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Asthma specialist care preferences among parents of children receiving emergency department care for asthma

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ABSTRACT

Objective: To learn factors associated with desire for asthma specialist care among parents of children seeking emergency department (ED) care for asthma, and if referral was indicated based on national asthma guidelines. **Methods:** We surveyed parents of children ages 0–18 years seeking pediatric ED asthma care, then comparisons were made according to parental level of interest in asthma specialist care, with regard to socio-demographics, asthma morbidity and care, by chi-squared and logistic regression. **Results:** Of 149 children, 20% reported specialist care, but 75% met guideline criteria for referral. About 80% of parents not seeing an asthma specialist expressed a desire to see one. Higher rates of prior urgent care visits (48% vs. 22%, $p = 0.03$), ED visits (82% vs. 35%, $p < 0.001$) and oral steroid use (53% vs. 22%, $p = 0.009$) were reported by parents who desired an asthma specialist compared with parents who did not. 87% of parents not seeing a specialist attributed this to a perceived lack of necessity by their primary care provider. An ED visit within the prior 12 months was the most significant predictor in parental desire for specialist care (odds ratio 9.75; 95% CI 3.42–27.76) in adjusted logistic regression models. **Conclusion:** High rates of parental preference for asthma specialist care suggest that directly querying parents may be an efficient method to identify children appropriate for specialist care in the ED.

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Introduction

One in five children with asthma seek care in the emergency department (ED) per year, resulting in greater than 900,000 visits annually [1–4]. In addition, low-income, urban and minority children experience high rates of ED visits for asthma [5–8]. While the high rates of ED visits among these patient populations likely have multifactorial explanations, including genetic predisposition, socioeconomic status, psychosocial factors and environmental exposures [9], poor asthma care remains a significant contributing factor.

Asthma specialist care improves consistency of care with asthma guidelines, increases anti-inflammatory medication use and reduces ED use [10,11]. NIH asthma guidelines also recommend asthma specialist care for children experiencing recurrent ED visits or other signs of poor control (patient has required two

or more courses of systemic corticosteroids in a 12-month period or has had an exacerbation requiring hospitalization). However, urban, minority and poor children with asthma, the same populations with increased rates of ED visits, are under-referred to asthma specialists [12–14]. It is unknown if parents of children seeking ED care would prefer post-ED follow-up specialist care for their child, which could help to redress under-treatment and poor asthma outcomes of this patient population.

The purpose of this study was to understand the prevalence of parental preferences for follow-up asthma specialist care among a population of children being seen for ED asthma care, to determine how these preferences relate to indicators of prior asthma morbidity and care, and to assess if specialist care was indicated based on NIH asthma guidelines. To

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identify factors associated with the use of and desire for asthma specialist care among parents of children seeking ED asthma care, we tested three hypotheses: (i) asthma specialist use would be low, (ii) parental desire for specialist care would be high and (iii) parental desire for specialist care would be associated with higher levels of asthma morbidity in their children.

Methods

Study population and recruitment procedures

This study was conducted at an urban tertiary children's hospital ED of parents of children seeking asthma care. A bilingual research assistant (RA) identified potential participants based on the presence of a respiratory chief complaint. Recruitment occurred during the typical daily peak ED census period, from approximately 3 pm–8 pm, weekdays and weekends. Eligibility criteria included English or Spanish-speaking parents with a child 0–18 years of age, carried a diagnosis of asthma or reactive airway disease, or screened positive using a validated asthma screening survey [15–17]. Exclusion criteria included those parents who had previously taken the survey, did not understand English or Spanish or whose child carried a diagnosis of cystic fibrosis, bronchopulmonary dysplasia, lung cancer or currently used a mechanical ventilator at home.

Parents were administered a written survey offered in both Spanish and English by the RA once the patient had been placed in a private room. The survey included questions regarding sociodemographics, asthma morbidity, acute health care use, asthma care and preference for asthma specialist care (additional specifics provided below). Participants were enrolled via verbal consent and provided an information sheet. If the participant was eligible and completed the survey, cash in the amount of \$20.00 was provided to the parent or legal guardian. Recruitment occurred from September 2015 to March 2017, based on RA availability. The hospital's Institutional Review Board approved the study protocol.

Survey items

Sociodemographics

Survey questions included demographic information about the child and child's parent, including age, race/ethnicity, gender, employment status, educational level and health insurance status.

Parental desire for follow-up specialist asthma care

Parents were asked whether they would like their child to see an asthma specialist (allergist or pulmonologist) in follow-up. Response options included "I'm not interested/I do not want to," "Yes, I would like my child to see an asthma specialist" and "My child already sees an asthma specialist." If they had not seen an asthma specialist, they were asked the reason they had not. Options included cost, inconvenient hours, lack of transportation or the specialist was too far away, or that the primary care provider did not suggest specialist care or did not think it was needed.

Lifetime asthma morbidity

Parents were asked to report the lifetime number of ED visits, hospitalizations and oral steroid courses for asthma.

Missed school and work

Parents reported the number of missed school and/or work days due to asthma over the prior 12 months.

Asthma action plan

Parents were asked to report if they had previously received an asthma action plan. This was assessed as an indicator of prior asthma care quality.

Asthma symptoms

Parents were asked about the presence of various general asthma symptoms and/or their impact during the recent and more distant past, including:

1. Repeated episodes of coughing, wheezing, chest tightness or trouble breathing during the past 1–2 years;
2. Coughing, wheezing, chest tightness or trouble breathing when they play or exercise
3. Missed school in the last year because of coughing, wheezing, chest tightness or trouble breathing
4. Coughing, wheezing, chest tightness or trouble breathing during the daytime in the past month
5. Coughing, wheezing, chest tightness or trouble breathing at night in the past month

Parents provided information on a variety of indicators of asthma morbidity, using the Pediatric Asthma Control and Communication Instrument-ED version (PACCI-ED) [18,19]:

1. *Asthma severity.* Subjects with asthma were categorized according to 2007 NIH guidelines as having mild intermittent, mild persistent, moderate

Table 1. Sociodemographics of participants, by level of interest in asthma specialist care.

	Preference for asthma specialist care			<i>p</i> -value
	No interest (<i>N</i> = 23) 15.5%	Interested (<i>N</i> = 96) 64.5%	Sees specialist (<i>N</i> = 30) 20%	
Gender of patient Male	52%	65%	60%	0.5
Age of patient (mean, years)	3.9	4.7	5.5	0.4
Age of parent (mean, years)	32	33	33	0.8
Race/Ethnicity (child)				
Latino	52%	69%	83%	0.05
African-American	4%	13.5%	3%	0.2
White/Caucasian	22%	3%	3%	0.008
Other	0%	1%	6%	0.166
Annual household income <\$20,000	62%	56%	50%	0.7
Marital status: married/single, living with significant other	74%	62%	80%	0.2
Private health insurance	22%	7%	3%	0.05

persistent, or severe persistent asthma based on parental report of daytime symptoms, night-time symptoms, activity limitation, and rescue medication use over the preceding 1–2 weeks [20].

2. *Disease trajectory.* Parents were asked about their perception of the direction of the child's asthma over the prior 12 months (getting better, staying the same or getting worse).
3. *Disease burden.* Parents were asked how bothered they were by their child's asthma over the prior 12 months (not bothered, somewhat bothered or very bothered).
4. *Evidence of asthma exacerbations over the prior 12 months.* Parents were asked to report the number of prior ED visits, urgent care visits, hospitalizations and courses of oral corticosteroid use for asthma. A summation of total asthma exacerbations was categorized as chronic asthma control: controlled (no events), partly controlled (1 event), mildly uncontrolled (2 events), moderately uncontrolled (3 events) and severely uncontrolled (4 or more events).

Analysis

Indicators of asthma care, prior asthma morbidity and need for referral to an asthma specialist (based on NIH asthma guidelines) were compared by asthma specialist care status as outlined above. Need for asthma specialist referral was based upon meeting one or more of the following asthma guideline criteria: history of 1 or more hospital stays or 2 or more of any one of the following: ED visit, urgent care visit and/or oral corticosteroid course. We examined the need for specialist referral using two different timeframes: (i) over the prior 12 months; (ii) over the patient's lifetime.

Categorical variables were summarized using frequencies and percentages, and compared between groups

using chi-squared or Fisher's exact tests as appropriate. Continuous variables were summarized using means and standard deviations, and compared between groups using one-way ANOVA *F*-tests. Logistic regression models were used to evaluate associations of prior asthma care and morbidity with parental desire for asthma specialist care, excluding those who already see a specialist, adjusting for insurance status and parental education. These social determinants of health were chosen since they could influence one's interest in seeking asthma specialist care, one's exposure to the concept of an asthma specialist and how one values what is offered through specialist care. Odds ratios, 95% confidence intervals and *p* values were reported. A *p* value of <0.05 denoted statistical significance. Analyses were performed using R v. 3.3.2 (<http://www.r-project.org/>).

Results

Asthma specialist care and sociodemographics

338 parents of children presenting to the ED for asthma care were approached, of whom 194 were consented for participation. Of these, we had useable data on 149. The majority of child participants were male (62%) and Hispanic (69%), with a mean age of just under 5 years (Table 1). More than two-thirds of parents reported being married or living with their significant other. A majority of parents reported a combined annual household income less than \$20,000, while nearly all reported having a primary care provider and having some form of health insurance.

About 20% of participants reported currently seeing an asthma specialist, while 65% expressed a desire to see a specialist, and 15% did not want to see an asthma specialist. A higher proportion of parents of Caucasian children did not want to see an asthma specialist than did want to (22% vs. 3%, *p* = 0.006). Conversely, a higher proportion of Latino mothers

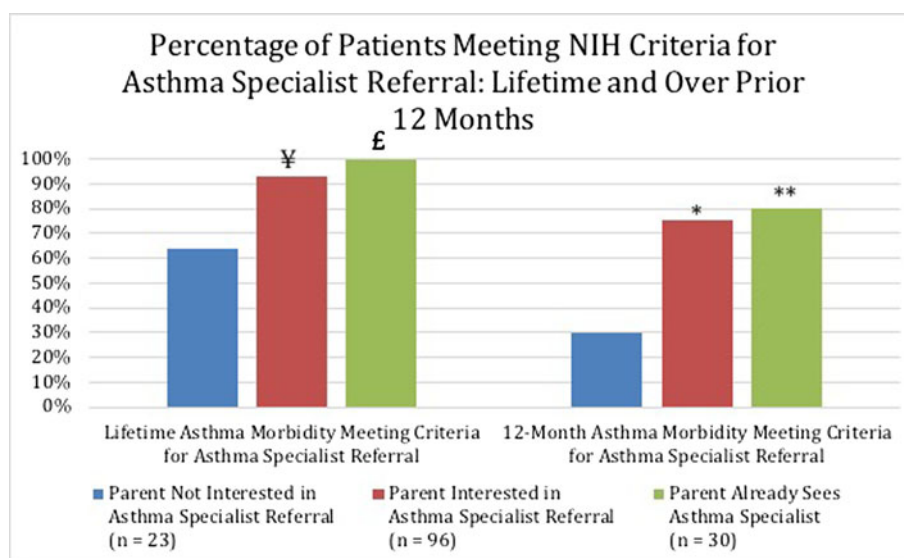


Figure 1. The proportion of patients meeting NIH criteria for asthma specialist care, by parent interest level in asthma specialist referral. Legend: £ $p = 0.008$ want a specialist versus do not want specialist (lifetime morbidity); ¥ $p = 0.003$ sees specialist versus do not want specialist (lifetime morbidity); * $p < 0.001$ want a specialist versus do not want specialist (12-month morbidity); ** $p < 0.001$ sees specialist versus do not want specialist (12-month morbidity).

expressed a desire for asthma specialist care than those who did not (65% vs. 39%, $p = 0.03$). No other sociodemographic characteristics were associated with seeing or desiring to see an asthma specialist.

Indications for referral

Overall, 78% of the children participants met NIH criteria for asthma specialist referral based on lifetime asthma morbidity. More specifically, among parents who did not want an asthma specialist referral, 64% of their children met referral criteria, in contrast to 93% of children whose parents desired a specialist referral ($p < 0.008$, Figure 1) and 100% of children already seeing a specialist asthma specialist referral ($p = 0.003$, Figure 1).

When examining asthma morbidity over the prior 12 months, 70% of the participants met NIH criteria for asthma specialist referral. More specifically, among parents who did not want an asthma specialist referral, 30% of their children met referral criteria, in contrast to 76% of children whose parents desired a specialist referral ($p < 0.001$, Figure 1) and 83% of children already seeing a specialist met criteria for asthma specialist referral ($p < 0.001$, Figure 1).

Associations with parental interest in asthma specialist care

Asthma symptoms, trajectory and burden

Parents not interested in asthma specialist referral consistently were less likely to report that their children were having “coughing, wheezing, chest tightness

or trouble breathing” over the past 1–2 years, during play, causing missed school or having these symptoms during the day (Table 2). There were no significant differences in reports of these symptoms at night in the past month. We observed no significant differences according to level of parental interest in asthma specialist care in relation to parent-reported disease trajectory or disease burden from asthma over the prior year.

Asthma severity

Children whose parents were not interested in asthma specialist care were less likely to have moderate-severe persistent asthma (39%) versus children of parents who were interested (58%, $p < 0.05$) or versus children already seeing a specialist (60%, $p < 0.05$). Importantly, the proportion with persistent asthma in both groups of children not seeing an asthma specialist was 79% and 84%, respectively ($p = 0.2$).

Asthma morbidity and care quality

Asthma morbidity and care quality were related to asthma specialist status in this population. First, more prior urgent care visits (48% vs. 22%, $p = 0.03$), ED visits (82% vs. 35%, $p < 0.001$), oral steroid use (53% vs. 22%, $p = 0.009$) for asthma over the prior 12 were reported by parents who desired an asthma specialist compared with parents who did not (Table 2). When we looked at this in terms of PACCI-ED chronic asthma control classification, we observed a similar trend in that children of parents who were not

Table 2. Asthma symptoms, morbidity and care of participants by asthma specialist interest status.

Morbidity Indicator	No interest in asthma specialist (N = 23)	Interested in asthma specialist (N = 96)	Sees specialist (N = 30)	p-value
Repeated episodes of coughing, wheezing, chest tightness or trouble breathing during the past 1–2 years	65%	87% ^a	93% ^b	See legend
Coughing, wheezing, chest tightness or trouble breathing when they play or exercise	17%	43% ^a	43% ^b	See legend
Missed school in the last year because of coughing, wheezing, chest tightness or trouble breathing	26%	51% ^a	59% ^b	See legend
Coughing, wheezing, chest tightness or trouble breathing during the daytime in the past month	56%	79% ^a	77%	See legend
Coughing, wheezing, chest tightness or trouble breathing at night in the past month	65%	80%	73%	NS
Parental perception of disease trajectory over past 12 months				NS
Getting better	19%	27%	41%	
Staying the same	62%	43%	41%	
Getting worse	19%	29%	17%	
Disease burden: How bothered parent has been over past 12 months				NS
Not bothered	35%	25%	30%	
Somewhat bothered	39%	26%	30%	
Very bothered	26%	48%	40%	
Asthma severity				
Intermittent	22%	16%	17%	
Mild persistent	39%	26%	23%	
Moderate/severe persistent	39%	58%	60%	
≥1 urgent care visit for asthma in Past 12 months	22%	48% ^a	50% ^b	
≥1 ED visit for asthma in past 12 months	35%	82% ^c	87% ^d	
≥1 hospitalization for asthma in past 12 months	13%	31%	50% ^b	
≥1 oral steroid course for asthma in past 12 months	22%	53% ^a	60% ^b	
≥1 ED Visit for Asthma in Lifetime	56%	80% ^a	87% ^d	
≥1 hospitalization for asthma in lifetime	17%	39%	67% ^b	
≥1 oral steroid course for asthma in lifetime	30%	52% ^a	60% ^b	
Parent reports child is not supposed to be on a daily controller medication	83%	56% ^a	27% ^{b,e}	
Mean school/daycare days missed due to asthma in past 12 months (SD)	6.9 (10.3)	6.2 (5.7)	15.1e (11)	See legend
Missed work due to asthma in past 12 months (SD)	2.3 (1.6)	6.5 (13.0)	17.8 (14.8)	0.008 ^f
Child has an asthma action plan	26%	19%	60% ^{b,e}	<0.001
Previously completed a validated asthma questionnaire	0%	1%	3%	NS

NS: no statistically significant difference between any of the comparison groups.

^a $p < 0.05$, children whose parents want a specialist versus children whose parents do not want a specialist.

^b $p < 0.05$, children who see a specialist versus children whose parents do not want a specialist.

^c $p < 0.001$, children whose parents want a specialist versus children whose parents do not want a specialist.

^d $p < 0.001$, children who see a specialist versus children whose parents do not want a specialist.

^e $p < 0.05$, children who see a specialist versus children whose parents want a specialist.

^fUsing analysis of variance.

interested in an asthma specialist had better levels of chronic asthma control compared with children of parents who did want to see an asthma specialist ($p < 0.001$). Second, higher levels of acute health care use and oral steroid use for asthma was observed between children who were already seeing a specialist versus the children of parents who were not interested in seeing an asthma specialist ($p < 0.05$ for each comparison). Third, when we examined the mean number of doctor visits (SD) for asthma in the prior 12 months, children of parents who did not want to see a specialist had fewer visits (0.9 {1.5}) than those seeing a specialist (3.4 {5.0}, $p < 0.05$) and children of parents interested in asthma specialist referral (1.9 {1.3}, $p < 0.05$). Fourth, missed school and work due to asthma differed significantly according to level of parental interest in asthma specialist referral (Table 2). Lastly, chronic asthma care quality was sub-

optimal across the board, regardless of level of asthma specialist interest (not interested in a specialist, interested in a specialist, currently seeing a specialist), including lack of prescribed controller medications (83%, 56% and 27%, respectively), receipt of an asthma action plan (26%, 19% and 60%, respectively) and prior use of a validated asthma questionnaire (0%, 1% and 3%). Notably, nearly all of those not seeing a specialist reported that it was because their primary care provider did not suggest it or think that a specialist was necessary (87% and 87%, respectively, $p = 1$).

In multivariable logistic regression models to determine predictors of parental interest in asthma specialist care (adjusted for parent education and insurance type), an ED visit for asthma within the prior 12 months (OR 9.75, 95% CI 3.42–27.76, $p \leq 0.001$) and oral steroid use in the last 12 months (OR 4.14,

Table 3. Logistic regression models: desire for asthma specialist care.

	Adjusted models	
	OR (95% CI)	p-value
Chronic asthma control (reference group: controlled)		
Partly controlled	2.31 (0.65, 8.19)	0.1
Mildly uncontrolled	8.62 (1.79, 41.41)	0.007
Moderately uncontrolled	7.08 (1.41, 35.63)	0.018
Severely uncontrolled	20.75 (3.31, 130.00)	0.001
Sub-acute asthma control (reference group: controlled)		
Partly controlled	0.96 (0.26, 3.49)	0.9
Uncontrolled	3.39 (0.78, 14.82)	0.1
Poorly controlled	1.34 (0.31, 5.70)	0.6
Missed school (reference group: never)		
Sometimes	3.34 (0.94, 11.89)	0.06
Child not in school/daycare	1.65 (0.48, 5.69)	0.4
Oral steroid		
Lifetime (1+ vs. 0)	2.10 (0.42, 10.51)	0.3
Last 12 months (1+ vs. 0)	4.14 (1.41, 12.13)	0.01
Prior ED visits		
Lifetime (1+ vs. 0)	0.24 (0.09, 0.65)	0.005
Last 12 months (1+ vs. 0)	9.75 (3.42, 27.76)	<0.001
Prior hospitalizations		
Lifetime (1+ vs. 0)	2.99 (0.92, 9.67)	0.06
Last 12 months (1+ vs. 0)	3.06 (0.84, 11.21)	0.09
PCP did not suggest specialist	0.90 (0.22, 3.62)	0.8

95% CI 1.41–12.13, $p=0.010$) were the strongest predictors of parental desire for asthma specialist care (Table 3) but not lifetime oral steroid use ($p=0.4$). Conversely, a lifetime ED visit for asthma was not a strong predictor of parental desire for asthma specialist care (OR 0.24, 95% CI 0.09–0.65, $p=0.005$). No other asthma morbidity indicators were significant predictors of parental interest in asthma specialist referral.

Discussion

In this study of children presenting to the emergency department for asthma care, we observed that ongoing asthma specialist use was low even though more than 75% met national asthma guideline criteria for asthma specialist care. Furthermore, more than 80% of parents not seeing a specialist expressed a desire to see one. A higher burden of asthma morbidity was observed among parents who desired asthma specialist care compared with parents who did not desire such care. Specifically, a significantly higher percentage of parents desiring asthma specialist care had also reported prior asthma-related urgent care visits, ED visits and use of oral steroids. While not statistically significant, there was a clinically meaningful 20% higher proportion of children with a prior hospitalization for asthma among parents who desired asthma specialist referral versus those who did not. While there were similar rates of missed school between the two groups, parental desire appeared to be more appropriately associated with the acute health care

visits and exacerbations reported above. This increased parental interest in specialist care in association with indicators of more significant morbidity suggests that parental desire for asthma specialist care in this ED population was a valid, but unmet need.

It is important to note that nearly two-thirds of children of parents not interested in specialist care met national asthma guideline criteria for referral based on lifetime morbidity. When we narrowed the time-frame of asthma morbidity to the prior 12 months to participation in our study, 30% still met NIH asthma specialist referral criteria. We were not able to evaluate why these parents were uninterested in asthma specialist care, but these findings suggest that a meaningful portion of parents would need to be persuaded that their child should be referred for asthma specialist care. Furthermore, this group of parents suggests that relying exclusively on parental preference will not identify all children in need of asthma specialist referral, although that strategy would have resulted in an increase in children receiving asthma specialist care from 20% to 64%. With a protocol in place based on asthma morbidity, the proportion of children receiving asthma specialist care would increase to 77%.

Our results suggest that a practical strategy to identify children in need of specialist care may be to screen for an ED visit or oral steroid use for asthma in the prior 12 months: providers in the emergency department as well as in the primary care office should be aware of this when taking the history of asthma patients. Interestingly, more than 85% of those not seeing a specialist indicated that the number one reason was that the PCP did not suggest seeing an asthma specialist or conveyed to the parents that a specialist was not necessary. However, this finding was not significant in the multivariable logistic regression model. We did not evaluate PCP perceptions of these patients, but under-assessments and under-referral of pediatric patients has been well-described in the literature [13,14,21–23] and likely are contributing factors to the under-use of asthma specialists in this population.

Our study also revealed that many patients' have inappropriately managed asthma symptoms, regardless of receipt or desire for asthma specialist care. In particular, less than half of the participants in this ED-based study reported a prescribed daily controller medication—while upward of 83% should have been on daily controller medications, based on meeting criteria for asthma specialist referral or having persistent symptoms, respectively. Similarly, an inadequate

proportion of parents reported possession of an asthma action plan—28% overall, and only 60% of those seeing an asthma specialist. Based on national asthma guidelines, 100% should have reported possession of an asthma action plan. While we do not know the reasons for such poor care in this high-risk population, it is telling that only 1% had ever previously completed an asthma morbidity assessment questionnaire—so the possibility of each child's regular health care provider to inadequately evaluate the child's asthma is significant—resulting in under-prescribing of controller medications and under-use of asthma action plans. It is possible that with more accurate assessments of asthma morbidity by each child's regular health care provider that a higher proportion of children would receive optimal asthma care. The fact that the rates of parental desire for asthma specialist care exceed rates of daily controller medication use and asthma action plan possession may suggest that parents realize that higher quality care is needed for their child.

Studies have shown that parents of children with frequent emergency department use for asthma have reported receiving no preventive counseling and little education on the disease, lack standardization of treatment protocols, and have problems with coordination of care between health care providers [24]. Patients with uncontrolled asthma have more visits to the emergency department or urgent care facilities and have more hospitalizations [25]. Similarly, parents with a preference to see an asthma specialist in this study visited the emergency department and were more frequently hospitalized than parents with no desire to see a specialist. National guidelines recommend that all patients with asthma receive an asthma action plan and referral to an asthma specialist for uncontrolled asthma, however this study shows that primary care providers may not be making these referrals [20]. A referral to an asthma specialist could potentially decrease their health care visits, decrease medical costs and improve their child's asthma [25].

This study has several limitations. First, it was completed at a single tertiary care pediatric emergency department during a limited enrollment period, and may not necessarily be generalizable throughout the country. However, this pediatric hospital is the largest in Los Angeles County with a high volume of patients with asthma and enrollment time was selected to occur during the highest volume time in the ED. In addition, a large proportion of the participants in this study are representative of the pediatric populations at-risk for poor asthma care and/or

poor asthma outcomes—those on public health insurance and/or those of African-American and Hispanic ethnicities. Second, parents were not surveyed as to whether they had tried to seek asthma specialty care and insurance had denied it, which could have led to lack of specialty care. However, we did survey parents about barriers to previously seeking asthma specialist care and 88% of those not seeing a specialist cited lack of referral or expression of need for referral by their PCP as the reason. Furthermore, our goal was to understand if there was both a desire and an unmet need for asthma specialist care, regardless of the barriers—our findings suggest that insurance or any other types of barriers are medically inappropriate. Third, we focused on an ED population with access to primary care, so the results may not be representative of children cared for in other settings or those without access to primary care. However, the ED visits for asthma are common, so our findings should be relevant for a significant portion of the pediatric asthma population. Fourth, parental recall may not necessarily be accurate which can lead to recall bias, particularly as we were unable to access patients' outside ED visits or PCP visits. Lastly, the survey took 45 min to complete and may have only been completed by parents with children presenting with a more severe exacerbation than those that may have had a mild exacerbation and a shorter length of stay in the ED. However, the participants in our study included a broad range of asthma severity levels, ranging from intermittent to severe persistent.

Conclusions

Among this ED population with significant asthma morbidity, ongoing asthma specialist care is uncommon, despite national asthma guideline indications and common parental preferences for it. Eliciting parental preference for specialist care may be an efficient method to identify children appropriate for specialist care. Future studies should be performed to evaluate whether increased use of asthma specialists may improve asthma care and outcomes in children routinely seen in ED settings.

Disclosure statement

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

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