsy_sleath@unc.edu.

Declaration of Interest
The authors report no conflicts of interest. The Authors alone are responsible for the content and writing of this article.

Results—Only 13% of children and 33% of caregivers asked one or more questions about asthma management. Caregivers were most likely to ask questions about their child's medications. Providers obtained child input into their asthma management treatment plan during only 6% of encounters and caregiver input into their child's asthma management treatment plan during 10% of visits.

Conclusion—Given the importance of involving patients during health care visits, providers need to consider asking for and including child and caregiver input into asthma management treatment plans so that shared decision-making can occur more frequently.

1. Introduction

Asthma is a worldwide problem and it is the most common chronic condition among American children (1). There are more than 7 million children under age 18 in the United States with asthma (2). Healthcare costs for asthma are estimated at more than 6 billion dollars per year and the loss in productivity by working parents caring for children who miss school due to asthma is estimated at one billion dollars per year (3–5).

The National Heart, Lung, and Blood Institute (NHLBI) guidelines provide several recommendations for proper asthma management to minimize uncontrolled asthma. These guidelines include: use of pharmacologic therapy, reduction in environmental triggers, assess and monitor asthma control, and patient education (3). The patient education guidelines specifically emphasize teaching patients how to effectively manage their asthma as well as the importance of using a collaborative approach between providers, parents, and children to develop an appropriate asthma management plan for the child. However, recent studies have found that these guidelines are not being met, with less than half of families ever receiving any education about their child's asthma (6, 7). It is important to better understand provider-child-caregiver communication about asthma during pediatric visits because asthma patients who report poor communication with their providers have been found to be less adherent with inhaled corticosteroids and have worse health outcomes than patients who report good communication (8–10).

The U.S. Institute of Medicine report in 2001 endorsed patient-centered or family-centered care and recommended that health care professionals implement the shared decision-making model in clinical settings (11, 12). However, little empirical research, especially in pediatric settings, has actually examined the extent to which shared decision-making is used in practice with families. Charles et al. (13) argued that for shared decision-making to occur, there needs to be a two-way exchange not only of information but also of treatment preferences. Very few prior studies have examined the shared decision-making model with families, and to our knowledge no prior work has examined the extent to which providers ask for and include caregiver and child input into asthma management regimens during primary care pediatric visits. Most prior studies that have examined provider-child-caregiver communication during general pediatric visits have not examined the extent to which the child and caregiver are sharing involvement in treatment decisions (14–18). Wassmer et al. (19) examined communication during 51 pediatric visits and found that caregivers sought information during 13% of visits and children asked for information during only 3% of visits. The purpose of this study was to examine: (a) the extent to which caregivers and children asked asthma management questions during pediatric asthma visits, (b) the extent to which providers engaged in shared decision-making with these caregivers and children, and (c) the factors associated with question-asking and shared decision-making.

2. Methods

Participants—The cross-sectional study was approved by the University of North Carolina Institutional Review Board. Providers were recruited at a convenience sample of five pediatric practices in non-urban areas of North Carolina and provider consent was obtained. Children and their caregivers of these providers who agreed to participate were recruited. Children were eligible if they: (a) were ages 8 through 16 years, (b) were able to speak English, (c) could read the assent form, (d) had been seen at the clinic at least once before, (e) were present at the visit with an adult caregiver (parent or legal guardian) who could read and speak English and who was at least 18 years of age, and (f) had mild, moderate, or severe persistent asthma. Persistent asthma was defined as experiencing asthma-related daytime symptoms more than twice a week, asthma-related nighttime symptoms more than twice a month, or receiving one or more long-term control therapies for asthma (4, 20).

Clinic staff referred potentially eligible and interested patients to a research assistant, who explained the study; obtained caregiver consent and child assent, and administered the eligibility screener (9). Providers and families were told that the study was examining communication during pediatric visits. All of the medical visits were audio-tape recorded. Children were interviewed after their medical visits. Caregivers completed self-administered questionnaires. Data was collected between 2005 and 2008.

Audio-tape coding—All of the medical visit audio-tapes were transcribed verbatim, and a detailed coding tool was developed to assess provider, child, and caregiver communication about asthma. This tool was refined and tested over a one-year period. The categories used in the coding tool for communication about asthma medications were adapted from the categories used in prior studies of provider-patient communication about medications (21–24) and the categories for child and caregiver input into the asthma management treatment plan were created based on existing literature on shared decision-making and a thorough review of the transcripts (11–13). The transcripts were reviewed by two research assistants who met twice a month with the investigators to develop and refine the coding rules until saturation of themes was achieved. The categories are described in detail below.

Using the coding tool for transcribed medical visits, coders recorded the following: (a) the number and types of questions that children and caregivers asked about asthma medications, asthma triggers and environmental trigger control, and monitoring devices such as peak flow meters, (b) whether the provider asked for the child's input into the asthma management treatment plan, (c) whether the provider included the child's input into the asthma management treatment plan, (d) whether the provider asked for the caregiver's input into the asthma management treatment plan, and (e) whether the provider included the caregiver's input into the asthma management treatment plan.

Throughout the study period, two research assistants coded 20 of the same transcripts to assess inter-coder reliability, which was calculated using inter-rater correlations. The inter-rater correlation was 1.0 for the provider asking for caregiver input into the asthma management treatment plan, 0.88 for the provider asking for child input into the asthma management treatment plan, 1.0 for the provider including caregiver input into the asthma management treatment plan, 0.88 for the provider including child input into the asthma management treatment plan, 0.97 for number of caregiver questions about asthma management, and 1.0 for whether the child asked one or more questions about asthma management.

Measures

Asthma health and medication characteristics—Medication use was assessed on the caregiver eligibility screener, which asked about asthma symptoms and medication use. When administering the eligibility screener, the research assistants showed caregivers a list of asthma medications and asked them to indicate which one(s) the child was taking. Responses were dichotomized based on whether the caregiver reported that the child was taking a controller medication versus not taking a controller medication. Asthma severity was classified as mild versus moderate/severe persistent by a research assistant based on recent symptoms and medication use reported by the caregivers when research assistants administered the eligibility screening instrument for the study (4, 5, 20). Our eligibility screening instrument utilized the primary NHLBI asthma severity classification system that was being used when the study was designed and conducted (4, 5, 20).

All child information was then reviewed by a pediatric pulmonologist or a clinical pharmacist with expertise in asthma to verify the severity classification as mild or moderate/severe persistent asthma and this classification was used in our analyses. The research assistants and pediatric pulmonologist/clinical pharmacist agreed 99.4% of the time. Percent agreement was calculated with the following formula: number of severity classifications that were the same divided by the total number of classifications multiplied by 100. Severity was classified using two different methods. The first method was medication use; any child receiving a single long-term controller agent was considered to have mild persistent asthma. Any child receiving two or more long-term controller agents was categorized as having moderate-to-severe persistent asthma. The second method classified severity based on symptom frequency. Caregivers were asked to think about their child's symptoms over the past 12 months. Subjects who reported the occurrence of any one of eight symptoms as occurring two or more times per week or who reported awakening with asthma symptoms two or more times per month was classified as mild persistent. The eight daytime symptoms included: wheezing with a cold, wheezing without a cold, an episode of wheezing that made it hard to breath or catch breath that lasted longer than a day or more, had a cough that would not go away, complained that chest felt tight or heavy, used rescue inhaler for symptoms, wheezed with exercise or running or playing hard, and coughed with exercise or running or playing hard. The nighttime symptoms asked about how often the child's sleep had been disturbed because of wheezing, coughing, chest tightness, or shortness of breath. Reports of daily symptom occurrence or awakening > 5 times a month resulted in a classification as moderate or severe persistent. In situations where the two methods (medication use and symptom frequency) resulted in discordant classification, the more severe category was used.

Sociodemographic, cultural, and visit-related characteristics—A variety of demographic, socio-cultural, and visit-related factors were examined as potential confounders. Child and caregiver age, caregiver education, and years the child had asthma were measured as continuous variables. Child and caregiver gender were also recorded. For descriptive purposes, child race was re-coded into four categories: White, African American, Native American/American Indian, or Other (includes categories of: Hispanic, Asian American, other). However, for the bivariate analyses, child race was re-coded into a dichotomous variable (White versus non-White). The child's insurance status was assessed using the following categories: none, private insurance, Medicaid, the State Children's Health Insurance Program (SCHIP), and other. How well the child thinks the provider knows him/her as a person was measured with the following categories: hardly at all, slightly, moderately well, and very well. Length of visit was measured in minutes. Whether the child was currently taking a controller medication was measured as a dichotomous variable. How long the caregiver and their family have known the doctor was measured with

the following response categories: less than one year, between 1 and 2 years, between 3 and 4 years, and more than 4 years.

Statistical Analyses—All analyses were conducted using SPSS v. 14. First, we present descriptive statistics for the child and caregiver demographic, socio-cultural, and visit characteristics and the communication variables. Second, we examine bivariate relationships between these variables using correlation coefficients, t-tests, or Pearson chi-square statistics, as appropriate.

Next, we used generalized estimating equations (GEE) to examine how child, caregiver, provider, and visit characteristics, as well as child and caregiver question-asking were associated with: (a) whether the provider included child input into the asthma management treatment plan and (b) whether the provider included caregiver input into the asthma management treatment plan. All generalized estimating equations were clustered by provider.

3. Results

Sample characteristics

The five participating clinics were all primary care pediatric practices. Forty-one providers agreed to participate in the study; two providers refused to participate for a participation rate of 95.3%. Providers completed a short demographic questionnaire after providing consent. Clinic staff referred eligible families to research assistants in the clinics. If families were interested, they approached the research assistant. We do not know how many patients were referred to the research assistants by the clinic staff because the clinic staff did not have time to track this information.

Three hundred and thirty-three of the 377 families (88%) who approached the research assistant to learn more about the study agreed to participate in the study. Two-hundred and ninety six patients of the 333 participating patients (89%) had useable audio-tape data and these patients were seen by 35 of the 41 providers who agreed to participate in the study.

Four of the 35 providers were nurse practitioners or physician assistants, and they saw seventeen of the participating children. Fifty-one percent of the providers were female. Twenty-seven of the providers were White, two were American Indian, three were African American, one was Asian, and two classified their race as other. Providers ranged in age from 30 to 70 years (mean = 44.8 years, standard deviation = 9.4).

Table 1 presents the child and caregiver demographic characteristics. Forty-six percent of the children were female. The average age of the children was 11 years. Approximately 62% of the children were White, 30% were African American, and 10% were Native American/ American Indian. In terms of the child's asthma, caregivers reported that their children had asthma for an average of six years. Seventy-two percent of these children had moderate-to-severe persistent asthma. Only three families in the sample did not have health insurance. Eighty-three percent of patients were on a controller medication.

Child question asking—Table 2 presents the extent to which children asked questions about asthma management. Only 13% of children asked one or more questions about asthma management. Children were most likely to ask about medications. Seven percent of children asked clarifying questions and 4 percent asked about how to use asthma devices (e.g. multi-dose inhalers). Only 2 children asked about peak flow meters and only 2 children asked about environmental trigger control or asthma triggers. Table 3 presents the actual questions that children asked about asthma management. Children were more likely to ask one or more

questions about asthma medications during longer visits (t-test = 3.12, $p \leq 0.01$); the average length of visits where children asked one or more asthma management questions was 18.6 minutes (standard deviation = 7.0 minutes), whereas the average length of visits where children did not ask one or more asthma management questions was 14.7 minutes (standard deviation = 8.6 minutes).

Caregiver question asking—Table 2 also presents the extent to which caregivers asked questions about asthma management. Thirty-three percent of caregivers asked one or more questions about asthma management. Caregivers were most likely to ask medication questions. Thirteen percent asked clarifying questions and 12% asked frequency of use or timing questions. Only 5% of caregivers asked environmental trigger control or asthma trigger questions and 3% asked peak flow meter questions. Table 4 presents examples of the types of questions that caregivers asked about asthma management.

Caregivers were significantly more likely to ask any questions about asthma management if their child was on one or more controller medications (Pearson chi-square = 4.04, $p \leq 0.05$). Thirty-five percent of caregivers whose children were on controller medications asked one or more questions compared to 19% of caregivers whose children were not on controller medications. Caregivers were also significantly more likely to ask any questions about asthma management during longer visits (t-test = 3.05, $p \leq 0.01$); the average length of visits where caregivers asked one or more asthma management questions was 17.3 minutes (standard deviation = 7.9 minutes), whereas the average length of visits where caregivers did not ask asthma management questions was 14.2 minutes (standard deviation = 8.6 minutes). Caregivers were significantly more likely to ask one or more asthma medication questions if they were present with younger children (t-test = 3.5, $p \leq 0.01$).

Providers asking for and including child and caregiver input into the asthma management treatment plan—Providers asked for child input into the asthma management treatment plan during only 7% of encounters. Providers included child input into the asthma management regimen during only 6% of encounters (n = 19). During 18 of these 19 visits, the provider asked for the child's input and included it, but during only one visit was the child's input included when the provider had not asked for it. Below is an excerpt from a visit where the provider asked for the child's input and included it in the asthma management treatment plan:

Provider:	The Advair now comes in an inhaler, and the one that you are used to, the purple disk? Which one do you prefer? Using an inhaler or the round disk?
Patient:	The inhaler.
Provider:	The inhaler? You felt much better? Okay. It is still the same medication it is just in a different form? It doesn't have that powdery taste.
Patient:	Alright.
Provider:	So, um, we can talk about switching your medication to an inhaler form, okay? But again it comes in different strengths. It also has the same three strengths, the 100/50, the 250/50, and the 500/50, do you remember which one it was? Did it come in the green, yellow, or red?
Patient:	I'd say green.
Provider:	Green? Cause that is the lowest. Green is the 100/50, the yellow is the 250/50, and the red is the 500/50, okay? So, it is like the stop sign: green is good, yellow is caution, red is bad, okay? So, you need to take your medicine every single day okay? Otherwise you will be back here, and you will say I don't feel good. Your Advair, you have got to take it every single day whether you are well or not, okay? So it just depends on you not feeling good and that needs to you need to carry yourself to the doctor because sometimes we need to bump up your dose of the Advair, like right now I am leaning on putting you on the middle strength of the Advair, okay? Because you have had symptoms for the last three months and then we start backing up. That's why it's important you come back, okay?
Patient:	Okay.

Provider:	In about three weeks, let's see if we need to bump him up more, or we can go down to the green but right now we are going to go with the yellow, okay? Advair, got it?
Patient:	Yep.
Provider:	And you need to use it properly, first time you use a canister of albuterol, or the Advair, whichever you have, you have to shake it good and prime it. Prime it is when you waste a few squirts ok? And then you use it, next time you use it you don't have to prime it. Ok?
Patient:	Okay.
Provider:	Do you have any questions for me?
Patient:	No.
Provider:	No? Okay.

In the above excerpt, the provider asked for the child's input, but the provider does it in a more close-ended way and the child chooses the dosage form that he prefers.

Table 5 presents the GEE results examining whether providers included child input into the asthma management treatment plan. Providers were significantly more likely to include child input into the asthma management treatment plan when the children were at visits with male caregivers ($p \leq 0.01$). Providers asked for child input during 21% of visits when children were present with male caregivers, whereas they only asked for child input during 5.1% of visits when children were present with female caregivers. Including child input into the asthma management treatment plan was not significantly associated with any of the other child, caregiver, or provider characteristics or length of visit.

Providers asked for caregiver input into the asthma management regimen during 10% of visits (N=29). Providers included caregiver input into the asthma management regimen during 10% of visits (N = 29). During 25 of the visits, the provider asked for the caregiver's input and included it, but during only four visits was the caregiver's input included when the provider had not asked for it. Below is an example of caregiver input into the asthma management regimen:

Caregiver:	(Unclear) doing so good and I thought yeah, we've been taking this medicine since he was six months old he has been taking this medicine.
Provider:	Okay.
Caregiver:	And I'm, I'm just I'm tired however I know that he has to have it because I, I, we've missed it one night. __ walked in the house he said __ get him up out of bed and give him his medicine. I know there's no way you could have given his medicine because I can hear him.
Provider:	Snoring?
Caregiver:	Yeah, he could just hear him breathing. He wasn't really snoring. It was, I mean I don't know how it was just (unclear).
Caregiver:	So he I gave him, I got him up and gave him his medicine. Um, about…
Child:	About four or five o'clock in the morning.
Caregiver:	well you know it wasn't that late. About a week after that he just, he fell asleep before I gave him his medicine and um, and it was the same thing. He just was tossing and turning and he just couldn't sleep. His breathing was just labored.
Provider:	Now and we're just on singulair and zyrtec, right?
Caregiver:	Yeah.
Provider:	That's not terrible.
Caregiver:	I know but…
Provider:	Those have really got a great safety profile.
Caregiver:	I understand but I you know I, I was just saying that I was tired of, of us doing it
Provider:	Summertime next year we'll try him off then.
Caregiver:	Okay.

In the above encounter, the caregiver is admitting that she is tired of the current medication regimen but the provider cuts off the caregiver and says they will try to get the child off of the medication next summer. By ignoring this request, non-adherence may continue which could be causing the increased need for albuterol. It is important for providers to listen and respond to concerns so that medication regimens that fit the family's lifestyle better can be put into place.

Table 6 presents the GEE results predicting whether providers included caregiver input into the asthma management treatment plan. Younger providers were significantly more likely to include caregiver input into the asthma management treatment plan than older providers ($p \leq 0.05$). Providers were significantly more likely to include caregiver input into the asthma management regimen if caregivers asked more asthma management questions during the visit ($p \leq 0.05$).

4. Discussion

Providers asked for child input into the asthma management treatment plan during less than 10% of visits which is contrary to the current clinical practice guidelines of the National Asthma Education and Prevention Program of the National Heart Lung and Blood Institute which encourages providers to jointly determine the goals of treatment with the patient and family (3, 4). Shared decision-making is not occurring to a large extent with children with asthma, because for shared decision-making to occur there needs to be a two-way exchange not only of information but also of treatment preferences (13). Providers need to consider asking and including child input into their treatment plans because including child input could possibly improve adherence and health outcomes (19, 25).

Encouraging child involvement may enhance the child's self-confidence and improve their management skills (26–28). Information received from a child may provide information that differs from the caregiver's report and may actually improve the child's care (15, 29). Future research needs to design and test interventions that can be used to facilitate child involvement during pediatric asthma visits.

Providers did not include caregiver input into the asthma management treatment plan much more than they included child input. This indicates that shared decision-making with caregivers is also not occurring very often. If caregivers asked more questions about asthma management during the visits, providers were more significantly more likely to include caregiver input into the asthma management regimen. Only one-third of caregivers asked questions about asthma management during these pediatric visits. Caregivers should be encouraged to ask questions about asthma management because it could lead to more shared decision-making occurring during pediatric asthma visits. Innovative methods to encourage caregiver question-asking could be developed and tested.

Younger providers were significantly more likely to include caregiver input into the asthma management treatment plan than older providers. Our finding is similar to that of Young et al. (30) who found that younger physicians used shared decision-making more than older physicians during depression care visits. Future research should examine how providers of all ages can be taught and encouraged to include caregiver and child input into asthma management regimens. Wales, Elwyn and colleagues conducted a randomized trial that educated physicians about risk communication and shared decision-making (31, 32). Physicians attended four workshops that were three hours each (two workshops were on risk communication and two were on shared decision-making). Shared decision-making improved after providers attended the workshops. Other countries could attempt to design

programs similar to the ones Elwyn et al. (31) used in Wales to see if the shared decision-making skills of providers can be improved.

Less than 5 percent of caregivers and less than 1 percent of children asked questions about asthma triggers or environmental trigger control. Providers should educate caregivers about what types of things might trigger their child's asthma symptoms, such as pollens, indoor mold, cigarette smoke, animal dander, cockroaches, dust mites, and other irritants. Once caregivers have been educated about common asthma triggers, they may be better positioned to identify methods for eliminating triggers or ask their providers for suggestions on how to eliminate them. Simple communication-focused interventions that encourage caregivers or children to ask "What types of things or activities might trigger asthma symptoms?" and "How could I avoid these triggers?" may help encourage trigger-related discussions during asthma visits. Our work found that environmental control strategies were discussed in less than 27% of visits (33), which further reinforces that this is an area of communication that needs improvement.

Children were significantly more likely to ask questions during longer visits. The mean visit length was approximately 4 minutes longer if children asked questions about their asthma management. Future research should examine whether child self-management skills and their asthma outcomes are improved if they ask questions during medical visits so that we can examine whether increased visit lengths might be cost effective.

The study is limited in generalizability in that it was conducted in five pediatric clinics in non-urban areas of North Carolina. Another limitation is that clinic staff referred potentially eligible patients to the research assistant, and we do not know how many patients that the clinic staff referred chose not to talk with the research assistant. However, we could not ask the clinic staff to track these numbers because of how busy the clinics were and our promise not to interrupt clinic flow. Another limitation is that we measured basic child demographics and we did not include intelligence or personality measures which could impact provider-patient communication. Another limitation is that we chose audio-taping rather than video-taping the medical visits because it is less intrusive and fewer individuals mind being audio-taped as opposed to being video-taped. Our multivariable GEE analyses might have yielded few significant findings because of the skewed nature of the outcome variables (child and caregiver input was not included into asthma management regimens very often). Despite the limitations of the study, it presents new information on child and caregiver question-asking about asthma management and the extent to shared decision-making occurs with children and caregivers during pediatric asthma visits.

Conclusions

Only 13% of children asked questions about asthma management and the majority of questions they asked were about medications. The U.S. Pharmacopoeia (USP) supports the rights of children and adolescents to receive developmentally appropriate medication information (34). Two of their guiding principles are: (a) children want to know about medicines-health care providers and health educators should communicate directly with children about medicines and (b) children's interest should be encouraged, and they should be taught how to ask health care providers questions about medicines (33). Future research should develop and test ways to find out what types of questions children have about their asthma and how to motivate children to ask more questions about their asthma management.

Providers obtained child input into their asthma management treatment plan during only 6% of encounters and caregiver input into their child's asthma management treatment plan during 10% of visits. Providers need to consider asking for and including child and caregiver input into asthma management treatment plans so that shared decision-making can occur

more frequently. Future work should develop and test interventions that train providers on how to ask for and include child and caregiver input more when asthma management treatment plans are being put together.

Acknowledgments

This project was funded by the National Heart Lung and Blood Institute (Grant # HL069837).

The project was also supported in part by grant UL 1RR025747 from the National Center of Research Resources, NIH.

References

1. NAAS, National Academy on an Aging Society. Childhood Asthma: The most common chronic disease among children, website. 2000. Available from: http://www.agingsociety.org/agingsociety/pdf/asthma.pdf
2. CDC. Summary health statistics for US Children: National health interview survey. 2008.
3. NHLBI. NIH, National Heart Lung and Blood Institute. Guidelines for the Diagnosis and Management of Asthma; Expert panel report. 2007. p. 3Publication Number 08-5846Available from http://www.nhlbi.nih.gov/guidelines/asthma/index.htm
4. NHLBI. National Heart Lung and Blood Institute, Publication Number 97-4051. 1997.
5. NIH. NAEPP. Expert Panel Report: Guidelines for the Diagnosis and Management of Asthma, Update on Specific Topics (02-5075). Washington, DC: 2002.
6. Mansour ME, Lanphear BP, DeWitt TG. Barriers to asthma care in urban children: Parent perspectives. Pediatrics. 2000; 106 (3):512–519. [PubMed: 10969096]
7. Peterson-Sweeney K, McMullen A, Yoos HL, Kitzman H. Parental perceptions of their child's asthma: Management and medication use. Journal of Pediatric Health Care. 2003; 17 (3):118–125. [PubMed: 12734458]
8. Zolnierek KBL, DiMatteo MR. Physician communication and patient adherence to treatment: A meta-analysis. Medical Care. 2009; 47:826–834. [PubMed: 19584762]
9. Howell G. Nonadherence to medical therapy in asthma: risk factors, barriers, and strategies for improving. J Asthma. 2008; 45:723–729. [PubMed: 18972285]
10. Apter A, Reisine ST, Affleck G, Barrows E, ZuWallak R. Adherence and twice-daily dosing of inhaled steroids. American Journal of Respiratory and Critical Care Medicine. 1998; 157:1810–1817. [PubMed: 9620910]
11. Berwick D. A user's manual for the IOM's "Quality Chasm" report. Health Affairs. 2002; 21:80–90. [PubMed: 12026006]
12. Institute of Medicine (IOM), Committee on Quality of Health Care in America. Crossing the quality chasm: A new health system of the 21st century. Washington, DC: National Academy Press; 2001.
13. Charles G, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Social Science & Medicine. 1997; 44:681–692. [PubMed: 9032835]
14. Tates K, Meeuweesen L. Doctor-parent-child communication. A (re)view of the literature. Social Science & Medicine. 2001; 52(6):839–851. [PubMed: 11234859]
15. Butz AM, Wasler JM, Pussifer M, Winkelstein M. Shared Decision Making In School Age Children with Asthma. Pediatric Nursing. 2007; 33(2):111–116. [PubMed: 17542232]
16. Pantell R, Stewart T, Dias J, et al. Physician communication with children and parents. Pediatrics. 1982; 70:396–402. [PubMed: 7110814]
17. Stewart T, Pantell R, Dias JK, Wells PA, Ross AW. Children as patients: a communication process study in family practice. The Journal of Family Practice. 1981; 13:827–835. [PubMed: 7031173]
18. Wissow L, Roter D, Bauman LJ, Crain E, Kercsmar C, Weiss K, et al. Patient-provider communication during the emergency department care of children with asthma. Medical Care. 1998; 36:1439–1450. [PubMed: 9794338]

19. Wassmer E, Minnaar G, Abdel Aal N, Atkinson M, Gupta E, Yuen S, Rylance G. How do paediatricians communicate with children and parents? Acta Paediatr. 2004; 93:1501–1506. [PubMed: 15513580]
20. Cabana MD, Slish KK, Nan B, Clark NM. Limits of the HEDIS criteria in determining Asthma severity for children. Pediatrics. 2004; 114:1049–1055. [PubMed: 15466104]
21. Sleath B, Roter D, Chewning B, Svarstad B. Asking questions about medication: analysis of physician-patient interactions and physician perception. Medical Care. 1999; 37:1169–1173. [PubMed: 10549619]
22. Sleath B, Tulsky JA, Peck BM, Thorpe J. Provider-patient communication about antidepressants among veterans with mental health conditions. The American Journal of Geriatric Pharmacotherapy. 2007; 5:9–17. [PubMed: 17608243]
23. Young HN, Bell RA, Epstein RM, Feldman MD, Kravitz RL. Types of information physicians provide when prescribing antidepressants. Journal of General Internal Medicine. 2006; 21:1172–1177. [PubMed: 17026727]
24. Scherwitz L, Hennrikus D, Yusim S, Lester J, Carlos Vallbon C. Physician communication to patients regarding medications. Patient Education and Counseling. 1985; 7(2):121–136. [PubMed: 10272530]
25. Bush PJ, Davidson FR. Medicinesand “Drugs”: What do Children think? Health Education Quarterly. 1982; 9:209–224. [PubMed: 7169328]
26. Vessey JA, Miola ES. Teaching adolescents self-advocacy skills. Pediatric Nursing. 1997
27. Holtzheimer L, Mohay H, Masters IB. Educating young children about asthma: Comparing the effectiveness of developmentally appropriate asthma education videotape and picture book. Child: Care, Health and Development. 1998; 24:85–99.
28. De Winter M, Baerveldt C, Kooistra J. Enabling children: Participation as a new perspective on child-health promotion. Child: Care, Health and Development. 1999; 25:15–25.
29. Guyatt GH, Juniper EF, Griffith LE, Feeny DH, Ferrie PJ. Children and adult perceptions of childhood asthma. Pediatrics. 1997; 99:165–168. [PubMed: 9024440]
30. Young HN, Bell RA, Epstein RM, Feldman MD, Kravitz RL. Physicians’ shared decision-making behaviors in depression care. Arch Intern Med. 2008; 168 (13):1368–1370. [PubMed: 18625916]
31. Elwyn G, Edwards A, Hood K, Robling M, Atwel C, Russell I, Wensing M, Grol R. Achieving involvement: process outcomes from a cluster randomized trial of shared decision making skill development and use of risk communication aids in general practice. Family Practitioner. 2004; 21:337–346.
32. Edwards A, Elwyn G. Involving patients in decision making and communication risks: a longitudinal evaluation of doctors’ attitudes and confidence during a randomized trial. Journal of Evaluation in Clinical Practice. 2004; 10 (3):431–437. [PubMed: 15304143]
33. Washington D, Yeatts K, Sleath B, Ayala G, Gillette C, Williams D, Davis S, Tudor G. Communication and education about triggers and environmental control strategies during pediatric asthma visits. Patient Education and Counseling. 2011; 23:53–56.
34. Bush P, Ozias J, Walson P, Ward R. Ten guiding principles for teaching children and adolescents about medicines. Clinical Therapeutics. 1999; 21:1280–1284. [PubMed: 10463524]

Table 1

Child and Caregiver Demographic Characteristics (N = 296)

	Percent (N)
Child Age	
Mean (SD) Range	11.1 (2.4) 8–16 years
Child Gender	
Male	53.7 (159)
Female	46.3 (137)
Child Race	
White	61.5 (182)
African American	30.1 (89)
Native American/American Indian	10.1 (30)
Other	6.1 (18)
Asthma Severity	
Mild persistent	28.0 (83)
Moderate/Severe persistent	72.0 (213)
Number of years living with asthma	
Mean (SD) Range	6.0 (3.9) 9–16 years
Caregiver relationship status	
Never	16.2 (48)
Married	57.8 (171)
Separated	9.5 (28)
Divorced	12.5 (37)
Widowed	3.0 (9)
Caregiver Age	
Mean (SD) Range	42.0 (8.4) 27–81 years
Caregiver Gender	
Male	14.2 (42)
Female	85.8 (253)
Caregiver Education in Years	
Mean (SD) Range	12.8 (2.5) 2–20 years
Insurance Type	
None	1.0 (3)
Private	26.4 (78)
Medicaid	51.7 (153)
State Children’s Health Insurance Program	17.6 (52)
Other	2.7 (8)

Table 2

The frequency and types of questions asked about asthma by children and caregivers (N=296)

Types of Questions Asked	Subcategory	Children Percent (N)	Caregivers Percent (N)
Medications	Asks for clarification or checks for understanding	7.1 (21)	13.2 (39)
	Barriers or Side effects	0.7 (2)	3.7 (11)
	Device/Technique	3.7 (11)	4.7 (14)
	Dosage	0 (0)	2.0 (6)
	Duration	0.7 (2)	3.0 (9)
	Frequency/Timing	3.0 (9)	11.5 (34)
	Purpose	0.3 (1)	3.0 (9)
	Quantity/Supply	1.0 (3)	6.4 (19)
	School use	0.7 (2)	2.4 (7)
	Type of medicine	0 (0)	2.4 (7)
	Other	1.0 (3)	3.4 (10)
Peak Flow Meter		0.7 (2)	3.0 (9)
Environmental Trigger Control or Asthma Triggers		0.7 (2)	4.8 (14)

Table 3

Actual questions asked by the children

Types of Questions Asked	Subcategory	Actual Question
Medication	**Asks for clarification or checks for understanding**	Which one is that?
		It is, ain't it?
		That's the maxair stuff?
		Oh, it is?
		What's that one?
		The one I ((sounds of inhaling))? … the purple thing, advair, what you call it?
		The inhaler?
		Them little white pills?
		The purple thing advair what you call it?
		So is that the advair?
		The q-var?
		So what do I get?
		Is that like with the (unclear)?
		My inhaler?
		What is that?
		What is that again?
		What's that?
		And then that's (unclear) for hours?
		I need an inhaler?
		Was I supposed to use the um, pulmicort once a day?
		So that's eight puffs a day?
	Barriers or Side Effects	Is it going to taste better?
		It won't hurt me will it?
	Device/Technique	What's a spacer?
		Mom is the spacer that green thing?
		How many times do I click it?
		You can tilt it?
		Was I supposed to take that um, stuff for my nose?
		What's a disc?
		When you say two puffs do I close it again and do it?
		Okay, how long should I hold it?
		Is that a right?
		Can I try it?
		What's that?
	Duration	Twelve hours?
		Oh, so I still use both?

Types of Questions Asked	Subcategory	Actual Question
	Frequency/Timing	As many times a day?
		If I go swimming or something like that will I still take the albuterol?
		Ok so before we get active go ahead and do it?
		Well, am I supposed to use both of these things twice a day (unclear)?
		Two per day?
		At bedtime?
		Once a day?
		How many times do I take that?
		I do it when I don't need it?
	Purpose	Is it, was it like the albuterol?
	Quantity/Supply	Will I get it today?
		Does that have medicine in it?
		Will I get to keep the inhaler?
	School Use	Can I get one of those pump things for school?
		Do you think I should take it to PE?
	Other	What's a pulmicort?
		Can I (unclear) if I take the medicine?
		Can I throw the pulmicort in the trash can?
Peak Flow Meter		So my green is like two seventy?
		What happens when it's red?
		Have I got to use that?
Environmental Trigger Control or Asthma Triggers		How about exercise at my daycare?
		Just like me jumping on the trampoline?

Table 4

Actual questions asked by the caregivers

Types of Questions Asked	Subcategory	Actual Question
Medication	Asks for clarification or checks for understanding	So, it is that one you turn at the bottom?
		Do you think that would be something appropriate to do?
		So actually he don't need the machine anymore just the spacer?
		Does she need both of those together?
		Is it the advair or the inhaler, I forgot?
		Advair is the purple thing, what's the other?
		Which one is she supposed to be on?
		When he finishes that do another puff and do the same thing?
	Barriers or Side Effects	What are the side effects of singulair?
		There is not any kind of danger in that advair is there?
		Are you going to keep her on this … it made her sick and throw up?
		And it's safe together?
	Device/Technique	The thing like what you just used?
		But you don't turn like the advair every time?
		Okay, so when he is wheezing that is when he uses [the inhaler with the spacer]?
		You were talking about doing a nebulizer treatment when you say twenty minutes or does it matter which?
	Dosage	The dose he is taking is still okay?
		Is it the same one, but it's the higher dose?
		Umm, does he need to go up on that or is that still okay?
	Duration	Okay, he's not going off the singulair?
		Yeah, now how long does he need that?
	Frequency/Timing	The steroid inhaler would he do it every day?
		What time do I give him the prednisone in the morning or at night?
		But you do want him before he goes outside to play to use?
		The advair that she takes is everyday two times a day, right?
		Is that one the same like in the morning or just as needed?
	Purpose	Should that help her too with like exercising and stuff like that?
		For like a rescue?
		Would you expect that with his advair using it twice a day the way you had recommended that at some point he would be able to run as hard as he wanted to?
		Is that why it didn't work at all on Sunday then?
	Quantity/Supply	Does he need two prescriptions one for school and one for home?
		How will I know the advair gets low?
		So I would need probably two air chambers then?
		It does, how much it have in it?

Types of Questions Asked	Subcategory	Actual Question
		So there's enough in there for three months?
		Will you write me a new prescription for singulair?
		How often is she supposed to get a new machine?
	School use	Do you think he would need um, some medicine at school?
		So there will be two?
		Will she have one for home and one to keep at school?
	Type of medicine	All those are rescue type medicine?
		But it's not albuterol?
		What is serevent another antibio, I mean um, um, steroid?
		So Advair is an inhaled corticosteroid right?
	Other	Can you give him a pill if you give him that?
		Because doesn't singulair contain an antihistamine?
		If he needs his inhaler he can still use that?
		Okay, it seems like the pills he takes now is chewable, the 10's are not chewable?
		Okay, so that is something you do daily?
Peak Flow Meter		Yeah, I just wasn't sure what it was supposed to go up to for him.
		How many do you want me to record?
		Okay, now how often does he do that little thing?
		So we have to carry that with us too then?
Environmental Trigger Control or Asthma Triggers		I know something else I was going to ask you, he cuts grass, is it good for him to cut grass?
		How would playing the clarinet, flute, or drums affect her asthma?
		Do you think this season is going to be worse with the drought on allergies, ragweed, and stuff?
		Do you think that mold in our house, we have an old house?
		Do you think the cat would be a factor that we should eliminate?
		So, she shouldn't be around him smoking and stuff, that's bad on her asthma?

Table 5

Generalized estimating equation results predicting whether provider includes child input into the asthma management regimen (N=296)

Independent Variables	Odds Ratio (95% Confidence Interval)
Child's severity of asthma- moderate severe	0.85 (0.23, 3.10)
Years living with asthma	1.03 (0.90, 1.19)
Taking a controller medication	0.97 (0.30, 3.20)
Child age in years	1.15 (0.86, 1.53)
Child gender- female	0.84 (0.20, 3.46)
Child race- White	2.34 (0.86, 6.37)
How well child feels provider knows them as a person	0.77 (0.36, 1.66)
Caregiver gender- female	0.19 (0.06, 0.57)**
Caregiver years of education	1.01 (0.87, 1.18)
Provider gender- female	0.65 (0.15, 2.77)
Provider race- White	0.26 (0.06, 1.13)
Provider age	0.95 (0.88, 1.03)
Length of visit	1.00 (1.00, 1.00)
Did the child ask any asthma management questions	1.11 (0.18, 6.94)
Number of caregiver asthma management questions	1.20 (0.85, 1.71)

** $p < 0.01$

Table 6

Generalized estimating equation results predicting whether the provider includes caregiver input into the asthma management regimen (N=296)

Independent Variables	Odds Ratio (95% Confidence Interval)
Child's severity of asthma- moderate severe	0.63 (0.22, 1.80)
Years living with asthma	1.01 (0.98, 1.03)
Taking a controller medication	1.41 (0.34, 5.82)
Child age in years	0.87 (0.70, 1.09)
Caregiver age	1.00 (0.94, 1.06)
Caregiver gender- female	4.11 (0.50, 34.04)
Caregiver race- White	0.52 (0.19, 1.47)
Caregiver years of education	1.07 (0.88, 1.30)
How long you and your family have known the doctor	1.79 (1.00, 3.22)
Provider gender- female	1.02 (0.32, 3.28)
Provider race- White	0.43 (0.10, 1.79)
Provider age	0.93 (0.87, 0.99)*
Length of visit	1.00 (1.00, 1.00)
Did the child ask any asthma management questions	1.84 (0.51, 6.67)
Number of caregiver asthma management questions	1.39 (1.06, 1.81)*

* $p < 0.05$