

Provider-Caregiver-Child Discussions About Risks Associated With Asthma Control Medications: Content and Prevalence

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Summary. Objectives: The objectives of this study were to: (1) describe the extent to which general pediatric providers discuss risks associated with asthma control medications with families, and (2) examine factors that are associated with risk discussions. Study Design: This study was a cross-sectional secondary analysis of audio taped medical visits involving 35 pediatric providers and 248 children with asthma with their caregivers. Transcripts of the visits were coded for discussions about asthma medication risks. Generalized estimating equations were used to analyze the data. Results: Providers discussed asthma control medication risks during 23% of visits. Risks were more likely to be discussed when the visit was longer and when the provider prescribed a new asthma control medication. When providers discussed asthma control medication risks, they were most likely to ask the family general questions and make general statements. Across all of the visits, caregivers asked a total of 16 questions and made a total of 20 statements about risks associated with asthma medications; children asked a total of 3 questions and made two statements about risks associated with asthma control medications. Conclusion: Providers discussed risks associated with asthma control medications in less than one-quarter of medical visits. Providers should involve families in discussions about risks associated with medications during every visit to assess potential barriers to medication adherence. **Pediatr Pulmonol.** © 2013 Wiley Periodicals, Inc.

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INTRODUCTION

Childhood asthma is a significant public health problem. Asthma affects about nine million children in the United States alone.^{1–2} It is characterized by inflammation and constriction of the airways, leading to breathing difficulties.³ Children diagnosed with asthma are likely to experience symptoms that negatively affect

everyday living. The onset of symptoms can lead to limited daily functioning, decreased quality of life, and avoidance of physical activities. The current treatment for asthma consists of “rescue” medications and “control” medications. “Rescue” medications are for immediate relief of an asthma exacerbation while “control” medications are to be taken on a daily basis to reduce

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the likelihood of an exacerbation. However, parent and children's concerns about the risks of asthma control medications have been shown to be prevalent and associated with poor adherence to control medications.^{4–7} Specific concerns that have been raised include: reduction in growth velocity and linear growth, dependence on the medication, and a belief that inhaled corticosteroids are unnecessary when the patient is not experiencing symptoms.^{3,5}

Medical providers are an ideal resource for families to obtain information about the risks and benefits of using asthma control medications. Effective communication between providers and patients is associated with positive health outcomes, including improved medication adherence.^{8,9} National guidelines encourage providers to discuss risks and benefits of asthma control medications with patients at every visit, which may alleviate concerns and result in improved asthma control medication adherence.³ Further, in order for true shared-decision making to occur, providers must discuss and educate about the risks of treatment.⁹

Few studies have investigated provider-caregiver-child communication, and instead have focused on provider-caregiver communication.^{10,11} When studies have examined child participation during medical visits, researchers have found that children rarely speak during visits. Both medical providers and parents restrict children's participation in the visit, even though the restriction may be unintentional.¹⁰ Research shows that patient-centered care may be associated with improved health outcomes and satisfaction with the visit, but very few providers engage in patient-centered discussions in visits in adults and children.^{9,12–14} Given that prior research has shown that patients know little about the risks associated with the medications they are taking, it is important to research how often providers discuss medication risks with families.^{15,16}

Prior research examining provider-child-caregiver communication has found that increased parent participation was more likely when both caregivers were present during the visit, when the physician had been in practice longer, and when the medical visit was longer.¹⁷ Also, prior research has shown that both children and parents speak more during a medical visit when the physician is female.¹⁸ Another study found that 76% of patients wanted to hear all risks associated with their medications, no matter how rare. Interestingly, those with lower education and lower income wanted more information about risks, which may occur because they may be uncomfortable dealing with numbers.¹⁹

To our knowledge, this is the first study to examine the extent to which providers discuss risks of asthma medications with caregivers and children. The objectives of the study were to: (1) describe the extent to which primary care pediatric providers discuss risks associated

with asthma control medications with families and (2) examine the relationship between child, caregiver, provider, and clinic visit characteristics and discussions about risks associated with asthma control medications. We hypothesized that discussions about medication risks would be more likely to occur when: more than one caregiver was present during the medical visit, when the provider was older, when the medical visit was longer, when the physician was female, the family had a lower income, and the caregiver had fewer years of education.

METHODS

Overview

The University of North Carolina-Chapel Hill Institutional Review Board approved this study. This study was a secondary analysis of cross-sectional audiotaped clinic visit data collected from a previous National Heart, Lung, and Blood Institute funded study that examined provider-caregiver-child communication about asthma in primary care visits. The original study did not examine communication about risks associated with asthma control medications. The original study examined the relationship of provider-caregiver-child communication and asthma control medication adherence 1 month later. The data were collected from June 2006 through October 2009. The study sample includes 295 children with persistent asthma and 35 medical providers (physicians, physician assistants, and nurse practitioners) from North Carolina. Providers, children, and their primary caregivers were recruited from five primary care pediatric clinics, all of which were located in North Carolina. Study data included de-identified clinic visit audiotapes, child interviews, and caregiver surveys.

PARTICIPANTS

Children were eligible for the original study if they: (1) were between the ages of 8 and 16, (2) were able to speak English and could read the assent form, (3) had been seen at the clinic at least once before, (4) 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 (5) 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.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 an eligibility screener. The research assistant then followed the caregiver and child back to the room where

the child saw the provider. The research assistant then set up a microphone and audio-recorder when the provider came in the room to start the consultation. Providers and families were aware that they were being recorded. After the visit, the research assistant came back in and stopped the recording. Children were interviewed immediately after their medical visits and caregivers completed self-administered questionnaires.

Measures

Child Demographic Characteristics. The following variables were collected by child self-report: child age in years, child gender, and child race. For descriptive purposes, child race was coded into four categories: White, African American, Native American/American Indian, or Other. For the bivariate and multivariate analyses, child race was dichotomized (white, nonwhite).

Caregiver Demographic Characteristics. The following variables were obtained from caregiver self-report: age in years, caregiver gender, years of education, total household income, reason for visit, whether the caregiver was married (dichotomous, yes/no), and the number of children per household (continuous). For descriptive purposes, total household income was assessed as a categorical variable with the following categories: Less than \$10,000, \$10,000–\$19,999, \$20,000 through \$29,999, \$30,000–\$49,999, \$50,000–\$69,999, and \$70,000 or more. For the bivariate and multivariate analyses, total household income was dichotomized as \$19,999 or less versus \$20,000 or more. This was chosen because \$20,000 or less was classified as the federal poverty level in 2006 for a family of four, when data collection for the parent study commenced.²¹

Provider Demographic Characteristics. The following provider characteristics were assessed: age in years, gender, and race. Provider race was measured as four categories: White, African American, Native American/American Indian, or Other. Like child race, provider race was dichotomized (white, nonwhite) for the bivariate and multivariate analyses.

Provider Discussion and Medical Visit Characteristics

Audiotape Coding. All of the medical visit audiotapes were transcribed verbatim with removal of all personal identifiers. A detailed coding tool was developed to assess provider-caregiver-child communication about medication risks. The coding tool was developed specifically for this study. All of the transcripts were coded using this coding tool by professional transcriptionists. Their work was regularly checked by the PI of the parent study (BLS).

Using the coding tool for transcribed medical visits, coders recorded the following dichotomous variables:

was there a discussion about asthma control medication risks, did the provider start at least one new asthma control medication during the visit, did the provider continue at least one asthma control medication during the visit, and did the provider have the child discontinue an asthma control medication during the visit. Risks were defined as any adverse effect or potential adverse effect that children could experience as a result of using an asthma control medication.

The first author (CG) trained another coder (3rd year pharmacy student) to ensure that the coding was reliable. After initial training, both coders coded 20 of the same transcripts throughout the study period to assess inter-coder reliability using Cohen's kappa coefficient. Inter-coder reliability was 1.0 for discussions about medication risks. All discussions about risks were excerpted from the transcripts. The coders then analyzed each excerpt to identify the main themes discussed. Categories of risk communication were identified based on the transcript review. The name for each category identifies the main idea of the question/statement. The coders then coded 30 of the same transcripts to check for inter-rater reliability regarding names of categories. The categories for risk questions that were created by examining the actual discussion of the communication were: asking for clarification, bad taste, cough, dose, drug–drug interaction, general, medication causing harm, probability of risks occurring, and weight gain. The categories for risk statements that were created by examining the discussions about risks were: anabolic steroid risks, assurance, bad taste, concerns in media, dose, drowsiness, drug–drug interaction, feels like taking albuterol, general, headache, hyper-activity, long-term effects, medication causing harm, nosebleeds, reduced immunity, reduction in growth velocity, safety, thrush, and unaware of risks caused by medication.

Statistical Analysis

All analyses were conducted using SAS v9.3. First, we present descriptive statistics for the demographic, clinical, and communication variables. Next, we present examples of the actual discussions about risks associated with asthma control medications.

Finally, we used generalized estimating equations (GEE) to examine how child, caregiver, provider, and visit characteristics were associated with discussions of asthma control medication risks. Patients were clustered by provider. An alpha level of 0.05 was used to assess statistical significance. GEE results are presented as odds ratios. To be included in these analyses, providers had to discuss at least one asthma control medication during the visit (N = 248). In other words, children whose visits did not include any discussion about asthma control medications were not included in these analyses.

RESULTS

Demographics

Table 1 shows the child and caregiver demographic characteristics of our sample. The mean age of the children was 10.9 years (SD = 2.4). Females comprised 43.2% of the sample (n = 107). Children who had moderate/severe persistent asthma comprised 75.4% of the sample (n = 187).

The mean age of caregivers was 41.1 years (SD = 8.4). Most caregivers were female (85.8%) and married (58.8%). The mean years of caregiver education was 12.8 (SD = 2.3) and the mean number of children per household was 2.4 (SD = 1.3). A family income of \$30,000 through \$49,999 was chosen by 22.6% of caregivers. The mean age of providers in our sample was 44.0 years (SD = 9.3). Most providers were white (77.1%), female (51.4%), and physicians (88.6%).

Communication and Medical Visit Characteristics

The mean length of the medical visits was 15.8 minutes (SD = 8.7 min, Range = 2.5–45.7 min). There were discussions about asthma control medication risks during 23.0% (n = 57) of those medical visits.

Qualitative Description of Risk Discussions-Provider Questions and Statements. Table 2 presents the categories of questions about risks that medical providers asked during

TABLE 1—Child and Caregiver Demographic Characteristics (N = 248)

	Percent (n)
Child-reported characteristics	
Child age	
Mean (SD), range	10.9 (2.4), 8–16 years
Child female	43.2 (107)
Child race gender	
White	61.3 (152)
African American	31.5 (78)
Native American/American Indian	9.3 (23)
Other	6.0 (15)
Caregiver-reported characteristics	
Caregiver age	
Mean (SD), range	41.1 (8.7), 26–80 years
Caregiver female gender	85.8 (253)
Family income ¹	
Less than \$10,000	21.0 (52)
\$10,000–\$19,999	20.2 (50)
\$20,000–\$29,999	13.7 (34)
\$30,000–\$49,999	22.6 (56)
\$50,000–\$69,999	7.3 (18)
\$70,000 or more	12.9 (32)
Caregiver education (years)	
Mean (SD), range	12.8 (2.3), 6–19 years
Clinical characteristic	
Asthma severity	
Moderate/severe persistent	75.4 (187)

¹Does not add to 100% because of missing data (n = 6).

TABLE 2—Categories of Questions Providers Asked about Risks during Medical Visits (N = 57*)

Category	Percentage of visits (N)
Asking for clarification	1.8 (1)
Bad taste	1.8 (1)
Cough	0
Dose	0
Drug–drug interaction	0
General	8.8 (5)
Medication causing harm	1.8 (1)
Probability of risks occurring	0
Weight Gain	0

*Visits with discussions about risks associated with asthma control medications.

visits. Providers asked a total of nine questions to caregivers and children about risks of asthma control medications. Providers were most likely to ask general, non-specific questions such as, “So you emailed me that you are concerned that ___ Singulair gave him kind of these funky side effects?”

Table 3 presents the types of statements that providers made about risks during these visits. Providers made a total of 99 statements about risks associated with asthma control medications and were most likely to make general, non-specific statements and statements about safety. The following excerpt presents a discussion about how providers spoke in general terms about the risks of asthma control medications.

Caregiver: When the steroids were in her system she had really good health

MD: Yeah but you don’t want to do that all the time

TABLE 3—Categories of Statements Providers Made about Risks during Medical Visits (N = 57*)

Category	Percentage of visits (N)
Anabolic steroid risks	5.3 (3)
Assurance	7.0 (4)
Bad taste	12.3 (7)
Concerns in media	1.8 (1)
Dose	5.3 (3)
Drowsiness	5.3 (3)
Drug–drug interaction	1.8 (1)
Feels like taking albuterol	1.8 (1)
General	21.1 (12)
Hyper-activity	3.5 (2)
Long-term effects	3.5 (2)
Medication causing harm	8.8 (5)
Reduced immunity	3.5 (2)
Reduction in growth velocity	7.0 (4)
Safety	14.0 (8)
Thrush	12.3 (7)
Unaware of risks caused by medication	1.8 (1)

*Visits with discussions about risks associated with asthma control medications.

Caregiver: No right maybe if it's just in there (unclear)

MD: In the lungs

Caregiver: Yeah

MD: And it tends not to have effect all over the body because we don't want to do that

Caregiver: Yeah

In the above excerpt, the caregiver and provider are discussing the benefits of an asthma medication. The provider then tells the caregiver: "you don't want to do that all the time" "And it tends not to have effect all over the body because we don't want to do that." This was the entirety of the risk communication during that visit.

Qualitative Description of Risk Discussions-Caregiver Questions and Statements

Table 4 presents the types of questions that caregivers asked about the risks associated with asthma control medications. Caregivers asked a total of 16 questions. Caregivers were most likely to ask the provider if the asthma control medication was going to harm the child, such as "And that [montelukast] won't hurt him?"

Caregivers made a total of 20 statements about the risks associated with asthma control medications. Caregivers were most likely to make general, non-specific statements and statements about headaches. An example of a general risk statement from the caregiver is: "We did Advair [fluticasone and salmeterol] one time and I didn't like that at all." An example of a statement about headaches is: "I took his Singulair [montelukast] away, he has not complained to me about headaches."

Qualitative Description of Risk Discussions-Child Questions and Statements

Children asked a total of three questions about risks associated with asthma control medications. Children asked one question each about anabolic steroid risks, bad taste, and the medication causing harm. An example of a

child question about anabolic steroid risks is: "Wait, does steroids um, cut off my fat or something?" An example of a child question about the bad taste of the asthma control medication is: "Is it going to taste better?"

Children made a total of two statements about risks associated with these medications, which were both anecdotal after the parent made a statement about the risk. The next excerpt shows a typical discussion with the caregiver starting the risk discussion:

MD: Yeah, the Advair is one that you don't want to do right together. You do it in the morning and at night and it will make a big difference. If you don't use it, it can't help you when you start having trouble breathing.

Caregiver: Actually he was using the Advair everyday twice a day like he was supposed to been and he started complaining of a sore throat.

MD: Uh, huh.

Patient (Child): Like I couldn't swallow or nothing.

MD: Then you need to make sure you rinse out your mouth after you use the Advair right afterwards.

The above excerpt starts with the provider telling the patient that taking the medication twice daily will benefit the child. The caregiver then states that the child had been taking Advair twice daily as directed but experienced a sore throat. The child then speaks anecdotally from what the caregiver said. The provider then instructs the child to rinse his/her mouth out after they use the control medication to prevent future sore throats.

Multivariate Results

Table 5 presents the GEE results examining the association between discussions of medication risk and characteristics of the child, caregiver, provider, medical visit, and communication. Risks were significantly more likely to be discussed when the visit was longer (OR = 1.10, 95% CI = 1.05–1.15) and when at least one new asthma control medication was prescribed (OR = 3.24, 95% CI = 1.56–6.72).

DISCUSSION

In our clinic-based sample, providers rarely discussed medication risks with children and their caregivers. According to clinical practice guidelines of the National Asthma Education and Prevention Program of the NHLBI, it is important for providers to discuss medication risks with children who have persistent asthma and their caregivers at every asthma visit.³ The goal of the discussion could be to screen for barriers to adherence or to a change of medication if the risk is too bothersome.³ The discussion can also include caregiver or child concerns about risks associated with asthma control medications.³

TABLE 4—Categories of Questions Caregivers Asked about Risks during Medical Visits (N = 57*)

Category	Percentage of visits (N)
Asking for clarification	1.8 (1)
Bad taste	3.5 (2)
Cough	1.8 (1)
Dose	3.5 (2)
Drug–drug interaction	1.8 (1)
General	3.5 (2)
Medication causing harm	8.8 (5)
Probability of risks occurring	1.8 (1)
Weight gain	1.8 (1)

*Visits with discussions about risks associated with asthma control medications.

TABLE 5—GEE Results Predicting Discussions about Medication Risks with Children and Caregivers (N = 248)

Variable	OR	95% CI	P-value
Child age	0.91	0.78–1.07	0.26
Child sex-male	1.99	0.74–5.37	0.18
Child race-white	1.20	0.46–3.11	0.71
Asthma severity-moderate/severe persistent	1.34	0.57–3.18	0.50
Patient on/prescribed inhaled corticosteroid-yes	3.22	0.77–13.44	0.11
Provider age	1.01	0.97–1.05	0.62
Provider sex-female	1.73	0.74–4.04	0.20
Provider race-white	0.80	0.26–2.44	0.69
Caregiver age	1.00	0.96–1.03	0.85
Caregiver sex-female	1.56	0.47–5.22	0.47
Caregiver education	0.99	0.85–1.14	0.86
Family income above \$20,000	0.84	0.35–2.03	0.70
Length of visit-minutes	1.10	1.05–1.15	0.00
Other caregiver present during visit-yes	1.06	0.22–2.10	0.94
Asthma visit-yes	1.33	0.58–3.04	0.50
At least one new asthma control medication started-yes	3.24	1.56–6.72	0.00
At least one new asthma control medication continued-yes	0.89	0.37–2.13	0.79
At least one new asthma control medication discontinued-yes	2.58	0.84–7.96	0.10

When providers start the discussion about asthma control medication risks, they could ask the following question to both children and caregivers: “What concerns do you have about your asthma medication?” This simple, open-ended question can be used to gauge any problems the family may have while using the medication and is also a way for providers to tailor their discussion to the family’s specific concerns. It is important for providers to engage families in discussions about healthcare for true shared-decision-making to occur.^{9,22–24} Discussions about medication risks should occur with children and caregivers separately to give children the opportunity to talk without infringing on the caregiver’s ability to speak.

Providers were significantly more likely to discuss risks when the visit was longer and when the provider prescribed a new asthma control medication during the visit. Future research should investigate the relationship between the length of the visit and risk discussion because it is not clear whether or not discussions about the risks of asthma control medications directly leads to longer visits. Providers also need to establish an open dialogue with families about their concerns of their medications and continually ask them if they have any problems or concerns with using their asthma medications. This may help the provider to identify potential barriers to medication adherence and may help alleviate concerns about risks that children or caregivers may have.

Confirming earlier research,^{10–11} children rarely spoke during their clinical visits while providers and their

caregivers spoke the most. Interestingly, the only time that children spoke on their own about risks of their asthma medication, they asked questions. When children made statements, it was only to add to the caregiver’s statement. The US Pharmacopeia recommends that all children should be involved in discussions with health care providers and that they should receive age-appropriate education.²² Providers should also use the “Teach-Back Method” of confirming understanding of the risk concepts that were discussed during the visit.²⁵

The study’s generalizability is limited by being conducted in five pediatric clinics in North Carolina. This study only examined one visit per child and risks may have been previously discussed, especially for children whose provider did not prescribe any new asthma control medications. However, the national asthma practice guidelines recommend that providers discuss risks at every visit to monitor barriers to adherence and address any concerns that may lead to decreased control medication adherence. Our study is also limited because participants may have altered their behavior because they knew they were being recorded. However, providers were blinded to the hypotheses of this particular study because the study hypotheses were developed after the parent study concluded enrollment.

Despite the study’s limitations, this study is one of the first studies to present information on the extent to which providers discuss asthma control medication risks with children and their caregivers during routine pediatric medical visits. Our study found that discussions about medication risks rarely occur and that when they do occur, children are most likely to be left out of the discussion. Providers need to ask every family about their concerns or problems with using their asthma medications at every visit, not just when prescribing new medications.

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