Caregiver Asthma Knowledge, Aptitude, and Practice in High Healthcare Utilizing Children: Effect of an Educational Intervention

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Factors underlying high healthcare utilization among Hispanic and African American (AA) children with asthma are not well known. We hypothesized that low parental knowledge and suboptimal practices are associated with high healthcare utilization and sought to elucidate these factors and identify ethnicity-specific differences. We also hypothesized that a targeted educational intervention will decrease emergency department (ED) visits and hospitalizations. A 57-item questionnaire investigating asthma knowledge, aptitude, and practice was administered during a hospitalization to 268 caregivers (158 Hispanic and 110 AA) of high healthcare utilizer children. Responses were compared between ethnicities. Participants were randomized into an education group and a control group to investigate the impact of an in-hospital educational intervention on future ED visits and hospitalizations. More than 80% of caregivers knew that asthma is associated with muscle constriction and mucus production. Overall, 66.7%–86.9% of caregivers found preventive steps including allergen avoidance, regular primary care physician (PCP) follow-up, and medication adherence helpful, but only 45.2% reported adherence to controller medications. Similarly, caregivers found management steps, including albuterol use, avoidance of ineffective medications, and need to contact PCP helpful but 33% Hispanic caregivers contacted their child's PCP at the time of the exacerbation leading the current hospitalization, compared with 17% AA caregivers ($P=0.006$). Moreover, 40% and 30% Hispanic and 27% and 18% AA caregivers felt stressed and helpless, respectively, about their child's asthma. Despite high baseline levels of knowledge, there were fewer ED visits in the education group (1.56 ± 1.94) compared with the control group (2.05 ± 2.32) ($P=0.02$) 2 years after the intervention. Although Hispanic and AA caregivers of children with high healthcare utilization were knowledgeable of asthma pathophysiology, and preventive and management steps, they reported being stressed and helpless and were unable to implement the steps at the time of an exacerbation, seeking care at the ED rather than contacting their PCP. The high health utilizers who underwent a targeted educational intervention had fewer ED visits 2 years following the intervention.

Introduction

ASTHMA IS THE leading cause of pediatric hospitalizations,¹ particularly among children of Hispanic and African American (AA) ethnicity, who have higher asthma prevalence than non-Hispanic Whites.² Among these urban children, 15%–25% are high healthcare utilizers who have frequent emergency department (ED) visits^{3,4} and repeat hospitalizations.^{5,6} However, the factors associated with high utilization among these children have not been well characterized.

In addition to the inherent higher disease severity,² lack of knowledge among caregivers about the chronic nature of the disease process^{4,7} and suboptimal outpatient management by primary care physicians (PCPs)⁸ are potential factors as-

sociated with the high healthcare utilization among urban children with asthma. Lack of adherence to National Heart Lung and Blood Institute (NHLBI) guidelines in home management of asthma has also previously been associated with poor asthma control.^{9,10} Further, parental cultural beliefs, mental attitude toward a chronic illness, and psychological stressors can also impact asthma control.^{11,12} However, the extent to which any or a combination of these factors explain the high healthcare utilization among urban children has not been investigated.

To address these gaps in knowledge, we conducted a comprehensive assessment of knowledge, aptitude, and practice among the caregivers of high healthcare utilizer children with asthma and compared these measures between Hispanics and AA to identify the role of ethnicity-specific

cultural beliefs on asthma management. Based on the hypothesis that low asthma knowledge was associated with high healthcare utilization, we proposed to study the impact of a targeted educational intervention during the hospital stay on the number of future ED visits and hospitalizations.

Methods

Participants

Two hundred and sixty-eight primary caregivers (158 Hispanics and 110 AA) of 3–11 year-old children hospitalized with an asthma exacerbation who met the criteria of high health utilization defined by history of 2 or more ED visits^{3,4} in addition to those associated with 1 or more hospitalization⁶ in the preceding 12 months were recruited between 4/07–3/09. This age range was chosen since young children are more dependent on their primary caregivers for overall healthcare and medication administration. Children with history of prematurity, cystic fibrosis, and other chronic inflammatory lung diseases and those with family members other than the primary caregiver present at the bedside were excluded. The study was conducted at a tertiary care teaching hospital located in an inner-city neighborhood in New York City. The hospital's Institutional Review Board approved the study. A written informed consent was obtained from all participating caregivers and 7–11 year-old children signed an assent form.

Study procedure

Children with asthma hospitalized in the defined age range were identified by the ED roster and by the floor staff. Those who met the inclusion criteria were approached on the first day of the hospitalization. Hospital discharge was not affected by the enrollment in this study. The research team was not involved in the medical care during the hospitalization.

The questionnaire. A research team member administered a 57-item questionnaire (Appendix 1) to primary caregivers of high healthcare utilizing children within 24 h of admission to the pediatric floor to evaluate their baseline asthma knowledge, aptitude, and practice. The team member read the questions to the caregiver. The questionnaire (Appendix 1) was modified from the Child Asthma Risk Assessment Tool (CARAT) questionnaire used in the National Cooperative Inner-City Asthma Study¹³ (<http://Carat.asthmarisk.org/>). Additional questions were included on knowledge of asthma pathophysiology, preventive and management steps, including access to an asthma action plan and on symptom frequency and medication use that were used for objective classification of asthma severity and control as per the NHLBI guidelines.¹⁴ The questionnaire was initially administered to 10 caregivers to ensure that the language and content was appropriate for our patient population, the responses from which are not included in the current analysis.

Measures related to the questionnaire: In addition to demographic information, the questionnaire included the following measures to which the responses were recorded as a binary response (Yes/No) or as a 5-point response (1=not helpful, 2=slightly helpful, 3=moderately helpful, 4=quite helpful, and 5=extremely helpful):

1. Health characteristics, including family history, access to healthcare providers and facilities and their utilization, ED visits, and hospitalization.
2. Knowledge of pathophysiology, and preventive and management steps.
3. Environmental exposures.
4. Practices including medication adherence, steps taken in the setting of exacerbation leading to current hospitalization and access to healthcare at school and school absences.
5. Psychosocial effects and emotional burden of the child with chronic disease.

The intervention. Randomization: Following the completion of the questionnaire, using block randomization, the participants were randomized into the education or the control group with a 1:1 ratio. The groups were matched for ethnicity, and child's age and gender.

The intervention: The control group received routine inpatient asthma care. The education group received asthma education in addition to standard asthma care. The same team member who administered the questionnaire conducted the education session that involved the caregiver and children ages 7–11 years. The interactive education session was about 15 min in duration, and was based on a handout, primarily comprised of images¹⁵ specific to (1) asthma pathophysiology using an asthmatic airway picture emphasizing the chronic nature of the disease, (2) known indoor and outdoor asthma triggers, and (3) the role and use of controller medications. The handout was given to the primary caregiver at the end of the session.

Measures related to the intervention:

- (1) To assess evaluate their comprehension and short-term retention, a 7-item questionnaire (Appendix 2) comprised of 7 items from the preintervention questionnaire was administered 24 h after the education session to the caregivers enrolled in the education group.
- (2) To measure the long-term effect, ED visits and hospitalizations were monitored for 2 years following recruitment through electronic medical records. In addition, we also monitored number of PCP visits following the intervention. Follow-up visits in the medical records were available on all study participants for the 2 years following enrollment in the study.

Statistical analysis

Data were normally distributed and were analyzed by parametric tests. Descriptive analysis was conducted on the demographic data. Continuous variables were compared using *T*-tests, and they are reported as mean $\pm$ standard deviation while categorical variables, compared using the Chi-square test, and they are reported as percentages. Chi-square test was applied to compare responses to the 57-item questionnaire between the 2 ethnicities.

Short-term retention of knowledge measured by the 7-item questionnaire was analyzed using the McNemar test. *T*-test was used to compare the frequency of ED visits and hospitalizations postintervention between the 2 study groups. Repeat admissions for asthma in our hospital were 30% in the 2 years preceding our study. A sample size of 268 caregivers with 1:1 randomization was calculated based on the hypothesis that the educational intervention will lead to a 50% decrease in the repeat admission rates (30% to 15%) ($\alpha=0.05$ and $\beta=0.8$).

Results

Study population

The cohort included 158 (59%) Hispanic and 110 (41%) AA caregivers (Table 1). Several characteristics were similar between the 2 ethnic groups. The primary caregiver for most of the children in the study was their mother. The burden of passive smoke and indoor allergen exposure was high in our study sample, with roach exposure being the most common self-reported trigger for asthma (55.2%). A higher proportion of Hispanic children were insured on a managed care Medicaid insurance compared to AA children (54% vs. 34%,

$P < 0.01$). A higher number of AA households reported sighting rats and having rugs at home while more Hispanic households had dogs. A higher proportion of Hispanic children than AA children utilized school clinics (41% vs. 15%, $P = 0.006$). On an average, 10.5 ± 0.8 school days were missed per year among school-going children, and it did not differ by ethnicity. Further, only 26.1% participants reported having an asthma action plan completed by their PCP, which also did not differ by ethnicity.

Based on the caregiver responses on symptom frequency and medication use, asthma severity and control was classified as per the NHLBI criteria by the research team (Table

TABLE 1. CHARACTERISTICS OF THE STUDY POPULATION

Variable ^a	Hispanics N=158	African Americans N=110	P value ^b
Child's age	6.4 ± 2.4	6.4 ± 2.5	0.98
Caregiver's age	33.4 ± 7.5	34.2 ± 8.8	0.42
Child's age at time of asthma diagnosis	1.7 ± 1.9	2.1 ± 1.9	0.12
Average number of ED visits	4.6 ± 5.9	3.4 ± 3.5	0.05
Average number of hospitalizations	1.6 ± 0.03	1.4 ± 0.04	0.81
	N (%)	N (%)	
Primary care giver			0.46
Mother	139 (87)	91 (82.7)	
Father	13 (8.2)	15 (13.6)	
Grandparent	7 (4.4)	3 (2.7)	
Caregiver education level			0.19
High school not completed	36 (22.8)	12 (10.9)	
High school graduate	33 (20.9)	24 (21.8)	
Some college	59 (37.3)	47 (42.7)	
College graduate	30 (19)	27 (24.5)	
Insurance status			<0.01
Medicaid	27 (17.1)	15 (13.6)	
Managed care Medicaid	85 (53.8)	37 (33.6)	
Private	44 (27.8)	52 (47.3)	
Other		6 (5.5)	
Positive family history of asthma	126 (79.7)	80 (72.7)	0.25
Allergen/trigger exposure at home			
Rugs	31 (19.6)	39 (35.5)	0.003
Mildew	30 (18.9)	23 (20.9)	0.64
Roaches	93 (58.9)	55 (50)	0.21
Mice	63 (39.9)	37 (23.4)	0.36
Rats	7 (4.4)	16 (14.5)	0.05
Dogs	33 (20.9)	11 (10)	0.02
Cats	20 (12.7)	16 (14.5)	0.61
Passive smoke exposure			
Smoker at home	87 (55.1)	54 (49.1)	0.42
In room when child away	18 (11.4)	12 (10.9)	0.94
In room when child at home	4 (2.5)	2 (1.8)	0.71
Outside home	59 (37.3)	33 (30)	0.3
School health			
School days missed	10.7 ± 11.7	9.5 ± 17.4	0.5
Medication administration form	91 (57.6)	60 (54.5)	0.75
School clinic	41 (25.9)	15 (13.6)	0.006
School nurse	100 (63.3)	73 (66.4)	0.66
Asthma action plan	44 (27.8)	26 (23.6)	0.39
Site of education			
PCP	92 (58.2)	56 (50.9)	0.7
ED	56 (35.4)	34 (30.9)	0.4

^aContinuous variables are reported as mean ± standard deviation, categorical variables are reported as proportions [N(%)].

^bP values were determined by chi-square or Student's *t*-test used to compare Hispanics to AAs for each characteristic.

AA, African American; ED, emergency department; PCP, primary care physician.

TABLE 2. NHLBI-BASED CLASSIFICATION AND PARENTAL PERCEPTION OF ASTHMA SEVERITY AND CONTROL

	Hispanics N=158	African Americans N=110	P value ^b
Classification based on NHLBI guidelines ^a			
Asthma severity			0.09
Intermittent	26 (16.4)	16 (14.5)	
Mild persistent	65 (41.2)	32 (29.1)	
Moderate persistent	43 (27.2)	38 (34.5)	
Severe persistent	24 (15.2)	24 (21.9)	
Asthma control			0.3
Poorly controlled	106 (67.8)	79 (71.8)	
Well controlled	52 (32.2)	30 (27.2)	
Caregiver perception of severity and control ^a			
Asthma severity			0.27
Unknown	22 (13.9)	27 (24.5)	
Mild	51 (32.3)	28 (25.5)	
Moderate	62 (39.2)	38 (34.5)	
Severe	23 (14.6)	17 (15.5)	
Asthma control			0.1
Poorly controlled	116 (73.4)	70 (63.6)	
Well controlled	42 (26.6)	40 (36.4)	

^aThe variables are reported as proportion [N(%)].

^bP values were determined by chi-square test used to compare asthma severity and control between Hispanics to AAs.
NHLBI, National Heart Lung and Blood Institute.

2). Overall, 84.3% of children had persistent asthma, and 48.1% had moderate or severe persistent asthma. In keeping with being high healthcare utilizers, the vast majority of children had poor asthma control. Parental perception of asthma severity and control was similar to objective classification (Table 2). However, medication adherence was low; 46.2% Hispanics and 43.6% AAs were adherent to inhaled steroids ($P=0.4$), and 45.5% Hispanics and 44.3% AAs were adherent to leukotriene antagonist ($P=0.5$).

Measures related to the questionnaire

Caregiver knowledge of access to healthcare and its utilization for exacerbations. Ninety five percent of participant families reported having a primary care physician (PCP) in whom they had confidence and did not perceive any language barrier; this did not differ by ethnicity (Table 3). The majority of PCPs were based at a hospital-affiliated clinic. Although 61.9% of all caregivers reported that the PCP should be visited at the time of an exacerbation, 33% of Hispanic and 17% of AA caregivers ($P=0.006$) contacted their PCP for the exacerbation leading to the current hospitalization. Overall, 30.2% of children had access to pulmonologists and 27.6% had access to allergists, which also did not differ by ethnicity.

Caregiver knowledge of asthma pathophysiology, and effectiveness of preventative and management steps. A very high percentage (between 82%–97%) of caregivers correctly identified that asthma causes airway swelling, mucus production, and muscle constriction, demonstrating knowledge of asthma pathophysiology (Table 4). While 94%–99% of caregivers were aware of common triggers for asthma exacerbation like upper respiratory infection (URI), weather change, and allergens, 47%–53% were aware of triggers like exercise and smoke exposure. In addition, the caregivers were aware of benefits of preventive steps such as adherence to controller medications, avoiding allergens, and seeing their PCP at regular intervals with no differences observed between the 2 ethnicities (Table 4). Similarly, the caregivers reported good

understanding of treatment steps to be taken in the setting of an exacerbation (Table 5). The majority reported usefulness of albuterol and keeping calm during an exacerbation and lack of effectiveness of therapies like over the counter medications, ointments such as Vicks Vaporub[®], and herbal tea. Overall, while Hispanics trended to report higher use of and benefits with Vicks Vaporub ($P=0.05$), AA caregivers reported higher use of herbal tea ($P<0.001$).

Psychosocial effects and emotional burden of taking care of child with asthma. Caregivers from both ethnic groups reported frequently limiting their child's physical activity (Table 6). Forty-one percent of Hispanics and 26% AA perceived inability to ever achieve control and had concerns about the effect of medications on their child's behavior. Significantly more Hispanics (38%) than AA caregivers (24.5%) ($P<0.02$) were concerned with the side effects of the medications. While 23.5% of all caregivers felt helpless, 40.3% felt stressed about their child's asthma.

Measures related to intervention

Short-term retention of knowledge. The characteristics detailed above did not differ between the education and the control group, which were matched for ethnicity, and child's age and gender. Following the education session, caregivers in the education group were queried again on asthma pathophysiology, preventive and management steps, and potential triggers. They demonstrated good retention of knowledge 1 day after the educational session. As compared to preintervention levels (Table 4), 99% of caregivers recognized the role of inflammation ($P<0.0001$), and 100% recognized the role of mucus ($P<0.005$) and muscle constriction (<0.05) in the postintervention questionnaire. Further, postintervention, while 99.4% caregivers reported use of controller medications were quite to extremely helpful ($P<0.0001$), 99.9% reported allergen avoidance ($P<0.0001$) and 100% reported regular follow-up with PCP ($P<0.0001$) were quite to extremely helpful. Similarly, for management of an acute exacerbation, as compared to preintervention

TABLE 3. ACCESS TO HEALTH CARE AND ITS UTILIZATION

Variable ^a	Hispanics N=158	African Americans N=110	P value ^b
Have a primary care physician (PCP)	154 (97.5)	104 (94.5)	0.2
Location of PCP			
Private practice	51 (32.3)	27 (24.5)	0.42
Hospital clinic	93 (58.9)	67 (60.9)	1
Community clinic	10 (6.3)	10 (9.1)	1
Have confidence in PCP	139 (87.8)	94 (85.5)	0.84
Perceive language barrier with PCP	4 (2.5)	1 (0.9)	0.34
Have pulmonologist	54 (34.2)	27 (24.5)	0.12
Have allergist	47 (29.7)	27 (24.5)	0.4
Have had allergy testing	47 (29.7)	29 (18.4)	0.2
Actions to be taken with exacerbation			
Visit PCP	90 (57)	76 (69.1)	0.15
Go to ED	71 (44.9)	34 (30.9)	0.08
Physician contacted for exacerbation			
PCP	74 (46.8)	54 (49.1)	1
Specialist	21 (13.3)	11 (10)	0.8

^aThe variables are reported as proportion [N(%)].

^bP values were determined by chi-square test used to compare the listed variables between Hispanics to AAs.

levels (Table 5), 99.9% reported albuterol use ($P < 0.0001$), 97.3% reported avoidance of over-the-counter medications ($P < 0.001$), and 100% reported contacting PCP ($P < 0.0001$) to be quite to extremely helpful.

Long-term effect of educational intervention on ED visits and hospitalization. While ED visits did not differ between the education (2.13 ± 1.49) and control groups (2.97 ± 2.54) ($P = 0.13$) in the year prior to the intervention, 2 years post-

intervention, ED visits were significantly lower in the education group (1.56 ± 1.94) compared with the control group (2.05 ± 2.32) ($P = 0.02$). There were no differences by ethnicity in the decrease in ED visits among those who underwent the educational intervention. No differences were observed in the frequency of hospitalizations pre- and postintervention. There was no significant difference between the proportions of caregivers from the education group (16.1%) and from the

TABLE 4. ASTHMA KNOWLEDGE ABOUT EFFECTIVENESS OF PREVENTATIVE STEPS

Asthma knowledge and preventative steps ^a	Hispanics N=158	African Americans N=110	P value ^b
Asthma pathophysiology			
Airway swelling	131 (82.9)	90 (81.8)	0.8
Mucus production	146 (92.4)	97 (88.2)	0.51
Muscle contraction	154 (97.5)	105 (95.5)	0.78
Known Triggers			
URI	151 (95.6)	104 (94.5)	0.80
Weather	157 (99.4)	103 (93.6)	0.21
Exercise	74 (46.8)	51 (46.4)	0.95
Allergens	126 (79.7)	80 (72.7)	0.30
Smoke exposure	87 (55.1)	54 (49.1)	0.42
Preventative steps			
Routine use of inhaled steroids			
Not helpful	123 (14.6)	9 (8.2)	0.36
Slightly to moderately helpful	34 (21.5)	25 (22.7)	0.9
Quite to extremely helpful	101 (63.9)	76 (69.1)	0.36
Avoidance of allergens			
Not helpful	11 (7)	7 (6.4)	1
Slightly to moderately helpful	18 (11.4)	6 (5.5)	0.25
Quite to extremely helpful	130 (82.3)	97 (88.2)	0.93
Routine use of albuterol			
Not helpful	11 (7)	9 (8.2)	1
Slightly to moderately helpful	32 (20.3)	24 (21.8)	1
Quite to extremely helpful	118 (74.7)	77 (70)	0.52
See PCP at regular intervals			
Not helpful	11 (7)	1 (0.9)	0.06
Slightly to moderately helpful	17 (1.1)	9 (8.2)	0.03
Quite to extremely helpful	133 (84.2)	100 (90.9)	0.2

^aThe variables are reported as proportion [N(%)].

^bP values were determined by chi-square test used to compare asthma knowledge and preventive steps between Hispanics to AAs.

URI, upper respiratory infection.

TABLE 5. KNOWLEDGE ABOUT EFFECTIVENESS OF TREATMENT STEPS AT TIME OF EXACERBATION

<i>Treatment steps^a</i>	<i>Hispanics N=158</i>	<i>African Americans N=110</i>	<i>P value^b</i>
Albuterol use			
Not helpful	11 (7)	9 (8.2)	1
Slightly to moderately helpful	32 (20.3)	24 (21.8)	1
Quite to extremely helpful	118 (74.6)	77 (70)	0.06
Keep calm			
Not helpful	15 (9.5)	4 (3.6)	0.08
Slightly to moderately helpful	30 (19)	15 (13.6)	0.32
Quite to extremely helpful	116 (73.4)	91 (82.7)	0.07
Use of over the counter meds			
Not helpful	129 (81.6)	89 (80.9)	1
Slightly to moderately helpful	18 (11.4)	11 (10)	0.8
Quite to extremely helpful	9 (6)	5 (4.5)	0.8
Use of Vicks Vaporub			
Not helpful	97 (61.4)	77 (70)	0.15
Slightly to moderately helpful	41 (25.9)	17 (15.5)	0.05
Moderately to extremely helpful	18 (11.4)	12 (10.9)	1
Use of herbal tea			
Not helpful	129 (81.6)	80 (72.7)	0.09
Slightly to moderately helpful	21 (13.3)	14 (12.7)	1
Quite to extremely helpful	4 (2.5)	15 (13.6)	0.001
Call PCP			
Not helpful	31 (19.6)	19 (17.3)	0.63
Slightly to moderately helpful	17 (10.8)	16 (14.5)	0.45
Quite to extremely helpful	112 (70.9)	74 (67.3)	0.59

^aThe variables are reported as proportion [N(%)].

^bP values were determined by chi-square test used to compare treatment steps between Hispanics to AAs.

control group (11.9%) who regularly visited the PCP post-intervention ($P=0.5$).

Discussion

We investigated parental knowledge, aptitude, and practice among caregivers of Hispanic and AA children with asthma who were high healthcare utilizers.^{2,16,17} We found

that the majority of caregivers were aware of asthma pathophysiology including the role of airway inflammation and muscle constriction. Most caregivers were aware of the importance of avoiding allergens, using controller medications, and using albuterol with an exacerbation. Further, we found that overall knowledge of asthma triggers and management was high among caregivers of high healthcare utilizers and did not differ by ethnicity. Our findings differ from prior

TABLE 6. PERCEPTIONS ON MEDICATION USE, SIDE EFFECTS, AND EMOTIONAL BURDEN OF A CHILD WITH ASTHMA

<i>Variable^a</i>	<i>Hispanics N=158</i>	<i>African Americans N=110</i>	<i>P value^b</i>
Limit child's activity			
Never to sometimes	17 (10.8)	19 (17.3)	0.2
Frequently to always	141 (89.2)	91 (82.7)	0.15
Believe control can be achieved			
Never to sometimes	65 (41.1)	41 (25.9)	0.14
Frequently to always	93 (58.9)	69 (62.7)	0.52
Concern about side effects			
Never to sometimes	98 (62)	83 (75.5)	0.02
Frequently to always	60 (38)	27 (24.5)	0.02
Concern about child's behavior			
Never to sometimes	94 (59.5)	76 (69.1)	0.12
Frequently to always	64 (40.5)	34 (30.9)	0.13
Helplessness			
Never to sometimes	117 (74.1)	90 (81.8)	0.14
Frequently to always	43 (27.2)	20 (18.2)	0.11
Stress			
Never to sometimes	97 (61.4)	76 (69.1)	0.24
Frequently to always	64 (40.5)	34 (30.9)	0.35

^aThe variables are reported as proportion [N(%)].

^bP values were determined by chi-square test used to compare the variables between Hispanics to AAs.

studies that report limited parental asthma knowledge,^{18,19} primarily related to parental literacy,²⁰ among caregivers of children with asthma in both Hispanic and AA households.⁷ However, despite having high knowledge levels, the caregivers had high usage of ED and hospitalization for management of their child's asthma. This observation suggests that factors other than caregiver knowledge play a role in healthcare utilization.

One potential factor that may explain high utilization may be the underlying disease severity and control. We found that about half of the high healthcare utilizers had moderate to severe persistent asthma with poor control. High levels of self-reported passive smoke and allergen exposure,²¹ to which urban children are frequently sensitized,^{22,23} likely contributed to the disease severity. While suboptimal prescription habits of PCPs have been linked to low controller medication use,^{24,25} in our study all children with persistent asthma were prescribed controller medications. However, while caregivers knew the importance of controller medication use, a third of the caregivers were concerned about the side effects of the medications, particularly on their child's behavior. The low adherence to controller medications observed in our study, although based on self-report, may also be a potential contributor to poor asthma control, as previously observed in a multicenter study,²⁶ which may in turn contribute to increased healthcare utilization. The reported concerns about controller medication use, despite high level of knowledge regarding its efficacy, identify the need for targeted education to address these specific concerns, particularly among high healthcare utilizers. Further, since inhaled steroids are now known to not have a disease-modifying effect,²⁷ it may be worthwhile to discuss with caregivers the possibility of decreasing the dose or stopping the medication after 3 months of good asthma control.¹⁴ It may allay caregiver concerns about the side effects of the controller medications and may increase compliance at times of poor asthma control based on the child's individual patterns of asthma presentation.

Access to PCP may be another contributing factor to high utilization. Primary caregivers of high healthcare utilizers reported being confident in their child's PCP, found regular evaluations with PCP very helpful for asthma care, knew that they should contact their PCP for an exacerbation, and did not perceive any language barrier. However, despite this knowledge and confidence, less than half of the caregivers contacted their PCP at the time of an exacerbation and all caregivers went to the ED, which led to the current hospitalization, suggesting that caregivers were unable to translate their knowledge and awareness into action in the setting of an exacerbation. Although we did not specifically query parental anxiety in our cohort, the relatively high levels of helplessness and stress reported in association with having a child with asthma may have potentially played a role in the setting of an exacerbation. Given the high disease severity among high healthcare utilizers, their caregivers may be more anxious than caregivers of other children with asthma^{21,28} and may therefore be unable to reach out to the PCP in the setting of an exacerbation. Perceived access to the PCP may have also played a role in the increased ED use. Although a large number of children in our study were cared for by PCPs located in our hospital-based clinics, which are equipped to handle sick visits, limited access to direct physician evaluation rather than telephonic contact, particularly

after hours, may have also contributed to the higher ED visits in this cohort.

Despite the high levels of asthma knowledge reported by caregivers in our study cohort, additional education was associated with fewer ED visits in the following 2 years, findings that were similar to those reported in an adult cohort of high healthcare utilizers⁶ and differing from a pediatric study among a similar cohort in California.²⁹ These results suggest that education provided in the setting of an inpatient stay may further re-enforce key concepts that may potentially play a role in reducing future unscheduled healthcare visits.

There are certain limitations to our study. Since high healthcare utilization is not defined in the pediatric age range, we extrapolated the definition of more than 1 hospitalization from previously published adult studies to our population.⁶ Further, we did not have details on the subgroups within Hispanic and the AA groups, based on their country of origin, which may have differing beliefs and practices. However, since our primary aim was to identify factors associated with high healthcare utilization and differences between ethnicities, we proposed to broadly compare Hispanics to AA. Our lack of differences between the 2 ethnicities provides pilot data to develop future studies to further subcategorize the study groups by their country of origin and identify subgroup-specific factors associated with high healthcare utilization.

We primarily queried caregivers of children hospitalized with an asthma exacerbation and did not have a comparison group of caregivers seeking care in the ED without an associated hospitalization or a group of low healthcare utilization. Moreover, our sample included children in the 3–4 year age range in whom earlier ED visits and hospitalizations may have reflected bronchiolitis episodes. However, since these children represented the subset who continued to have symptoms with poor control, they likely comprised early persistent wheezers.³⁰ We did not directly investigate parental anxiety in our modified questionnaire but their level of stress and helplessness gives us an indirect assessment of their anxiety. Given the length of the primary questionnaire applied in the inpatient setting, we were concerned about lack of focus from caregivers with additional time spent on completing questionnaires. We did not enquire into the presence of gastroesophageal obstructive disease or obesity, 2 co-morbidities that have been linked with poor asthma control.³¹ We also did not access time of ED use and hence do not have information on how many children were seen in the ED after hours. However, irrespective of the time being seen in the ED, the majority of the caregivers did not call the PCP, reiterating the need for identifying barriers to accessing the PCP for an exacerbation. Further, while we observed a decline in ED visits in the intervention group, we recognize that our follow-up is limited by access to health utilization data to our center and its affiliated clinics and did not include ED visits or hospitalizations at other healthcare facilities.

In summary, our results suggest that high healthcare utilization among urban minority preadolescent children is multifactorial and does not differ by ethnicity. While core asthma knowledge was good among caregivers of high healthcare utilizers and did not differ by ethnicity, an aspect not previously investigated, it was not associated with better implementation of steps to avoid ED visits. These

findings highlight the need to identify factors other than knowledge that may be contributing to high healthcare utilization. While high healthcare utilizers had high disease severity and poor control, there was suboptimal compliance with controller medication regimens in this population associated with concerns about daily medication use and its side effects. In addition, caregiver reports of being stressed and feeling helpless likely affected decision making on a daily basis and with an exacerbation. Further, the association between fewer ED visits and our short and targeted intervention to caregivers with good core asthma knowledge emphasizes the need for continued targeted education focusing on specific aptitudes and practices that lead to ED visits. Thus, targeted individualized interventions addressing specific concerns and the psychological burden of caring for a child with poorly controlled asthma of higher severity are needed for caregivers of high healthcare utilizers.

Author Disclosure Statement

No competing financial interests exist for any authors.

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APPENDIX 1: QUESTIONNAIRE 1

Children's Hospital at Montefiore Asthma Questionnaire 1

A. Patient Information

1. Patient MR Number:
2. Date of interview (mm/dd/yy):
3. Interviewer (initials):
4. Pt. Floor Number:

B. Demographic Information

5. What is your child's date of birth? (mm/dd/yy):
6. What is your date of birth? (mm/dd/yy):
7. What race or ethnicity do you consider yourself?
 1 = Hispanic 2 = Black 3 = White 4 = Other 9 = Unknown
- 7a. How are you related to the child?
 1. Mother
 2. Father
 3. Grandparent
 4. Other
- 7b. What is your parental role?
 1. Biological Parent
 2. Foster Parent
 3. Adopted Parent
 4. Legal Guardian
- 7c. At what age was the child adopted or placed in foster care?
8. What is your highest level of education?
 0 = 1–8, 1 = 9–11, 2 = high school grad, 3 = some college, 4 = college grad, 9 = unknown
9. How do you pay for your child's healthcare?
 1 = self-pay 2 = Medicaid fee for service 3 = Medicaid managed care
 4 = private 5 = other 9 = unknown

C. Health

10. When was your child diagnosed with asthma? (mm/dd/yy)
11. Do any of your child's parents, brothers, sisters, or grandparents have asthma? (0 = no 1 = yes)
 - 11a. If so, who:
 1. Mom
 2. Dad
 3. Siblings
 4. Grandparents

12. When was your child's last "well-child" visit (a regular visit when he/she was not sick)? (mm/dd/yy)

13. Does your child have a primary doctor or a place where he/she usually receives care? (0 = no 1 = yes)

13a. If yes: is it: [read choices]

- 1 = A private practice
- 2 = A hospital clinic
- 3 = A community-based clinic
- 4 = Other

5 = Don't have a primary doctor

14. Does your child see an asthma specialist? (0 = no 1 = yes)

15. Has your child seen an allergy specialist? (0 = no 1 = yes)

16. Has your child undergone skin testing for allergies? (0 = no 1 = yes)

17. When your child has an asthma emergency who are you more likely to contact, your primary doctor or your asthma specialist?

(1 = primary doctor 2 = asthma specialist)

[Ask the following questions in relation to the primary doctor (if patient does not see a specialist) or whichever doctor patient is more likely to contact in an emergency]

The following questions are about your primary doctor or specialist:

18. Are you confident with the way your child's doctor or doctors treat the asthma? (0 = no 1 = yes)

19. Is language a problem in communicating with your child's doctor or doctors about the asthma? (0 = no 1 = yes)

20. When your child is sick, do you tend to go to the Emergency Room (ER) or the doctor's office?

(1 = Emergency Room 2 = doctor's office)

21. Would you say that your child's asthma is (read choices)

1 = mild 2 = moderate 3 = severe 9 = unknown

22. Do you think your child's asthma is (read choices)

- 1 = poorly controlled
- 2 = well controlled

23. In the last one year, since (month), how many times did you take your child to the ER for asthma? Include this visit in your count. (code number of visits)

23a. How many asthma ER visits does your child have per year (average)? (code number of ER visits)

24. In the last one year, since (month), how many times was your child admitted to the hospital for asthma? (code number of admissions)

25. Has your child ever been admitted to a hospital other than the Children's Hospital at Montefiore, in the past two years? (0 = no 1 = yes)

25a. If yes: How many times has your child been admitted to another hospital in the past two years? (code number of outside admissions)

26. Was your child ever admitted to the Intensive Care Unit (ICU) for asthma treatment?

(0=no 1=yes)

26a. If yes: Was your child put on a breathing machine? (0=no 1=yes)

27. Over the last 3 months, since (month), how often did your child have symptoms such as wheezing and tightness of chest or have to use asthma quick-relief medicines like albuterol or proventil during the day?

1 = daily

2 = 1–6 times/week

3 = 1–3 times/month

4 = < 1 month

5 = only with a URI or weather change

6 = never

28. Over the last 3 months, since (month), how often did your child have symptoms such as wheezing and tightness of chest or have to use asthma quick-relief medicines like albuterol or proventil during the night?

1 = daily

2 = 1–6 times/week

3 = > 2 times/month

4 = < 1 month

5 = only with a URI or weather change

6 = never

D. Knowledge/Aptitudes

29. Were you ever taught about asthma? (0=no 1=yes)

29a. If so, by whom:

1 = primary care doctor

2 = ER

3 = asthma specialist

4 = internet

5 = friend/family

30. Do you believe that the following causes asthma? (0=no 1=yes)

A. swelling of the lungs?

B. mucus production?

C. muscle tightening?

31. Tell me how helpful you think the following are in preventing asthma.

1 = not helpful 2 = slightly helpful 3 = moderately helpful 4 = quite helpful 5 = extremely helpful

A. Taking preventive medicines every day?

B. Avoiding things that cause allergic reactions?

C. Using your Albuterol?

D. Seeing a doctor regularly even if you are in good health?

32. Tell me how helpful you think the following are in treating asthma exacerbation.

1 = not helpful 2 = slightly helpful 3 = moderately helpful 4 = quite helpful 5 = extremely helpful

A. Taking inhalers

B. Keeping a child calm

C. OTC cough medicines

D. Rubbing ointment on your child's chest (like Vicks vapor-rub)

E. Applying alcohol over your child's forehead or chest

F. Giving your child tea or herbal tea

G. Calling your clinic for advice

33. What are the things that trigger your child's acute asthma attack? (0=no 1=yes)

A. URI

B. Weather

C. Exercise

D. Allergens: such as pets, mice, cockroaches, dust, mold, cleaning supplies (laundry detergent, kitchen/bathroom sprays)

E. Smoking

34. If allergens are a trigger for your child's asthma, which ones specifically affect your child's asthma? (0=no 1=yes)

A. Pets

B. Mice

C. Cockroaches

D. Dust

E. Mold

F. Cleaning supplies

E. Environment

35. Do you or anyone else in your house smoke? (0=no 1=yes)

[Probe the relationship of this person]

If yes: Answer yes or no to each of these statements about smoking. (0=no 1=yes)

35a. I (or another family member) smoke inside the house when my child is not home.

35b. I (or another family member) smoke inside the house as long as my child is in another room.

35c. I (or another family member) smoke inside the house when my child is in the same room

35d. I (or another family member) smoke outside the house and then come inside the house.

36. Do you use a humidifier/vaporizer in your home? (0=no 1=yes)

37. Do you have carpeting (or rugs) in your home? (0=no 1=yes)

38. Is there any mold or mildew in the house or apartment? (0=no 1=yes)

39. In your home do you see ... (0=no 1=yes)

A. Cockroaches

B. Mice

C. Rats

40. Do you have any pets? (0=no 1=yes)

A. Dog

B. Cat

C. Other

F. Practice

41. The following is a list of some asthma medicines that your child may use at home. Tell me whether your child never takes it, takes it every day, or takes it less than once/day.

0=never prescribed 1=never 2=every day 3=less than every day

A. Albuterol by nebulizer:

B. Albuterol by pump with spacer:

- C. Albuterol by pump without spacer:
- D. Oral albuterol (liquid):
- E. Advair:
- F. Flovent or Pulmicort:
- G. Foradil:
- H. Prelone (oral corticosteroids):
- I. Singulair:
- J. Other medicine:

42. How many days of school has your child missed this year?

(If asked in Sept. or Oct. ask about days of school missed in the past year)

43. Have you given your child written permission for school allowing him/her to keep and use the asthma pump and spacer when needed? (0=no 1=yes)

44. Is there a school health clinic? (0=no 1=yes)

45. Is there a school nurse? (0=no 1=sometimes 2=always)

46. Do you have a written Asthma Action Plan of what to do in case of an asthma emergency? (show the sample) (0=no 1=yes)

Please answer these questions in relation to today's episode of asthma.

47. When did you start treating your child?

- 1=when he started coughing
- 2=when he started wheezing
- 3=when he had difficulty breathing

48. Which of these did you do when this asthma attack started?

(0=no 1=yes)

- A. Measure peak flow
- B. Begin treatment with quick-relief medications like albuterol
- C. Start oral steroids, e.g. prednisone
- D. Call your doctor
- E. Visit your doctor
- F. Come to ER

49. If you gave nebulizer or inhaler: After starting treatment with albuterol at home, how long did you wait before bringing your child to the ER? (code in hours)

G. Psychosocial

50. In the past year, have you had any trouble making or keeping appointments in regard to your child's asthma? (0=no 1=yes)

51. Does your child take his/her own asthma medication?

- 1. Never
- 2. Sometimes
- 3. Frequently
- 4. Always

52. Are you concerned about your child's behavior?

- 1. Never
- 2. Sometimes
- 3. Frequently
- 4. Always

53. Do you feel stressed because of your child's asthma?

- 1. Never
- 2. Sometimes
- 3. Frequently
- 4. Always

54. Do you allow your child with asthma to be physically active?

- 1. Never
- 2. Sometimes
- 3. Frequently
- 4. Always

55. Do you believe that your child's asthma can be controlled, so that he/she does not have symptoms?

- 1. Never
- 2. Sometimes
- 3. Frequently
- 4. Always

56. Do you believe that the asthma medicines that your child takes daily can cause problems?

- 1. Never
- 2. Sometimes
- 3. Frequently
- 4. Always

57. Do you feel helpless with your child's asthma?

- 1. Never
- 2. Sometimes
- 3. Frequently
- 4. Always

APPENDIX 2: QUESTIONNAIRE 2

Children's Hospital at Montefiore Asthma Questionnaire 2

1. Date of interview (mm/dd/yy):
2. Interviewer (initials):
3. Pt. Floor Number:
4. Do you believe that asthma causes the following? (0=no 1=yes)
 - A. swelling of the lungs?
 - B. mucus production?
 - C. muscle tightening?

5. Tell me how helpful you think the following are in preventing asthma.

1=not helpful 2=slightly helpful 3=moderately helpful 4=quite helpful 5=extremely helpful

- A. Taking preventive medicines every day?
- B. Avoiding things that cause allergic reactions?
- C. Using your Albuterol?
- D. Seeing a doctor regularly even if you are in good health?

6. Tell me how helpful you think the following are in treating asthma exacerbation.

1=not helpful 2=slightly helpful 3=moderately helpful
4=quite helpful 5=extremely helpful

- A. Taking inhalers
- B. Keeping a child calm
- C. OTC cough medicines
- D. Rubbing ointment on your child's chest (like Vicks Vaporub)
- E. Applying alcohol over your child's forehead or chest
- F. Giving your child tea or herbal tea
- G. Calling your clinic for advice

7. What are the things that trigger your child's acute asthma attack? (0=no 1=yes)

- A. URI
- B. Weather
- C. Exercise
- D. Allergens such as pets, mice, cockroaches, dust, mold, cleaning supplies (laundry detergent, kitchen/bathroom sprays)
- E. Smoking