

Asthma-Related Educational Needs of Families With Children With Asthma in an Urban Pediatric Emergency Department

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Objective: The aim of this study was to identify the educational needs of inner-city children with persistent asthma and their caregivers who utilize the emergency department (ED) for asthma care as well as determine their guideline adherence, factors associated with ED use, and comfort with computers.

Methods: Cross-sectional survey of children aged 2 to 18 years with previous diagnosis of asthma presenting with asthma-related complaints or acute asthma exacerbations to an urban pediatric ED. Data on demographics, families' response to acute asthma, approach to asthma prevention, access to care, educational topics of interest, and sources of health information were collected.

Results: Of approximately 1500 asthma-related visits, 218 caregivers were approached, and 200 completed the survey. In the past 12 months, 31% had experienced at least 1 asthma-related hospitalization, and 55.5% had had at least 3 ED visits. Although 184 (92.9%) of 198 caregivers were able to identify a primary physician, 37% reported they were more likely to take their child to the ED in response to acute asthma during the day as opposed to their physician (17%). Approximately half of patients were not on any preventive medication, with 57% not having had received an Asthma Action Plan. Caregivers expressed the most interest in learning about long-term controller medications (44.2%), use of metered dose inhalers or nebulizers (44.2%), and trigger avoidance (35.2%). Most caregivers (approximately 68%) reported ease of use with computers and the Internet.

Conclusion: There was discordance between caregivers' reports of primary care provider teaching on asthma management and the use of the controller medications and possession of the Asthma Action Plans for persistent asthma. Education could focus on caregiver concerns of the safety and benefits of the controller medications.

Key Words: asthma, asthma care, urban

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Asthma is the most common childhood chronic illness, affecting more than 5 million children.^{1,2} Children younger than 18 years account for an estimated 700,000 to 1.6 million emergency department (ED) visits annually.^{3–6} Nationally, 10.5 million school days were lost because of asthma in children aged 5 to 17 years in 2008.⁷ Urban minorities bear a

disproportionate burden, with more school days lost⁷ and more asthma-related ED visits.^{8–11} Poor and/or minority children are also the group least likely to receive adequate long-term controller medications.^{12,13}

Minority children living in urban settings frequently have little continuity of asthma care. In the National Cooperative Inner-City Asthma Study, although 95% of children had a primary care provider (PCP), 75% of caregivers said they would go to the ED for asthma care for their children instead of their PCP.¹⁴ Studies have shown ED use is associated with various factors, including lower level of parental confidence in the efficacy of medicines, failure to use a criterion for deciding when to seek emergency care, parental beliefs about asthma severity, and the lack of understanding of the benefits of having controlled asthma.^{15–17} The few hours of an ED visit may represent an opportunity to begin to address misconceptions about asthma therapy, and the importance of following up with their PCP for continuity of asthma care.^{14,18}

Although the ED visit provides an opportune moment for educational intervention, an urban ED environment may be a difficult place to provide tailored, guideline-specific recommendations. Limited data suggest that computerized kiosks have the potential to effectively provide patients with a customized educational intervention and implement clinical practice guidelines.^{19,20}

The purpose of this study was to identify the educational needs of inner-city children with persistent asthma and their caregivers who utilize the ED for asthma care as well as determine their guideline adherence, factors associated with ED use, and comfort with computers.

METHODS

Study Design

We conducted a prospective cross-sectional survey in a single pediatric ED. The study protocol was approved by the local institutional review board with written consent obtained from the legal guardian.

Study Setting and Population

This study was conducted in an urban, academic, university-based pediatric ED. We enrolled a convenience sample of caregivers who brought their children (between 2 and 18 years) with previous diagnosis of asthma to the ED for acute asthma exacerbations, presenting from 8:30 AM to 11:30 PM daily. Asthma was defined as previous diagnosis of asthma or history of 2 or more wheezing episodes that responded to bronchodilators. We excluded patients with comorbidities such as congenital heart disease, cystic fibrosis, congenital pulmonary diseases, neurological illnesses, and developmental delay because their educational needs were expected to differ.

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Study Procedure

Formally trained research assistants collected data, first by asking each caregiver open-ended questions, followed by a multiple-choice question on the same topic. The open-ended questions allowed subjects to express their unbiased opinions and helped us to identify additional health education needs (eg, “What do you do when your child is having an asthma attack?”). Each open-ended question was followed by a multiple-choice question. We added a residual “other” category to each multiple-choice question to allow subjects to elaborate if the answer choices listed did not adequately reflect their desired response. To avoid bias in the caregivers responses caused by surveying them during an asthma exacerbation, research assistants were trained to inquire about symptoms outside the current exacerbation. This approach allowed us to gain insights regarding the educational needs of the subjects, the potential means to deliver these educational needs, and factors associated with the use of the ED.

Measures

The study survey instrument consisted of 6 domains: (1) demographics, (2) families' response to acute asthma, (3) approach to asthma prevention/preventive measures, (4) barriers/access to asthma care, (5) educational topics of interest, and (6) sources of health information. The survey was based on a questionnaire previously developed by a coinvestigator¹⁵ and the National Heart, Lung, and Blood Institute (NHLBI) Expert Panel Review 3 guideline.²¹

Demographics and Child Asthma Severity

We obtained standard demographic information. The child's asthma control was assessed by determining the child's prior asthma-related hospitalizations and ED visits. We assessed chronic asthma severity based on asthma symptoms in the daytime and nighttime and with activities based on the NHLBI asthma guideline.²¹

Response to Acute Asthma

We inquired about the symptoms that caregivers ascribed to acute asthma in their child. We asked about how they would manage their child's acute asthma in terms of restricting the child's activities, using various medications (homeopathic remedies vs asthma medications), and seeking help (from PCP or ED). We presented caregivers with an acute asthma scenario and asked how they would manage the scenario both during the day (ie, during PCP business hours) and at night (ie, outside PCP business hours).

Approach to Asthma Prevention

The National Heart, Lung, and Blood Institute first issued recommended guidelines for the management of asthma in 1991 and reconvened to update these guidelines in 1997 and 2007. The latest NHLBI guideline emphasizes the importance of using long-term controller medications, having an Asthma Action Plan, avoidance of triggers, and close monitoring to reevaluate asthma status. We included questions concerning use of long-term controller medications and possession of an Asthma Action Plan in the survey. We also inquired about the caregivers' knowledge of their child's triggers, avoidance of triggers, and frequency of PCP follow-up.

Barriers/Access to Care

Through the interview, we first explored factors related to access to care, such as access to PCPs, insurance status, transportation availability, and telephone access. Finally, we explored the barriers guardians experienced to optimal management of chronic asthma, including the caregivers' reasons for not having their child use long-term controller medications.

Educational Topics of Interest

We asked caregivers what they remembered being taught by their children's PCPs and topics on which they would like to receive further education from the ED clinicians. Using the NHLBI asthma guideline recommendations for asthma education, we listed 5 topics and asked which one(s) they recalled their children's PCPs had addressed and which one(s) they would like the ED physicians to focus on as part of the education. The 5 educational topics were as follows: (1) How to recognize signs and symptoms of asthma, (2) when and how to correctly give asthma medications via nebulized machine and/or metered dose inhaler, (3) how to prevent an asthma attack, (4) how to identify and prevent exposure to triggers, and (5) facts about long-term controller medications.

Sources of Health Information

In order to determine where families sought health-related information, we asked whether they typically received information from health care professionals, friends and families, the Internet, and/or other sources. To explore the potential utility of an educational computer kiosk, we also inquired about their comfort with using a computer, the Internet, and their access to the Internet and e-mail.

TABLE 1. Demographics*

Caregiver Ethnicity/Race (n = 200)		Caregiver Education (n = 196)		Caregiver Insurance (n = 194)	
Mixed	108 (54.0%)	Graduate	13 (6.6%)	Medicaid	123 (63.4%)
Black	61 (30.5%)	College	96 (49.0%)	Private	54 (27.8%)
Latino	24 (12.0%)	High school	62 (31.6%)	None	10 (5.2%)
White	3 (1.5%)	Junior high	7 (3.6%)	Medicare	4 (2.1%)
Asian	2 (1.0%)	Elementary	15 (7.7%)	Self-pay	3 (1.5%)
Unknown	2 (1.0%)	Other	3 (1.5%)		

*Median patient age, 5.9 years (interquartile range, 3.8–10.3 years; mean, 7.3 [SD, 4.5] years).

TABLE 2. Asthma Severity and Level of Control of Children

Chronic Asthma Severity (n = 198)		Level of Asthma Control Among Patients With Persistent Asthma (n = 149)	
Intermittent	49 (24.7%)	Well controlled	25 (16.8%)
Mildly persistent	44 (22.2%)	No preventive medication and poorly controlled	71 (47.7%)
Moderately persistent	91 (46.0%)	On preventive medication but poorly controlled	53 (35.6%)
Severely persistent	14 (7.1%)	Has Asthma Action Plan	85 (43.1%)*

*n = 197.

Analyses

Using SPSS-PC version 11 (SPSS Inc, Chicago, Ill), we conducted standard descriptive statistics, including summarizing the educational needs of the caregivers and their comfort level of using computerized systems such as e-mail and the Internet. For the qualitative data (from open-ended questions and those documented in the residual “other” descriptive field), we created new categories as necessary to include in the descriptive summaries. We used Pearson χ^2 test to determine potential associations between asthma severity and long-term controller medications use, educational needs and caregivers' educational level, and caregiver comfort level with the use of information and communication technology such as the Internet and e-mail and educational level.

RESULTS

Between July 2007 and August 2008, there were approximately 1500 asthma-related ED visits (assessed retrospectively from administrative database). We approached 218 caregivers, of whom 205 caregivers consented to participate. Five failed to complete the survey because of ED discharge prior to completion of the surveys, leaving 200 for analysis.

Demographics and Asthma Severity

Table 1 displays the patient demographics. The majority of the participants were of mixed race, with slightly more than half having a college degree or higher and two-thirds having public insurance. Of the children, 31.0% (62/200) had at least 1 asthma-related hospitalization in the past 12 months, and 55.5% (111/200) had had at least 3 ED visits in the past 12 months. As shown in Table 2, three-quarters of the children had persistent asthma. Most of the children's asthma was not well controlled, with approximately half not on any long-term controller medications. Overall, 56.9% (112/197) of the children had never received an Asthma Action Plan, including 55.0% (82/149) of those with persistent asthma (Table 2).

Response to Acute Asthma

Table 3 depicts caregivers' response to the signs of acute asthma, with the majority able to recognize signs of acute asthma. Although most would administer bronchodilators, nonpharmacological approaches to managing asthma exacerbations were also used.

When asked what they might do (allowing participants to choose >1 response) if their child had an acute episode, 72.5% (145/200) said they would bring their children to the ED, 51.5% (103/200) reported they would bring their child to their PCP, and 12.5% (25/200) reported they would call their PCP for advice. When given a scenario where their child was having an asthma exacerbation during the day, one-third would go to the ED. When the same scenario except the exacerbation occurred at night, more than half reported they would go to the ED (Table 4). For both day and night scenario, the likelihood of using the ED for asthma care was not associated with the caregivers' educational level ($P > 0.05$ on χ^2 test).

Approach to Prevention of Asthma Exacerbations

The majority of the caregivers were able to identify at least 1 known asthma trigger for their child (Table 5). The most commonly reported triggers were weather changes and upper respiratory tract infections. Among those who identified upper respiratory tract infection as a trigger, only 51.7% (77/149) would give bronchodilators at the onset of illness. Only 36.9% (31/84) of those with exercise as a trigger would give bronchodilators prior to exertion. Forty-one percent (82/200) reported trying to take actions to avoid their children being exposed to known triggers.

Barriers to Optimizing Chronic Asthma Care and Access to Care

Table 6 displays barriers to asthma control and the patient's access to care. More than 90% (184/198) of the subjects with persistent asthma were able to identify a PCP. However, more than half of caregivers were unsure of how to prevent their child from having an asthma attack. Concern regarding the adverse effects of the asthma medications was the most common concern that prevented caregivers from providing their children with long-term controller medications.

TABLE 3. Signs of Asthma and Caregiver Response (n = 200)

Signs of Exacerbation		Caregiver Response to Signs of Exacerbation*		Medication Administered for Signs of Exacerbation*	
Coughing (primary sign)	168 (84.0%)	Calm child	120 (60.0%)	Bronchodilators	178 (89%)
Wheezing	156 (78.0%)	Let rest/play quietly	83 (41.5%)	Give child a drink	79 (39.5%)
Shortness of breath	149 (74.5%)	Watch and wait	113 (56.5%)	Over-the-counter medications	31 (15.5%)
Change in breathing sounds	145 (72.5%)	Isolate child from trigger(s)	68 (34.0%)	Home remedies	26 (13.0%)

*Multiple responses were allowed.

TABLE 4. Caregiver Response to Day and Night Asthma Scenario* (n = 192)

Response to Acute Asthma Scenario	Day [†]	Night [†]
Stay home to watch child	88 (45.8%)	77 (40.1%)
Go to ED	71 (37.0%)	113 (58.9%)
Seek PCP	33 (17.2%)	1 (0.5%)

*Only 1 response was allowed.

[†]There was no statistically significant difference ($P > 0.05$) when we controlled for the educational level of the caregivers, type of insurance (public vs private), and the age of child.

Educational Topics of Interest

The majority of caregivers recalled that their children's PCPs provided instructions on how/when to give asthma medications (150/200 [75.0%]) and how to avoid triggers (150/200 [75.0%]). Caregivers reported that most of the PCPs demonstrated how to administer medications via inhaler and/or nebulizer machine (142/200 [71.0%]), taught signs for emergency medical care (130/197 [66.0%]), addressed adverse effect concerns (106/196 [54.1%]), and discussed goals of asthma treatment (104/196 [53.1%]). Fewer PCPs emphasized giving asthma medications at the first sign of a cold/exposure to triggers (77/200 [38.5%]).

Caregivers expressed interest in learning from the ED physicians about long-term controller medications (88/199 [44.2%]), the proper method to administer asthma medication using the metered dose inhaler or nebulizer (88/199 [44.2%]), how to avoid triggers (70/199 [35.2%]), asthma attack prevention (69/199 [34.7%]), and how to tell if their children were having an asthma exacerbation (37/199 [18.6%]). We found no statistically significant associations between the caregivers' educational topics of interest and their education level ($P > 0.05$).

Sources of Health-Related Information

The most common methods used by caregivers to obtain information about asthma care were via physicians/nurses (86.0% [172/200]), the Internet (56.0% [112/200]), and videos/DVDs (40.0% [80/200]). A majority (79.3% [157/198]) of the caregivers reported having a home computer, 70.7% (140/198) had e-mail access, and 74.2% (147/198) had Internet access. Moreover, 67.7% (134/198) of the caregivers reported that the computer and Internet were easy to use. Caregivers with a college degree or higher used e-mail more frequently ($P = 0.029$), found the Internet easy to use ($P = 0.001$), found it easy to use the airport kiosk ($P \leq 0.0001$), and sought health-related information from the Internet ($P < 0.001$).

DISCUSSION

In our survey, we found that a relatively highly educated group of caregivers of children with persistent asthma had frequently received asthma education from their child's PCP. However, they still had consistent knowledge gaps or misperceptions concerning the proper use of controller medications, when to initiate rescue medication based on triggers, and the safety profile of asthma medications.

The high proportion of patients who did not seem to adhere to the NHLBI asthma guidelines combined with frequency ED utilization, caregiver interest in ED education, and comfort with computers suggests a role and mode for ED education of this high-risk population.

The seeming lack of adherence to the NHLBI asthma guidelines is similar to prior studies performed more than a decade ago, in which more than 50% of children with persistent asthma were not on any long-term controller medications.^{13,14,22} Similar to our findings, recent and prior studies note that only a 32% to 44% of children have an Asthma Action Plan. In our study, caregivers appeared to have concerns particularly regarding controller medication dependency, desensitization, and effect on the child's growth. Scarfone et al²³ previously reported similar parental beliefs that impeded the use of long-term controller medications. These results suggest that dispelling these myths should be an important component of asthma education.

The chaotic nature of the ED and limited time to educate make it imperative that ED education does not tax resources and fits into workflow. One potential solution was studied by Sockrider et al,²⁴ which tested a tailored self-management intervention delivered in the ED for families of children with asthma. In that study, a trained asthma educator collected baseline asthma information from the family, provided asthma education to the families using a portable computerized tablet that contained videos and information to better manage asthma, and created a written Asthma Action Plan for the families. Patients in the intervention group reported significantly higher confidence levels in prevention of asthma episodes and exacerbations.²⁴ Although seemingly effective, EDs may not be able to garner similar resources to implement a similar program. Porter et al²⁰ found that parental report of their child's asthma history via a computerized asthma kiosk was accurate. Given caregiver comfort with computers in our study, further research should explore the utility and feasibility of parent-accessible ED kiosks to both obtain data and educate the caregivers.

Limitations

As a single-center study, our results reflect the needs of the particular population, although prior studies have noted similar findings.¹⁵ Our sample of children constituted a seemingly more severe population with the educational needs potentially not generalizable to children with more mild symptoms. Although the educational needs and concerns identified (use of longer-term controller medications, trigger avoidance, managing acute asthma at home) are in accordance with the educational topics recommended by the NHLBI EPR-3, we did not validate the instruments used to collect self-reported health care utilization information and prior education provided by the PCP.²¹ Finally, the time to administer the survey was restricted to the patient's ED stay. This may have resulted in a sample of patients with more severe asthma.

TABLE 5. Known Triggers Reported by Caregivers (n = 200)

Triggers	
Upper respiratory tract infection	149 (74.5%)
Exercise	84 (42.0%)
Weather changes	162 (81.0%)
Seasonal changes	135 (67.5%)
Allergens	95 (47.5%)
Irritants	75 (37.5%)
Emotional	45 (22.5%)

TABLE 6. Barriers to Physician Access/Care

Reasons for Not Taking Long-term Controller Medication		Physician Access		Source of Asthma Care	
Hyperactivity adverse effect	94/200 (47.0%)	Caregivers able to identify their PCP	184/198 (92.9%)	PCP	148/194 (76.3%)
Dependency fears	66/200 (33.0%)	Unscheduled appointments offered by PCPs	177/195 (90.8%)	ED physicians	23/194 (11.9%)
Believes medication will no longer work if relied upon	59/198 (29.8%)	Had not visited PCP for asthma in past year	99/188 (52.7%)*	Pulmonologist	10/194 (5.2%)
Fear of impact on growth	59/200 (29.5%)			Allergists	3/194 (1.5%)
General adverse effects	58/200 (29.0%)			Nurse practitioners	4/194 (2.1%)
Medication effects wearing off over time	56/198 (28.3%)			Inconsistent source	2/194 (1.0%)

CONCLUSIONS

In an inner-city population, caregivers often are able to identify signs and symptoms of acute asthma and triggers. However, although often educated by their PCPs, caregivers had persistent knowledge gaps or misperceptions regarding their child's asthma management, with frequent fear of medication adverse effects. Previous studies and comfort with computers reported by the caregivers in our study suggest a role for computers in ED asthma education.

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