Published in final edited form as:

Acad Pediatr. 2018 ; 18(8): 905–911. doi:10.1016/j.acap.2018.04.135.

Family Caregiver Marginalization is Associated with Decreased Primary and Subspecialty Asthma Care in Head Start Children

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Abstract

Background: Urban minority children are at risk for poor asthma outcomes and may not receive appropriate primary or subspecialty care.

Objective: We hypothesized that preschool children with asthma whose caregivers reported more barriers to care would be less likely to have seen their primary care provider (PCP) or an asthma subspecialist and more likely to have had a recent emergency department (ED) visit for asthma.

Methods: The Barriers to Care Questionnaire (BCQ) measures expectations, knowledge, marginalization, pragmatics, and skills. We assessed asthma control via TRACK and these outcomes: PCP visits for asthma in past six months, subspecialty care (allergist or pulmonologist) in past two years, and ED visits in past three months.

Results: 395 caregivers (96% African-American, 82% low-income, 96% Medicaid) completed the BCQ. Sixty percent (N=236) of children had uncontrolled asthma, 86% had seen a PCP, 23% had seen a subspecialist, and 29% had an ED visit. Barriers related to marginalization were associated with decreased likelihood of PCP (OR 0.95, p=0.014) and subspecialty visits (OR 0.92, p=0.019). Overall BCQ score was associated with decreased likelihood of subspecialty care (OR

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ClinicalTrials.gov id: NCT01519453

Declarations of interest: None

Competing Interests Statement: The authors have no competing interests to declare.

0.98, $p=0.027$). Barriers related to expectations, knowledge, pragmatics, and skills were not associated with any of the care outcomes.

Conclusions: Among low-income, predominantly African-American preschool children with asthma, primary and subspecialty care were less likely if caregivers reported past negative experiences with the healthcare system (marginalization). Clinicians who serve at-risk populations should be sensitive to families' past experiences and should consider designing interventions to target the most commonly reported barriers.

What's New: In a group of preschool-age, urban, predominantly African-American children with asthma, caregiver-reported barriers related to marginalization were associated with decreased likelihood of primary and subspecialty asthma care, indicating a potential target for future interventions to improve asthma outcomes.

Keywords

asthma; Head Start; barriers to care; marginalization

Introduction

African-American children with asthma suffer from excess asthma morbidity¹ and those affected by poverty and living in urban environments are particularly vulnerable. African-American children experience more frequent ED visits, hospitalizations, intensive care unit admissions, and intubations¹⁻³ and are less likely to have a written asthma treatment plan⁴ compared with white children, and African-American children are less likely to be prescribed⁵ and adhere to⁶ asthma control medications such as inhaled corticosteroids. Preschool-age children are particularly vulnerable, as most hospital admissions for asthma occur during this period of life.¹

The National Asthma Education and Prevention Program (NAEPP) guidelines recommend at least two preventative visits per year for children with a diagnosis of asthma.⁷ The primary care office should be the medical home and primary site of asthma care, but urban, low-income African-American children are more likely to use the ED as the main site of asthma care⁸ and are less likely to have seen a provider for asthma in the past year compared with white children.⁴ More frequent primary care visits for asthma monitoring have been associated with a reduction in ED visits^{9,10} and an increase in preventative medication prescription filling.¹⁰ The NAEPP also recommends that children at risk of poor asthma outcomes receive subspecialty care.⁷ Subspecialty care is more likely to be consistent with asthma guidelines, children receiving it are more likely to have a prescription for a daily asthma controller medication and more likely to have a written care plan with instructions for managing acute asthma symptoms and exacerbations^{6,11} Subspecialty care is also associated with significant reductions in asthma symptom frequency and ED visits and improved caregiver quality of life.^{12,13} Though urban African-American children with asthma may benefit from subspecialty care, they are less likely to receive it, particularly if they are from low-income households,⁸ and they are often sicker compared with white children by the time they reach it.² Improving access to both primary and subspecialty visits, at which asthma symptoms can be monitored, medication prescribed and adjusted, and

education provided, are potential targets to reduce health disparities in young urban minority children with asthma.

Barriers to care, which are social and behavioral processes or practical factors that interfere with a family's positive interaction with the healthcare system and reduce the likelihood of timely healthcare access.^{14,15} Barriers to care may contribute to health disparities for young urban African-American children with asthma. Among family caregivers of children with asthma, higher barriers to care have been associated with poorer quality primary care.¹⁵ Practical barriers, such as cost, lack of insurance, and lack of personal transportation, are common among low-income families of children with asthma.^{16,17,18} Children of caregivers who cite "taking time off work for doctor visits" as a barrier are more likely to have poorer asthma control.¹⁹ While many previous studies have focused on pragmatic and systemic barriers as obstacles to asthma care, parents of urban minority children frequently cite social factors.²⁰⁻²² Caregiver-cited family barriers affecting the child's asthma care and management include patient and family characteristics, health beliefs, and the social and physical environment;²⁰ caregivers may adapt their routines and behaviors to navigate social and ecological barriers in order to manage the child's asthma.²¹ Urban minority caregivers of children with asthma must also navigate the complex dynamics of low socio-economic status, discrimination, and the urban environment, in which exposure to asthma triggers (i.e., pollution, secondhand smoke, and allergens) is common.^{21,22} In qualitative studies, caregivers of high-risk children with asthma affected by poverty have cited a need for greater empathy and understanding among healthcare providers.²² Caregivers also perceive that healthcare providers don't trust their ability to understand and manage their child's asthma; thus impeding the effectiveness of caregiver/provider interactions.²⁰ Barriers to care are quantifiable, responsive to change,¹⁵ and potential targets for intervention. Some limited data have shown that interventions to reduce barriers have been associated with increased frequency of primary care visits for asthma.^{23,24} In addition, a culturally competent educational intervention led to decreased ED visits,²⁵ and another multi-modal intervention (improved access to primary care, addressed barriers to adherence, increased community supports, and more) led to improved symptom control and reduced ED visits and hospitalizations for asthma.²⁶

The purpose of this study was to examine the association between family caregiver-reported barriers to care and: a) primary care visits, b) subspecialty care, and c) emergency department visits among a population of students enrolled in Baltimore City Head Start programs. Our sample was comprised of preschool-age children who are predominantly African-American, low-income, and at risk of experiencing significant and disproportionate asthma morbidity. We hypothesized that family caregiver-reported barriers to care would be associated with decreased likelihood of a recent primary care visit where asthma was discussed, decreased likelihood of subspecialty asthma care, and increased likelihood of emergency department visits for asthma.

Participants and Methods

Participants were recruited from Baltimore City Head Start programs from April 2011-November 2016 as part of a randomized trial of a home-based asthma education program.

Eligible caregivers were the parent or legal guardian of a child aged 2-6 years who reported their child had a physician diagnosis of asthma, that they were the primary caregiver and responsible for managing the child's asthma, and who spoke English. An eligibility screening questionnaire was given to all enrolled students annually by Head Start staff. The forms asked if the Head Start student had asthma and if their caregiver was interested in being contacted about the research study and contact information. Potentially eligible families who gave permission were contacted by phone to confirm eligibility and schedule the first home visit to obtain written informed consent from the child's caregiver.

Procedures

The Johns Hopkins School of Medicine Institutional Review Board approved the study. Research assistants conducted a home visit to complete the baseline assessment. Informed consent was obtained prior to any data collection and the research assistant completed a survey with the primary caregiver. All questionnaire measures were orally administered by the research assistant to avoid issues of low health literacy. Caregivers were provided \$50 for completing the study visit. All measures presented in this paper were collected at the baseline visit, prior to randomization.

Measures

Baseline demographic information was reported by the caregiver, including yearly household income. Low-income was classified as <\$30,000.

Barriers to Care Questionnaire

The Barriers to Care Questionnaire (BCQ)¹⁴ was administered to assess caregiver-reported barriers pertaining to the child's healthcare that may interfere with use of or access to medical care. Reliability and validity among caregivers of children with asthma has been demonstrated (Cronbach α for overall BCQ: 0.93, subscales ranging from 0.7-0.89).¹⁵ The BCQ contains 39 items and broadly covers multiple subscales: 1) *Expectations* (7 items) relate to caregiver expectations of receiving poor-quality care, 2) *Health knowledge and beliefs* (4 items) describes popular notions about the nature and/or treatment of illnesses that may differ from mainstream medicine, 3) *Marginalization* (11 items) describes internalization and personalization of past negative experiences within the healthcare system, 4) *Pragmatics* (9 items) describes logistical or practical issues that may prevent or delay medical utilization and 5) *Skills* (8 items) relates to strategies to navigate and function properly within the healthcare system.^{14,15} Each question is assigned to a subscale. Responses consisted of a 5-point Likert scale: no problem, small problem, problem, big problem, very big problem. The original BCQ used 25-point increments (no problem=0, very big problem=100) and averaged the items on each subscale. We used a 0-4 scale (no problem=0, very big problem=4) and summed the items on each subscale. An example is "knowing how to make the healthcare system work for you." The rescored BCQ had a Cronbach α of 0.85 (overall), indicating good internal consistency. Cronbach α values for subscales were similar: expectations (0.78), knowledge (0.85) marginalization (0.79), pragmatics (0.82), and skills (0.83).

Asthma Control (TRACK)

The caregiver completed the Test for Respiratory and Asthma Control in Kids (TRACK) to assess degree of asthma control, which has been validated for preschool children. TRACK contains five standardized questions, each of which is scored using a 0-20 Likert scale for a total score range of 0-100. Higher scores indicate better asthma control, and a TRACK score less than 80 indicates that asthma is uncontrolled.²⁷

Healthcare utilization

Caregivers answered whether the child had seen their pediatrician in the past six months for asthma or for a routine visit in which asthma was discussed, had seen an asthma subspecialist (i.e., an allergist or pulmonologist) in the past two years, and how many times the child had an ED visit for asthma in the past three months. Hospitalizations (number in the past three months and in lifetime) were also measured. All outcomes were reduced to dichotomous variables for each category (0= no medical utilization over the specified time period, 1= one or more instances of medical utilization).

Statistical Analyses

We used Intercooled Stata 15.1 (StataCorp, College Station TX). We used descriptive statistics and visual displays of data to identify patterns in our data. We used simple and multiple logistic regression modeling to examine potential associations between our primary predictor: reported barriers to care (overall and for each subscale) and for each of our three primary outcomes related to medical utilization (i.e., primary care visit in the past 6 months, subspecialty care in the past 2 years, and ED visit in the past 3 months- all dichotomous). We used odds ratios from these models to compare barriers (total and subscales) and healthcare utilization. In multivariable logistic regression models, we adjusted for asthma control using TRACK (dichotomous-controlled/uncontrolled asthma) based on the established cutpoint of <80 for uncontrolled asthma.

Results

A total of 14,851 caregivers (representing 88% of all children enrolled in our Head Start sites) completed screening [Supplemental Figure 1]. Twenty-seven percent of children had a reported asthma diagnosis (N= 3318); 1,130 (34%) were both eligible and provided permission to be contacted for the study. Families of 1823 (15%) children with asthma did not provide permission to be contacted and 365 (3%) were ineligible according to inclusion/exclusion criteria. Overall, 404 caregivers provided consent, 401 completed the baseline visit, and 395 (35% of 1,130) had complete baseline utilization data. Baseline demographic characteristics are shown in Table 1. Of note, 148 (37%) of children were female, 380 (96%) were African-American, 82% were low-income, and most were receiving public insurance through Medicaid (375/391, 96%). The majority of children had uncontrolled asthma (N=236, 60%).

Barriers to Care

The mean overall BCQ score was 12.3(±17.06, range 0-98). Means for subscales were as follows: expectations (1.93±3.98, range 0-24), knowledge (0.84±1.94, range 0-12),

marginalization (2.78 ± 5.65 , range 0-35), pragmatics (4.55 ± 5.32 , range 0-32), and skills (2.17 ± 3.63 , range 0-20). Overall, 340 (86%) of caregivers reported at least one barrier (=1, or “small problem” or higher) on the BCQ while 148 (37%) caregivers reported at least one barrier on the expectations, 104 (26%) for knowledge, 186 (47%) for marginalization, 303 (77%) for pragmatics, and 179 (45%) for skills subscales. There were no associations between asthma control and BCQ score (overall or subscales).

Primary Care

Barriers related to marginalization were associated with decreased likelihood of a PCP visit within the last six months and the association persisted despite adjustment for uncontrolled asthma [Table 2]. There were no statistically significant associations between PCP visits and other barriers to care (overall BCQ or subscales) [Table 2]. There was no statistically significant association between uncontrolled asthma and PCP visits.

Subspecialty Asthma Care

Overall BCQ was associated with decreased likelihood of having seen a subspecialist in the past two years (OR 0.98 per 1 point BCQ change) [Table 3]. Within one standard deviation of the overall BCQ score (17.1 points), the OR becomes 0.71, or a 30% reduction in receiving specialty care. Barriers related to marginalization were associated with decreased likelihood of subspecialty care (OR 0.92 per 1 point change) [Table 3]. Within one standard deviation of the marginalization score (5.6), the OR becomes 0.63, or a 40% reduction in odds of receiving specialty care. For the other subscales (pragmatics, skills, expectations, knowledge) there were no statistically significant associations with subspecialty visits [Table 3]. Uncontrolled asthma was marginally associated with increased likelihood of having seen an asthma subspecialist in the past 2 years [Table 3]. After adjusting for asthma control the associations remained consistent in magnitude and statistical significance [Table 3].

ED Visits

BCQ scores (overall and subscales) were not associated with ED visits in simple or multiple logistic regression models [Table 4]. Uncontrolled asthma was associated with fivefold increased likelihood of having had an ED visit for acute asthma symptoms in the past three months [Table 4].

Specific Items Related to Marginalization

Due to the significant association between caregiver-reported barriers to care related to marginalization and decreased likelihood of the child having seen an subspecialist or having had a PCP visit for asthma, the individual items in the marginalization subscale were examined [Table 5]. Reporting barriers related to the following items were associated with decreased likelihood of both subspecialty care and PCP care: rude office staff and uncaring office staff [Table 5]. The following items were associated with decreased likelihood of subspecialty care: getting the doctor to listen to you and not knowing what to expect from one visit to the next [Table 5]. Items associated with decreased likelihood of PCP care included: feeling that doctors or the healthcare system are “trying to give as little service as

possible”, “being judged on your appearance, your ancestry, or your accent”, and “doctors rushing you and your child through the visit” [Table 5].

Discussion

We found that caregiver-reported barriers to care, and specifically barriers related to marginalization, were associated with decreased likelihood of recent primary care and also decreased likelihood of past subspecialty care, but not associated with recent ED visits for asthma. BCQ subscale means were all less than one, which indicate no to little barriers on average. However, nearly half (47%) of caregivers reported barriers related to marginalization. The associations between overall BCQ and marginalization, subspecialty, and primary care visits persisted despite adjusting for asthma control. It is concerning that few children with uncontrolled asthma had seen an asthma specialist (26%). A specialist could provide medication prescriptions and adjustments as well as important teaching (related to inhaler technique, adherence, trigger avoidance, etc.).

A notable aspect of this study is that participants were all participating in Head Start, and the means for overall BCQ and subscales were relatively low. The primarily low-income, minority urban families in our study experience negative effects from poverty. However, they also have access to family services that facilitate Medicaid enrollment and annual PCP visits through their involvement in Head Start. This results in a unique population of low-income families who have support to obtain and sustain Medicaid insurance and have an established relationship with a medical provider. An important finding of our study is that this population still experienced barriers and had difficulty accessing care, despite having insurance, a PCP, and family services through Head Start.

Barriers that are traditionally thought to influence primary and subspecialty care include lack of transportation and other logistical issues, most closely measured by the pragmatic subscale. Though the pragmatic barriers subscale was not associated with either subspecialty care or primary care in our study, these barriers were common (77%) and present in those who had and had not attended clinic visits. The high prevalence of pragmatic barriers could have limited our ability to detect associations between these barriers and asthma outcomes. Pragmatic barriers are likely still important and should be considered in future similar studies given their high prevalence.

Because barriers related to marginalization were significantly associated with PCP and subspecialty visits, it is helpful to note which specific items within the marginalization subscale were consistently associated with decreased likelihood of care: items such as rude and uncaring office staff were associated with a decreased likelihood of both subspecialty care and PCP visits. Rude or unhelpful front desk staff have been cited by African-American participants in other studies as an obstacle to making appointments.^{28,29} Provider-level factors were also reported as barriers in our study. For primary care, doctors rushing you/your child through visits and being judged by ancestry/appearance/accent were noted as barriers, and for subspecialty care, impatient and/or intimidating doctors were predictors of marginal statistical significance. The latter may provide support for medical homes where patients develop a relationship with a primary care provider and feel welcome. Others have

reported an association between increased barriers to care and caregiver perception of lower quality PCP care,³⁰ and parental depression has also been associated with lower parental perception of access to care.³¹ We did not measure caregiver perceptions of quality of care or include measures of parental depression in our analysis, but there may be associations between parental perceptions of care, parental depression, and marginalization. Though our data do not suggest that office staff are the only factor worth addressing, office staff are a consistent and integral part of the outpatient medical care experience and perceived cultural sensitivity of office staff has been associated with patients' adherence to treatment.²⁹ Providers and other office staff should keep barriers related to marginalization in mind for staff training, individual discussions with caregivers/families, and for case management. Training interventions for staff (administrative and clinical/providers) may be a novel target for intervention to improve clinical access and attendance. Incorporating aspects of cultural sensitivity and cultural competency into training interventions may also be beneficial. More work is needed in this area, but training could focus on customer service, cultural competency, and more.

Our study had a few limitations. First, we relied on parental recall for all of our outcome measures. Parental recall of medical visits is subject to bias and may be inaccurate. Second, these data are cross-sectional: though we report associations, we cannot assess whether the barriers to care are causal with respect to the outcomes we studied. Third, potentially important factors that we did not include in our models are literacy and health literacy. Ninety percent of caregivers in our sample reported adequate health literacy (via the Shortened Test of Functional Health Literacy in Adults, or STOFHLA). Literacy and health literacy may be important factors to consider in future studies. Finally, we cannot distinguish whether the lack of primary care and subspecialty visits were due to lack of referral, problems accessing care (e.g., insurance requirements, appointment availability), caregiver perceiving subspecialty care as unnecessary, or other unmeasured challenges in attending a scheduled visit. These are areas for future research, ideally in a prospective study.

Conclusion

Among a group of urban, preschool age, predominantly African-American children with asthma in whom the majority receive Medicaid, we report an association between barriers to care and decreased likelihood of subspecialty care, and barriers related to marginalization and decreased likelihood of both primary and subspecialty care, but no association between BCQ (overall or subscales) and ED visits. As interactions with office staff appear to be a driving factor for barriers related to marginalization, staff training interventions may be helpful to address these barriers and improve rates of outpatient care for vulnerable young children with asthma. Future studies could focus on the best methods to prevent and remediate these barriers and the best way to improve children's attendance in outpatient primary care and subspecialty clinics with the goal of decreasing asthma morbidity.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Funding Source: NIH HL 5R18HL107223

Abbreviations:

(BCQ)	barriers to care questionnaire
(ED)	emergency department
(PCP)	primary care provider
(NAEPP)	National Asthma Education and Prevention Program
(TRACK)	Test for Respiratory and Asthma Control in Kids

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Figure 1.
Asthma Basic Care study CONSORT diagram

Table 1.

Baseline and demographic data

Variable	N=395
Female (caregiver)	354 (90%)
Age (caregiver)	32 (± 8.5)
Female (child)	148/395 (37%)
Age (child)	4.2 (± 0.69)
African-American (child)	380 (96%)
Seen asthma subspecialist in last 2 years	89 (23%)
ED visit past 3 mo.	117 (29%)
PCP visit in past 6 months	339 (86%)
Asthma hospitalization (in lifetime)	151 (38%)
Hospitalized in last 3 months	16 (4%)
Low income (<30,000/year)	313/384 (82%)
Medicaid	375/391 (96%)
Uncontrolled asthma (TRACK<80)	236 (60%)
BCQ mean (SD)	12.3 (± 17.1)
Total	1.93 (± 4.0)
Expectations	0.84 (± 1.9)
Knowledge	2.8 (± 5.6)
Marginalization	4.5 (± 5.3)
Pragmatics	2.2 (± 3.6)
Skills	

Table 2.

Odds ratio of PCP visit for asthma in the past 6 months

Variable	OR	p-value	95% CI	aOR*	p-value	95% CI
Uncontrolled asthma (TRACK <80)	1.59	0.110	0.90-2.8	<i>n/a</i>		
Barriers to Care (overall)	0.99	0.093	0.97-1.00	0.99	0.079	0.97-1.00
Marginalization	0.95	0.014	0.91-0.99	0.95	0.011	0.92-0.99
Pragmatics	0.99	0.802	0.94-1.05	0.99	0.759	0.94-1.04
Skills	0.94	0.098	0.88-1.01	0.94	0.095	0.88-1.01
Expectations	0.95	0.109	0.90-1.01	0.95	0.087	0.89-1.01
Knowledge	0.97	0.714	0.85-1.12	0.97	0.665	0.84-1.11

*
aOR: Adjusted odds ratio. Adjusted for asthma control via TRACK.

Table 3.

Odds ratio of subspecialty asthma care in the past two years

Variable	OR	p-value	95% CI	aOR*	p-value	95% CI
Uncontrolled asthma (TRACK <80)	1.63	0.056	0.99-2.69	<i>n/a</i>		
Barriers to Care (overall)	0.98	0.027	0.96-0.99	0.98	0.024	0.96-0.99
Marginalization	0.92	0.019	0.86-0.99	0.92	0.019	0.86-0.99
Pragmatics	0.96	0.084	0.91-1.01	0.95	0.073	0.91-1.00
Skills	0.94	0.118	0.87-1.02	0.94	0.113	0.87-1.01
Expectations	0.93	0.061	0.86-1.00	0.93	0.055	0.86-1.00
Knowledge	0.92	0.249	0.80-1.06	0.92	0.226	0.79-1.06

*
aOR: Adjusted odds ratio. Adjusted for asthma control via TRACK.

Table 4.

Odds ratio of ED visits in the past 3 months

Variable	OR	p-value	95% CI	aOR*	p-value	95% CI
Uncontrolled asthma (TRACK <80)	5.14	<0.0001	2.98-8.87	<i>n/a</i>		
Barriers to Care (overall)	0.99	0.875	0.99-1.02	0.99	0.708	0.98-1.01
Marginalization	0.99	0.769	0.96-1.03	0.99	0.654	0.95-1.03
Pragmatics	1.02	0.451	0.98-1.06	1.01	0.567	0.97-1.05
Skills	0.98	0.518	0.92-1.04	0.98	0.467	0.91-1.04
Expectations	0.99	0.682	0.93-1.05	0.98	0.504	0.93-1.04
Knowledge	0.97	0.590	0.86-1.09	0.95	0.438	0.85-1.07

* aOR: Adjusted odds ratio. Adjusted for asthma control via TRACK.

Table 5.

Associations between marginalization items and attending a subspecialty or PCP visit

Question	Mean (SD)	Subspecialty Care		PCP visits	
		aOR [*]	p-value	aOR [*]	p-value
Feeling like doctors are trying to give as little service as possible	0.32 (±0.84)	0.81	0.207	0.75	0.044
Feeling like the health care system is trying to give as little service as possible	0.51 (±1.00)	0.83	0.180	0.74	0.014
Impatient doctors	0.19 (±0.62)	0.57	0.069	0.74	0.125
Intimidating doctors	0.15 (±0.59)	0.55	0.096	0.74	0.122
Rude office staff	0.32 (±0.78)	0.64	0.039	0.62	0.002
Uncaring office staff	0.30 (±0.75)	0.65	0.048	0.68	0.013
Getting the doctor to listen to you	0.16 (±0.55)	0.40	0.041	0.92	0.734
Getting your questions answered	0.14 (±0.51)	0.44	0.060	0.88	0.647
Not knowing what to expect from one visit to the next	0.30 (±0.71)	0.52	0.016	0.80	0.226
Being judged on your appearance, your ancestry, or your accent	0.13 (±0.54)	0.75	0.300	0.64	0.030
Doctors rushing you and your child through the visit	0.26 (±0.77)	0.63	0.054	0.73	0.041

* aOR: Adjusted odds ratio. Adjusted for asthma control via TRACK