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Child and caregiver reported problems in using asthma medications and question-asking during pediatric asthma visits

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Abstract

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Declarations
There is nothing to declare.

Conflict of Interest
The authors have no conflict of interest to disclose.

Objectives—The objectives of the study were to describe the extent to which lay caregivers and children who reported asthma medication problems asked medication questions during their medical visits.

Methods—Children with asthma ages 8 through 16 and their caregivers were recruited at five pediatric practices and their medical visits were audio-tape recorded. Children were interviewed after their medical visits and caregivers completed questionnaires. A home visit was conducted one month later. Generalized estimating equations were used to analyze the data.

Key findings—Two hundred and ninety six families participated. Among those caregivers who reported asthma medication problems, only 35% had asked at least one medication question during the visit. Among children who reported asthma medication problems, only 11% had asked at least one medication question during their consultation Caregivers and children who reported a problem with their asthma medications were significantly more likely to have asked medication questions if providers had asked more questions about control medications. Children who reported higher asthma management self-efficacy were significantly more likely to have asked an asthma medication question.

Conclusions—Only one in three caregivers and one in ten children who reported an asthma medication problem asked a question during their medical visits and many still reported these problems one month later. Pharmacists should encourage caregivers and children to report problems they may be having using their asthma medications.

Keywords

adherence; asthma; pediatric; communication

Introduction

Asthma is the most common chronic condition among U.S. children.[1, 2] In the U.S., asthma affects more than 6 million children and accounts for an estimated 20 billion dollars in health care costs annually.[3] The 2001 U.S. Institute of Medicine report endorsed patient-centered care and recommended that health care professionals implement the shared decision-making model in clinical settings.[4, 5] However, little empirical research, especially in pediatric settings, has actually examined the extent to which shared decision-making is used in practice with families.

For shared decision-making to occur, there must be a two-way exchange of information and treatment preferences.[6] In order for this two-way exchange to occur in pediatric settings, both children and caregivers should be able to ask questions and state preferences about treatment options. 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 ask questions or seek information from the provider about asthma management.[7–12] However, the limited literature that is available suggests that child and caregiver question-asking is minimal. In fact, Wassmer et al.[7] found that caregivers sought information during 13% of pediatric visits and children asked for information during only 3% of visits.

In our prior work we found that only 33% of caregivers and 13% of children asked asthma management questions during pediatric office visits; the majority of these questions were about medications.[13] One could assume that the relative lack of caregiver and child question-asking may, in part, be caused by families' general lack of questions or concerns. However, we also found that 87% of these same children reported a problem or concern in using their asthma medications, 31% of caregivers reported that their children were bothered

by medication side effects, and 29% of caregivers were not sure if their children were using their inhalers the way that they should.[14] No prior work has examined whether caregivers or children who report asthma medication problems ask their providers questions about these problem areas. Although we have examined question-asking more generally in a previous manuscript[13], we have not specifically examined whether caregivers and children who report asthma medication problems had asked questions about these problems during their medical visits. This is important to understand, because patients who report problems with medications, such as side effects, tend to be less adherent to their medications. Moreover, the findings from this manuscript have implications for pharmacists, because pharmacists are in an optimal position to solicit and answer caregiver and child medication questions when they are filling their asthma prescriptions and pharmacists can play an important role in medication management.

The primary objective to the study was to examine the extent to which caregivers and children who reported asthma medication problems asked medication questions during their medical visits. The secondary aims were to examine: (a) the association, among caregivers and children who reported asthma medication problems, between the socio-demographic variables and whether caregivers and children had asked medication questions during their medical visits and (b) the extent to which caregivers and children still reported the same medication problems one month after the visit at a home visit interview.

Methods

Participants

The study was approved by the University of North Carolina Institutional Review Board (IRB). Providers from non-urban areas were recruited at five pediatric practices in North Carolina and consent was obtained. The principal investigator presented the project to each of the providers at each clinic during a lunch hour and obtained provider consent. Children and their caregivers of these participating providers were recruited between 2006 and 2009 by a research assistant. Each clinic had its own research assistant. Children were eligible if they: (a) were between the ages of 8 and 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.[15, 16] Both the child and caregiver needed to participate in order to be eligible.

Clinic staff referred potentially eligible patients who were interested in learning more about the study to a research assistant. The research assistant explained the study, obtained caregiver consent and child assent in accordance with IRB requirements, and administered the eligibility screen. All of the medical visits were audio-tape recorded. Children were interviewed after their medical visits. Caregivers completed self-administered questionnaires immediately after the visit while their child was being interviewed by the research assistant. The research assistant coordinated all data collection. A 30-minute home visit was conducted one month later by the clinic based research assistant.

Measures

Demographic and clinical characteristics—Asthma severity was classified as mild versus moderate/severe by a research assistant based on recent symptoms and medication use reported by the caregivers upon enrollment into the study.[4, 13,15,16] Our eligibility screening instrument utilized the primary asthma severity classification system that was being used when the study was designed and conducted.[4, 13, 15,16]

For descriptive purposes, child race was re-coded into four categories: White, African American, Native American/American Indian, or Other. However, for the bivariate analyses, child race was re-coded into a dichotomous variable (White, non-White). The child's insurance status was measured as: none, private insurance, Medicaid, the State Children's Health Insurance Program (SCHIP), and other. Caregiver self-reported education was measured in years. Length of the medical visits was measured in seconds by the research assistant who transcribed the audio-tape into text.

Child reported asthma management self-efficacy was measured at the home visit using a 14-item scale (α=0.87).[17] Child reported outcome expectations for asthma medications was measured as a continuous variable using an adapted version of Holden's 5-item outcome expectations scale(α=0.64).[18] Caregiver asthma management self-efficacy was measured as a continuous variable using a 13-item scale that has a reliability of 0.87.[17] Caregiver outcome expectations was measured as a continuous variable with a 5-item scale that has a reliability of 0.72.[18]

Child and caregiver reported medication problems

Problems with medications were assessed on the child interview and caregiver questionnaire immediately after the medical visit and then one month later at a home visit. Children were asked if they had had a problem in using asthma medications in each of the following areas: side effects, hard to remember when to take, hard to use medications at school, not sure they are using their inhalers correctly, hard to understand the directions on the medications, hard to read the print on the package, and other problems/concerns. Response options included: none, a little, or a lot. Caregivers were asked if they perceived their child had a problem in using asthma medications in each of the following areas: child has side effects, hard to remember when the child is supposed to take, hard to pay for medications, not sure child is using his/her inhaler correctly, hard to get the child's refills on time, hard to understand the directions on the medications, hard to read the print on the package, and other problems/concerns.

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.[19–22] 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.

Two research assistants coded 20 of the same transcripts throughout the study period to assess inter-coder reliability. Using the coding tool for transcribed medical visits, coders recorded the following: whether children asked one or more medication questions, whether caregivers asked one or more medication questions, the number of questions providers asked about control medications, whether provider asked (yes/no) for child input into the asthma treatment regimen, and whether the provider asked (yes/no) for caregiver input into the asthma treatment regimen. Inter-rater reliability ranged from 0.88 to 1.0 for the communication variables. Areas of overlap between the problems with medications measure and actual medication questions that children and caregivers asked were: asthma medication device technique, frequency of use/timing of medication use, quantity/supply of medication (caregivers only), side effects, and school use (children only).

Statistical Analysis

Each of the child and caregiver reported problem areas were recoded into dichotomous variables (no or a little problem versus a lot of a problem) and a summary score was created and then dichotomized to express whether each child and caregiver reported one or more asthma medication problems/concerns.

All analyses were conducted using SPSS. First, descriptive statistics were calculated. Second, bivariate relationships were examined between the independent and dependent variables using correlation coefficients, t-tests, or Pearson chi-square statistics.

Next all caregivers and children who reported one or more asthma medication problems immediately after the visit were separately selected. The extent to which these caregivers and children asked: 1) any asthma medication question, 2) an asthma medication device technique question, 3) a frequency/timing of use question, 4) a quantity/supply question, or 5) a side effect question during the visit were described. Generalized Estimating Equations (GEE) were used to predict whether caregivers and children asked one or more asthma medication questions during their medical visits. All GEEs were clustered by provider Finally whether caregivers and children who reported one or more medication problems immediately after the medical visit still reported the medication problem 1 month later at the home visit was described.

Results

The five participating clinics were all primary care pediatric practices. Forty-one providers agreed to participate in the study. Two providers refused resulting in a participation rate of 95.3%. Eighty-eight percent of the families who approached the research assistant to learn more about the study agreed to participate. Two-hundred and ninety six patients had useable audio-tape data and these patients were seen by 35 of the 41 providers who agreed to participate in the study. Two hundred and fifty-nine out of 296 children (88%) completed a home visit interview approximately one month after their audio-taped medical visit.

Four of the 35 providers were nurse practitioners or physician assistants and they saw seventeen of the participating children. The 31 other providers were physicians. 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. Eighty-three percent of patients were using a controller medication. Control medications included inhaled corticosteroids, leukotriene modifiers, cromolyn, nedocromil, or a long-acting beta agonist.

Among those caregivers who reported one or more asthma medication problems (N=179), only 35% asked at least one medication-related question during the visit (Table 2). In contrast, only 49% of caregivers who reported difficulty getting refills on time asked a question about quantity/medication supply. Similarly, only 13% of caregivers who reported problems with side effects asked one or more questions about side effects and only 15% of caregivers who reported a device technique problem asked at least one question about their child’s asthma medication device technique.

Among children who reported one or more asthma medication problems, only 11% had asked at least one medication-related question during their office visit. Nine percent of children who reported a problem with using their devices asked a question about how to use

their asthma medication devices. Only 4% of children who reported difficulty remembering when to take their asthma medications asked a question about the frequency or timing of using their asthma medication. Only one child asked a question about side effects when they reported a side effect problem (N=98). None of the 79 children who reported a problem or concern in using their asthma medications during school asked their provider questions about how to use their medications at school.

Table 3 presents the GEE results predicting which caregivers who reported one or more problems or concerns with their children's asthma medications would ask at least one medication-related question during the pediatric asthma medical visit. Older caregivers were significantly more likely to ask at least one medication-related question during the medical visit than younger caregivers (odds ratio=1.04, 95% confidence interval=1.01, 1.09). Caregivers who reported a problem or concern with their child's asthma medications were also significantly more likely to ask medication questions if providers asked more questions about control medications during the visits (odds ratio=1.17, 95% confidence interval=1.01, 1.36).

Table 4 presents the GEE results predicting whether children who reported at least one problem or concern with their asthma medications would have asked one or more medication questions during their pediatric asthma medical visits. Those who reported higher asthma management self-efficacy were significantly more likely to ask at least one asthma medication question than children who reported lower self-efficacy (odds ratio=2.34, 95% confidence interval=1.26, 4.33). Children were also significantly more likely to ask one or more asthma medication questions if providers asked more control medication questions during the medical visits (odds ratio=1.14, 95% confidence interval=1.02, 1.28).

Table 5 reports the percentage of children and caregivers who reported problems or concerns in using asthma medications at the initial medical visit who still reported having medication problems one month later at the home visit. Sixty-seven percent of caregivers and 74% of children still reported having one or more asthma medication problems one month later.

Discussion

We found that only 1 in 3 caregivers who reported a problem with their child using an asthma medication asked a medication question during their consultations. Caregivers who reported a frequency of use/timing problem almost always asked a question about this area; yet, only about half of them asked a quantity or supply question if they reported difficulty getting refills on time. Moreover, almost two-thirds of children who reported problems at their initial consultation reported having those same problems one month later. Fewer than 15% of caregivers asked questions about device technique or side effects if they reported problems in these areas. Only 1 in 10 children who reported a problem with using an asthma medication asked a medication question during their consultations. None of the 79 children who had problems using their medications at school asked about school use during their consultation An important finding was that if providers asked more questions about asthma control medications, both children and caregivers who reported at least one medication problem were significantly more likely to ask one or more medication questions. Also, among children who reported a medication problem, those with higher asthma management self-efficacy were twice as likely to ask at least one medication question during consultations than children with lower self-efficacy. visits.

Methodological Limitations

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 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 the busyness of the clinic and our promise not to interrupt clinic flow. Providers, children, and caregivers knew they were being recorded and may have changed their communication style and/or content, but they did not know the study hypotheses. Another limitation is that we do not know if caregivers and patients asked their medication-related questions in prior visits. Also, we did not use a validated scale to assess adherence and we did not assess if patients went to more provider visits in between their audio-taped visits and the 1 month follow-up home visits. We did not examine if the caregivers had asthma or if more than one caregiver was helping manage the child's asthma.

Methodological Strengths

Despite the limitations of the study, it presents new information on the extent to which caregivers and children ask questions during medical visits about asthma medication areas that they reported having problems with. The study examined actual transcripts of audio-taped pediatric asthma visits so we knew what actual questions caregivers and children asked their providers. We also knew what medication problems children and caregivers reported to the research assistant so we could compare what problems they stated having to what types of questions they asked their providers.

Implications

Pharmacists could help caregivers by asking them if they would like a demonstration of how to correctly use their child's asthma medication devices. Pharmacists could also ask questions like "Is your child experiencing side effects when using their asthma medications?" or "Is your child having any problems with their asthma medications?" to encourage caregivers to discuss side effects. Pharmacists should make sure to assess whether children are having difficulty using their asthma medications at school and help families work with the school system so the children can have access to their asthma medications if needed. This may involve confirming that children have medication permission forms and that those forms are required for their particular school district.

Only 9% of children who expressed a problem with asthma medication device technique asked a device technique question during their visits. If children are present with their caregivers when picking up their asthma medications, pharmacists should ask children to show them how they are using their asthma medication devices so they can correct anything the child is doing wrong and show them how to properly use the devices. The National Asthma Education and Prevention Program of the National Heart Lung and Blood Institute recommends that providers show children how to use asthma medication devices and that they assess how well children are using the devices.[3]

Pharmacists could help improve children's asthma management self-efficacy or self-confidence by educating them about their medications and encouraging them to ask questions about managing their asthma. In fact, the United States Pharmacopoeia (USP) adopted a position statement which supports the rights of children and adolescents to receive developmentally appropriate information and direct communications about medications.[23] Two of USP's guiding principles can be applied to provider-caregiver-child communication about asthma management: (1) health care providers and health educators should communicate directly with children about medications and (2) children's interest should be encouraged, and they should be taught how to ask questions of health care providers, parents, and other caregivers about medications and other therapies.[23]

We also found that a large percentage of children and caregivers who reported medication problems immediately after their medical visits still reported having these medication problems one month later. This finding illustrates that many caregivers and children have unresolved asthma medication problems that pharmacists could help children and caregivers overcome by addressing these problems and concerns when caregivers pick up asthma prescriptions. Pharmacists could also contact the family's provider if needed to help resolve problems that the child or parent might be having in using the asthma medications.

Conclusion

Only one in three caregivers and one in ten children who expressed an asthma medication problem asked a question during their medical visits and many still reported these problems one month later. Pharmacists should encourage caregivers and children to report problems they may be having using their asthma medications. Pharmacists could then help families work on the problems they may be having in using their asthma medications. Pharmacists could also help improve children's asthma management self-efficacy or self-confidence by educating them about their medications and how to use their asthma medication devices.

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Table 1

Child and Caregiver Demographic Characteristics (N = 296)

	N (%)
Child Age	
Mean (SD) Range 2.4 (11.1) 8–16 years	
Child Gender	
Male	159 (53.7)
Female	134 (46.3)
Child Race	
White	182 (61.5)
African American	89 (30.1)
Native American/American Indian	30 (10.1)
Other	18 (6.1)
Asthma Severity	
Mild persistent	28 (83)
Moderate/Severe persistent	72 (213)
Number of years living with asthma	
Mean (SD) Range	3.9 (6) 9–16 years
Child's caregiver is married	
Never	48 (16.2)
Married	171 (57.8)
Separated	28 (9.5)
Divorced	37 (12.5)
Widowed	9 (3.0)
Caregiver Age	
Mean (SD) Range	8.4 (42) 27–81 years
Caregiver Gender	
Male	42 (14.2)
Female	253 (85.8)
Caregiver Education in Years	
Mean (SD) Range	2.5 (12.8) 2–20 years
Insurance Type	
None	3 (1.0)
Private	78 (26.4)
Medicaid	153 (51.7)
State Children's Health Insurance Program	52 (17.6)
Other	8 (2.7)

Table 2

Percentage of caregivers and children who reported one or more medication problems after the visit who asked a medication question during the medical visit

Type of medication problem reported to research assistant	Percentage with a reported problem who asked a medication question during the visit
Caregivers N=179	
Any type of medication problem	62/179 (34.6%)
Asthma medication device technique Problem	14/94 (14.8%)
Frequency of use/timing problem	34/35 (97.1%)
Quantity/supply of medication	19/39 (48.7%)
Side effects	11/87 (12.6%)
Children N=230	
Any type of medication problem	26/230 (11.3%)
Asthma medication device technique	8/86 (9.3%)
Frequency/timing of use	7/159 (4.4%)
Side effects	1/98 (1.0%)
School use	0/79 (None)

Table 3

Generalized estimating equation predicting whether caregivers who reported one or more problems with their children's medication asked one or more medication questions during their medical visits (N=179)

Independent Variables	Odds Ratio (95% Confidence Interval)
Years living with asthma	1.00 (0.89, 1.11)
Asthma severity-moderate/severe	1.25 (0.49, 3.20)
Caregiver age	1.04 (1.01, 1.09)*
Caregiver gender-female	1.92 (0.78, 4.77)
Caregiver race-non-White	1.39 (0.67, 2.87)
Caregiver educational level	0.95 (0.86, 1.05)
Caregiver asthma management self-efficacy	0.84 (0.39, 1.82)
Caregiver asthma outcome expectations	0.93 (0.57, 1.53)
Number of control medication questions the provider asks	1.17 (1.01, 1.36)*
Provider asks for caregiver input into asthma treatment regimen	1.09 (0.40, 2.99)
Child using a controller medication	1.23 (0.41, 3.64)

* $p < 0.05$

Table 4

Generalized estimating equation predicting whether children who reported one or more problems with their children's medication asked one or more medication questions during their medical visits (N=179)

Independent Variables	Odds Ratio (95% Confidence Interval)
Years living with asthma	0.95 (0.86, 1.06)
Asthma severity-moderate/severe	1.60 (0.58, 4.41)
Child age	1.18 (0.96, 1.46)
Child gender-female	0.91 (0.39, 2.10)
Child race-non-White	2.60 (0.88, 7.64)
Child asthma management self-efficacy	2.34 (1.26, 4.33)**
Child asthma outcome expectations	1.0 (0.74, 1.36)
Number of control medication questions the provider asks	1.14 (1.02, 1.28)*
Provider asks for child input into asthma treatment regimen	1.23 (0.22, 6.78)
Child using a controller medication	0.58 (0.18, 1.91)

* $p < 0.05$,

** $p < 0.01$

Table 5

Percentage and number of caregivers and children who still reported having a medication problem one month after the medical visit

Type of medication problem reported to research assistant	
Caregivers who reported one or more problems at the medical visit (N=179)	**Percentage who still had a problem at home visit**
Any type of medication problem	120/179 (67.0%)
Asthma medication device technique problem	48/94 (51.1%)
Frequency of use/timing problem	15/35 (42.9%)
Quantity/supply of medication	9/39 (23.1%)
Side effects	46/87 (52.9%)
Children who reported one or more problems at the medical visit (N=230)	Percentage who still had a problem at home visit
Any type of medication problem	170/230 (73.9%)
Asthma medication device technique	29/86 (33.7%)
Frequency/timing of use	93/159 (58.5%)
Side effects	37/98 (37.8%)
School use	23/79 (29.1%)