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Pilot Study of Low-Income Parents' Perspectives of Managing Asthma In High-Risk Infants and Toddlers

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Abstract

This pilot study describes the challenges low-income parents face in managing asthma in their infants and toddlers who are at high risk of morbidity due to asthma. Five families of children younger than 3 years and recently hospitalized for asthma were interviewed from 1 to 5 times and asked to give narratives about the everyday management of asthma in their high risk infants and toddlers. Interpretive phenomenology was used as the method to describe parents' perspectives on managing the illness. The parents, all single mothers, struggled to manage asthma in crowded conditions, with limited transportation for frequently needed emergency care, and in face of the complicating needs of other children and family members. Not knowing then knowing the diagnosis, and provider availability and lack of availability were two dichotomous challenges mothers faced when managing asthma in their very young children.

In the United States, asthma prevalence and morbidity of asthma among children 4 years of age or younger is increasing, and disproportionately affects children who live in poverty or in urban areas, and who are African American or Latino (Chabra, Chavez, Adams, & Taylor, 1998; Shatin, Levin, Ireys, & Haller, 1998). Although much more is known about the pathophysiology of asthma today than was true 20 years ago, preventing, identifying, and controlling symptoms remains complex in children who are very young.

Review of the Literature

A disease of airway inflammation and reversible airway muscle constriction, asthma's classic symptoms include cough, congestion, labored breathing, air hunger, and wheeze. None of these alone is diagnostic nor do any indicate whether symptoms will recur, progress to a crisis that requires hospitalization, or require continuous preventative medication once the crisis is relieved. In infants and toddlers the early markers of distress are subtle and non-specific: decreased activity; increased work of breathing; cough; and difficulty vocalizing (Koenig, 1999). Providers, even with the aid of O_2 saturation monitoring, cannot easily determine if an asthma episode will moderate or progress (personal communication, Jay Hen, Pediatric Pulmonologist, July 9, 2004). Objective measurement of respiratory function for managing asthma in older children depends on peak flow meter readings, which are unreliable in children under 5 (Warman, Silver, McCourt, & Stein, 1999). Moreover, the inability of infants and toddlers to communicate their distress verbally complicates understanding and managing their asthma.

Two studies of children with asthma who were between 2 and 5 years at the onset of symptoms describe parents' management experiences, but did not identify ethnicity and income levels. When first recognized, symptoms of respiratory compromise brought confusion, fear, and feelings of vulnerability that were relieved when the diagnosis of asthma was made and more effective management plans were initiated (Horner, 1997; Jerrett & Costello, 1996). Jerrett and Costello report that although asthma management eventually became integrated into family life, uncertainty about recurrence and the possibility of threats to parents' sense of control over the illness persisted. In a study of parents of low income African American and Latino children younger than 4 years with severe persistent asthma, parents similarly found early symptoms frightening and confusing. Parents feared that their children would stop breathing, often found initial treatment recommendations inadequate, and developed varying strategies to obtain appropriate care (Koenig, Chesla, & Kennedy, 2003; Koenig & Chesla, 2004).

Asthma management begins prior to hospitalization when parents are first alerted to symptoms. Attention to identifying and assessing illness, and deciding how to manage the illness is ongoing. Because the vast majority of asthma exacerbations occur in the home and community after hospital discharge, parents and other caregivers of children who are very young are on the frontline of asthma management, both before and after professional intervention. Intensive national attention has been given to education about asthma diagnosis and management. However, the impact of better awareness has not decreased morbidity in very young children as measured by emergency department (ED) visits and hospitalizations (Mannino et al., 2002). The reasons for this failure are not well understood.

This pilot investigation's purpose was to describe low-income parents' perspectives on the challenges of managing asthma in their children younger than 3 years. The children have been hospitalized with asthma or wheezy respiratory illness and have demonstrated a period of moderate persistent or severe persistent asthma.

Method

Sample

Five families from among children at highest risk for morbidity due to asthma were chosen for this descriptive interpretive pilot study. This convenience sample was chosen from among children who had been hospitalized for wheezing or asthma in the northeastern United States from November 2002 to July 2003. All children were African American or Latino and Medicaid eligible. Approval for human subjects research was obtained. At the first interview, the written consent and the purpose of the investigation were explained. All families gave written approval to be interviewed. Families were included if children were less than 36 months of age, had been diagnosed with asthma or were on daily inhaled or oral steroids in addition to albuterol at the time of enrollment, and had no other chronic illnesses. Families were excluded if children had not had one consistent primary caregiver since the onset of symptoms and if the parents did not speak English (see Table 1).

Procedure

The author interviewed families from 1 to 5 times in their homes over periods that varied from 3 to 22 months following the hospitalization of their child. Initial interviews took place within 6 months of hospitalization. Of the five families that began the study, two families completed all 5 interviews. One family dropped out of the study when the mother obtained employment and the child had had no further exacerbations requiring emergency care, and two families were lost to follow up. The interview guide was modified from an interview guide used by the author in a larger study of shorter duration of Latino and African American children with severe persistent asthma (Koenig et al., 2003). Interviews lasted from 1.5 to 2 hours, were audiotaped, and transcribed verbatim. Interview questions were designed to elicit parents' understanding of asthma, narratives about illness onset and progression, and responses of family members to illness events as they unfolded. Key interview questions can be found in Table 2.

Analysis

Disciplined interpretation of parents' perspectives given in the interviews was conducted in the tradition of interpretive phenomenology (Benner, 1994; Chesla & Chun, 2005). The author sought to discover the participants' experiential worlds through interpretation of narratives about the everyday ways the participants manage the demands of caring for their infants and toddlers with asthma. Attention focused on understanding the concerns that guide these daily management practices (Dreyfus, 1993).

Narratives about family care before, during, and after the child's index hospitalization for acute asthma were interpreted. Analysis of narratives began after the first interview and continued over the course of the study. As data gathering proceeded, analysis was conducted within and between families. Details of narrative content were examined with the goal of making sense of the whole of the data as well as the parts. Following initial interpretations, data were read and reread to support or elaborate initial findings, to re-interpret initial findings, and as additional data were obtained, to confirm, modify, or supplement initial findings. All names reported here are pseudonyms. Description of the parents' perspectives of the family's social context served as background to the interpretive analysis.

Findings

Parents' descriptions of social context

Parents described three aspects of their social context: health care, family circumstances and living arrangements, and employment and school.

Health care—The families in this study were all low-income and headed by single mothers. All had access to medical services although the patterns differed (see Table 3). One child had a single provider group, all of whom were familiar with her asthma history. They gave both routine outpatient and asthma care, and were available by phone 24 hours a day to assist the mother in making decisions about asthma crises. Four children had received care in health centers and had seen numerous providers over the course of their lives. Generally, each child saw one provider fairly consistently for a period of time. However, rarely did they see the same provider in the ED or during hospitalizations. The children had varying relationships with pediatric pulmonologists, a circumstance that did not seem to depend solely on the frequency of the child's exacerbations. The mother of one child with frequent exacerbations and numerous specialist visits was advised to use the ED whenever asthma flared. More commonly children would first be seen by the primary care provider if symptoms flared during clinic hours. If symptoms were intractable or flared when the clinic was closed the children received care in the ED.

Family circumstances and living arrangements—Although all the mothers and children in this pilot study had regular involvement with extended family, the mix of responsibility and help family members gave and received varied considerably. All the mothers carried primary responsibility for the child with asthma. At least two fathers were incarcerated. Three mothers stated that the father was not expected to be part of the child's life at any time in the future. Only one father (who smoked in his home) was involved in his child's care. Every other weekend he and his wife of 10 years cared for his daughter. After each weekend visit, to the mother's dismay, the child routinely had asthma exacerbations requiring emergency care or hospitalization.

In all other households no one smoked. All families lived in neatly kept apartments without carpet or pets. Exemplary of living conditions was Lisa (note: all names cited as psuedonyms; see Table 4) who lived with her toddler with asthma and her older daughter, 8 years, in a ground floor apartment that had one living-room/kitchen area and two small bedrooms. Her parents, the maternal grandparents, rented the apartment and shared one bedroom. Lisa and her two daughters slept in a bedroom approximately 12′ × 6′ that held two twin beds and a crib. The room was so hot in the winter that even on the coldest nights a window had to be kept open and a humidifier kept running to humidify and cool the dry, hot air, and ease the child's breathing. Lisa had given up her job to stay vigilant to her child's symptoms and to care for the household. The maternal grandmother was, by Lisa's definition, so obese and compromised by asthma and heart failure that she could not walk across the small living space to pick up a toy without becoming short of breath. She relied on Lisa to shop, cook, clean, and do laundry. In return she provided emotional support and as much care as she could for her granddaughter with asthma. During the mid-winter study period, Lisa's 22-year-old brother lived in the apartment as well, sleeping in the living room on a pullout sofa. During the day Lisa took care of her own children and his 12-month-old daughter. Despite the crowded living conditions and the responsibility for managing the larger household, Lisa valued the interpersonal support her extended family provided.

One mother lived alone with her three children, an elementary school-aged boy and girl, and her 9 month-old daughter with asthma. She rented a two-bedroom apartment in a neighborhood where drugs were sold regularly, and where a person had recently been shot and killed less than a block away. This mother worked full time to pay the bills but always was behind financially. She had decided to go back to work because the state assistance to which she was entitled on the basis of the child's severe asthma barely covered the rent, leaving only $93 a month for food, clothes, gas for her car, utilities, etc.

Employment and school—Four mothers relied on extended family to care for the child with asthma at least some of the time. The fifth mother hired a former neighbor. Two of the mothers worked full time and another attended state sponsored educational and job training every morning. The latter relied on her mother and her sister to care for the child with asthma. Because the sister had type 1 diabetes mellitus, the family's experience of managing chronic illness with life threatening crises was familiar. However, the decision to seek care for the child was always left to the mother.

The two mothers who worked full time were the only mothers with their own cars. Two mothers relied entirely on public transportation. In one household where the maternal grandmother had the only car and a full time evening job in a town 30 minutes away, the mother had to rely on bus or ambulance to take the child for asthma care.

Each mother who worked left the care of her child to caregivers familiar with asthma in their own children. These caregivers felt confident about the management of exacerbations. If symptoms worsened and were unresponsive to more frequent inhaled albuterol treatments, they would call the mother and take the child to the ED. The mother would leave work and meet the caregiver and child in the ED. On many occasions these two mothers noticed their children's increased symptoms before leaving for work, informed the caregivers, and worried that they might need to leave work to go to the ED to be with the child.

One of the mothers, who worked and lived alone, woke up at 5 am each morning and woke her children at 5:30 to prepare for the day. If her daughter had had trouble with asthma during the night she might forego work to seek medical care. If, on the other hand, the child seemed to be breathing better in the morning she would carry on her usual routine. The babysitter/caregiver lived in a town 15 minutes by car in one direction from the home. After leaving her children there, the mother reversed direction and drove another 45 minutes passing her apartment to arrive at her job at 7:30. This mother, who estimated her daughter had been hospitalized 10 or 11 times for asthma since 3 months of age, endured the anger of several “bosses” and lost several jobs because she missed work due to doctor appointments and hospitalizations.

Summary—The social background on which these families cared for their children with asthma was marked by crowded living arrangements, and for some, dangerous neighborhoods and extreme poverty. The demands of asthma forced two mothers to give up or lose employment. Financial stress, fatigue, interpersonally stressful work environments, limited transportation, responsibility for other dependent family members, concern for other family members' health, and the need to depend on family members or friends in order to maintain daily routines and the care of the child with asthma defined their lives.

Parents' narratives of asthma management challenges

Two dichotomous tensions were found in the parents' narratives of asthma and asthma management: not knowing/knowing (the diagnosis) and provider availability/unavailability.

Not knowing/knowing—At the onset of compromised breathing mothers recognized various signs that their children were ill. One mother, Jessica, who had asthma herself and who knew asthma in other adult family members first noticed her 10 month-old, Daryl's illness in his markedly decreased activity, his cough, runny nose and rapid breathing, but did not identify these as asthma. When she took him for emergency care he was treated with nebulized albuterol only to return the next day with recurring symptoms. After several ED visits and repeated diagnoses of “bronchitis” she insisted at the next ED visit, when his symptoms seemed severe and she could no longer tolerate the waiting to be seen, that he had asthma.

> One time we had waited hours [in the ED]. And he still wasn't being seen. And he was wheezing and breathing very fast. I got loud and told the nurses and doctors that he had **asthma**, not bronchitis and that he needed to be seen right away. They took him right away. [Author's emphasis]

Lucia, who was unfamiliar with asthma, was likewise confused by her 3 month-old daughter, Janine's, initial symptoms. Moreover, she was frightened. Janine was congested, coughing, and Lucia saw “her lungs going in.”

> We were out all day until about 5 or 6 o'clock. Then I heard her, she was very congested. She started coughing then I seen her lungs going in. I called my neighbor. I was crying. I didn't know what to do…. And she's like, Lucia, you should take her to the hospital.
>
> And then I brought her to the hospital and they admitted her that night…. So she was in there for like four or five days. Then she kept going back and back and back. At first they were saying that it was bronchiolitis related then after awhile they just you know, said she has asthma.

Both Jessica and Lucia recall taking their 13-14 month-old children to the ED 3 or 4 times a month for almost a year. Such unsuccessfully managed asthma meant illness severity for the child and as the mothers noted, hassle and disruption to their work and their other children's rest and sleep. Not knowing the diagnosis left these families in the limbo of worry for the child and shared suffering.

Without a diagnosis 2 mothers imagined that their child's illness might be fatal, progressive, and or untreatable. Most of all they worried that their children might “just stop breathing.” A period of numerous ED visits, and diagnoses for episodic conditions and treatments that did not seem to bring lasting relief were common experiences for the families in this study. Lisa described how she took Patricia to several outpatient and ED visits over more than a month for continuing cough, congestion, intermittent fever, and lack of appetite. Each encounter brought Patricia a different diagnosis: upper respiratory infection; croup; and bronchiolitis.

> Like it was more frustrating when I didn't know [the diagnosis. And receiving various diagnoses] was frustrating 'cause I like, ‘OK, well what is it then?’ … This doctor is saying this. This doctor is saying that. … I talked to one of the doctors and they said that… it was upper respiratory infection and it turned into croup. And then with the croup it became bronchiolitis. … I'm not a doctor so I don't know if that's possible. I don't know if it's basically all the same thing but just different….

Jessica thought the ED providers did not understand how frightened she was about her child's difficulty breathing. She said she wanted providers to listen more and ask more about family history. When the diagnosis was made, Jessica was clear that she had first recognized Daryl's repeated respiratory crises as asthma and that doctors had “co-signed on the diagnosis.”

Knowing the diagnosis brought relief. All mothers described long ED waits (up to several hours) prior to diagnosis. The wait had become such a problem for one mother that she went “ED shopping” trying two different hospital ED departments before choosing one for her child's after hour visits. Three mothers in this study (Lisa, Jessica, Lucia) noticed that with the diagnosis of asthma access to ED care was more rapid. Staff recognized the children by name, and children received early initial treatment.

More importantly for parents, relief at knowing the diagnosis clarified the problem as a treatable condition with clearer prevention and management goals.

> [Now] I know how to manage it. [In the beginning] I didn't know what to do. It was just hectic because I didn't know whether or not, is he having an asthma attack or is he just sick?… but then once they told me about that asthma, I got kind of good on it knowing what to do… but I used to just panic sometimes just bring him to the emergency room [without using] the nebulizer.

After hearing the diagnosis Lisa found comfort that the doctors would know better what to do. “It's asthma so, it's not like a mysterious thing that we don't know about that we can't cure or help….They know what to do.”

For Lisa, the diagnosis of asthma not only confirmed for her what was happening with Patricia, the diagnosis also gave her a new understanding about what the providers knew and validated their recommendations. As Patricia's symptoms developed, Lisa, who is intimately familiar with asthma in her mother, suspected that Patricia also has asthma. However, when Patricia received the string of alternative diagnoses, Lisa worried about what the doctors knew and did not know. She wondered, “[Either] you [the doctors] know but you don't want to tell me, or you don't know what it is.” Diagnosis brought a shift and greater comfort with Patricia's doctors that extended to their education about the signs of serious disease that Lisa might recognize at home and that would indicate the need for emergency care.

> It's like she's sick, there's lots going on with her and then I go to the doctors and they tell me what it is. For some reason I feel at ease knowing what it is, [and] knowing they got it. … And they're not too concerned about it. So I'm not too concerned because they know what it is. They treat it… so it puts me more at ease that they know. [It's] not like when I'm at home, and something's going on… and it's serious, and I'm not going to the [ED.] And [the doctors] are not aware of it.

However, although diagnosis brought a measure of relief, anxiety about asthma continued for the mothers in this study. Lisa related the story of how although she felt relief at Patricia's admission when asthma was first diagnosed and aggressive treatment was initiated, she was also frightened by the experience. From the first steps of accessing emergency care until

Patricia finally found relief from her month long symptoms, Lisa was challenged. On Christmas day Patricia seemed to be worse. In the few days prior she had eaten very little and had no energy. Although Lisa had taken Patricia for an outpatient visit when her appetite first decreased dramatically, Lisa was very concerned. She consulted with her family and decided to take Patricia once again to the ED. Even though it was Christmas Day and she faced a long ED wait, Lisa judged that delaying until morning to seek care at an outpatient appointment was too risky. Once in the ED Patricia was admitted where she spent 1.5 days in the intensive care unit (ICU).

The ICU frightened Lisa. Especially forged in Lisa's memory of the ICU is one boy whom she was told had a bone disease. He “kept moaning and saying ahhh, ahh…. It was so sad being there….” In the ICU Lisa noticed other children sedated and with endotracheal tubes. The doctors told her they were considering sedating Patricia and placing an endotracheal tube to aid Patricia's breathing, Lisa was alarmed. She clung to the hope that intubation would not be necessary. “Luckily” intravenous steroids reversed Patricia's symptoms.

> I'm so glad that she [Patricia] didn't have to have the tubes down her throat because I [Lisa] would have went crazy. She [would] have to be sedated ‘cause she wouldn't tolerate it. I'm so happy that it didn't come to that.

Post diagnosis two other mothers employed distinct practices of assessing and managing their child's symptoms. As she had from the earliest onset of symptoms, Lucia maintained vigilance over Janine's symptoms by regularly interrupting her own sleep to touch Janine's back.

> I get nervous. When she's sleeping I stay up, sometimes a lot… I still wake up every night to feel her back… Sometimes her back is vibrating. You feel little vibrations in her back… Ever since she was little I've been doing it. And [even] when she's in the hospital.

Post diagnosis, Jessica managed her anxiety about Daryl's exacerbations with a clearly structured plan to access emergency care based on the frequency of albuterol treatments Daryl needs. Her plan turns on whether or not she finds Daryl's symptoms “life threatening.”

> If I feel his asthma is life threatening I will go to the emergency room… If it's just acting up he won't be rapid breathing and everything. He'll cough here and cough there…. If it's life threatening then I'll know because he's coughing and I'm giving him treatments every two hours instead of every four hours and that he's starting the rapid breathing and I'm looking at him and I'm watching his stomach suck in. I can see his rib cage… And another thing about him, if he's about to have an attack he'll go and sit down. He wants to just lay down.

For all mothers in this study the experience of assessing and managing symptoms, and making choices about how and when to access care helped them feel more confident about what to expect and what to do. Jessica said, “ In the beginning yeah, I was nervous but now I'm used to it so I know what to expect whenever it acts up.” Nevertheless, they were often surprised when minor symptoms could not be controlled or could flare rapidly and lead to hospital admission.

Professional availability/unavailability

Although on the recommendations of their children's providers, all mothers in this study used the ED for emergency treatment of asthma exacerbations in their children, some had more involvement from their child's primary care providers than others. Patricia particularly stands out in that her primary care was provided in a private group practice of pediatricians. All were familiar with Patricia's course of asthma. A provider was on call at all times and encouraged

Lisa to call even during the night if Patricia's symptoms worsened. Moreover, Lisa's family was immediately available to support her in the decision to access emergency care.

Interestingly, despite family and provider support, Lisa was often conflicted about accessing emergency care.

> I called the doctor and he told me, “Well, how do **you** feel?” They're like “you know your child better than we do so if you feel she needs to go to the hospital you bring her in.” So finally I counted her breathing. I think I counted like 61 or something. I freaked out. And I'm like OK “You know what Dad? We're going.” [Author's emphasis]

Lucia, by contrast, had access only to emergency care because Janine's primary care provider was not involved in her asthma care. On his advice Lucia went to the ED day or night when Janine's symptoms flared. Because she lived alone in a neighborhood miles away from supportive friends and relatives, each time Lucia accessed emergency care she did so on the basis of her own assessment of symptoms, and entirely on her own initiative. She also had to bring her older children along to the ED on nights when Janine's asthma flared uncontrollably. However, she felt little hesitation to seek emergency care for Janine when she thought it necessary. Even though more frequent treatments were the primary strategy of ED care, Lucia explained her reason for going. “It's like getting a second opinion on things. And I know if something was going to happen [the doctors and nurses would be] right there to help.”

Roberta and Jessica were like Lucia in not having after-hours medical advice. However, they both had regular primary care providers involved with their children's asthma care and both had nearby (but not household) supportive family. These mothers, like Lucia, accessed emergency care with much less hesitation than Lisa. If what they could do was not working to relieve symptoms they did not wait to consult primary care providers during daytime hours.

Discussion

Single mothers headed all the families in this study. Although all the mothers had different relationships with their health care providers and varying ability to access emergency care consultation, all used the ED for emergency care of their children's asthma exacerbations. Some used the ED on the advice of their primary care or specialist providers. Others decided on the basis of the child's symptoms whether to wait to access routine care or to seek emergency care rapidly when symptoms worsened.

All families relied on extended family or very close friends for emotional support and/or for child care of the child with asthma. Caregiving family and friends were either intimately familiar with the child or were intimately familiar with asthma in other family members. Lucia was most isolated from the support of family and most stressed by the need to seek night time emergency care for her daughter. She struggled to realize financial independence and predictable family routines.

Families in the study were dealing with symptoms and making decisions about how to respond well before they knew the underlying causes of their children's distress. Frightened by their children's fight to breathe mothers sought emergency care. However, the ambiguity of early diagnoses and the frequently ineffective initial treatments added confusion to their fears. Numerous ED visits often for symptoms that improved only temporarily, long ED wait times, and the suspicion that asthma was the cause of their child's distress frustrated mothers. Jessica thought if providers had asked more about family history with asthma, Daryl would have been diagnosed earlier and part of her struggle and his would have been relieved.

Knowing the diagnosis identified what symptoms meant and helped clarify what should be done to prevent and manage them. Mothers responded to continued fears and anxiety about post-diagnosis exacerbations with remembered clues of distressed breathing in their child but with increased confidence in the ways they could respond. Access to after-hours provider care varied. However, among these mothers close provider support did not completely relieve the anxiety involved in deciding whether or when to seek emergency care. They were not entirely comfortable in relying on their own judgment to manage exacerbations. The mothers sought emergency care to have the evaluation of their child's breathing shared with professionals and to be close to nurses and doctors who could help if symptoms worsened.

Implications

Persistent asthma is a frightening circumstance for families especially when families live in poverty and children are very young. Because parents in poverty struggle with stressful work and living arrangements that increase the difficulty of living with asthma in a very young child, it is essential for health care providers to inquire about family constellations and living situations as well as daily family routines. In addition, because parents are intimately familiar with distressed breathing and associated symptoms in the child and often in other family members as well, a supportive and respectful stance toward families' knowledge about the child's illness is critical even at the first health care contact for wheezy respiratory illness. Specifically, the history of symptoms in the child should be sought not just make a diagnosis but to understand how parents recognize the illness, to learn from these insights, and to show genuine respect for and to encourage parents' skills of observation. In addition, attention should be paid to the prevalence and severity of asthma in the family, and the meaning of asthma experience for the family. Parents also should be recognized for their expertise in evaluating their child's illness severity and their level of concern for what they assess as severe illness.

If the findings of this pilot are upheld in future studies, a priority for the care of families of infants and toddlers with asthma should be to engage parents in conversations about their particular concerns and fears regarding asthma in their child. Because it was from their frightened responses to the earliest severe symptoms that parents sought emergency care and developed management behaviors, hearing and validating these fears should be a starting point for promoting effective early management behaviors. In addition to education about symptom recognition and instructions about pharmacological intervention, crisis management plans should include collaboratively developed strategies that meet the individual contingencies with which each family must deal as they care their very young child with asthma.

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Table 1

Participant Demographics

Ethnicity	**n**	**%**
African American	4	80%
Latino	1	20%
Family Constellation		
Single mothers	5	100%
Children living in home[*]		
1	1	20%
2	0	0%
3	4	80%
Adults living in home		
1	3	60%
2	1	20%
3	0	0%
4	1	20%
Extended Family Role		
Extended Family Support in Home	2	40%
Extended Family Support in Proximity	2	40%
Without Family Support	1	20%
Fathers		
Not involved	4	80%
Involved on occasional weekends	1	20%
Household Income		
< $15,000	none reported	0%
$15,000 - 19,999	2	40%
$20,000 - 25,000	2	40%
Not provided	1	20%

[*] Including the child with asthma

Table 2

Key Interview Questions

About asthma
Can you tell me about what asthma is like in your child?
What were the first things you noticed about your child that made you suspect there was a problem?
Asthma in child
What are the chief problems that asthma has caused for your child?
Can you talk about what your child having asthma has been like for your child?
Parents' experience with child's asthma
What has it been like for you?
How did you respond when you first noticed your child's difficulty breathing?
Difficult time
Will you tell me about a time when your child had wheezing, coughing, or difficulty breathing that you could not bring under control?
Deciding on emergency care
Will you tell me what happened when your child needed to be hospitalized?
Will you tell me about what it was like during the time [name of child] was in the hospital?
How did [name of child] react to being in the hospital?

Table 3

Health Care Profiles

	n	%
Age at first symptoms per mother		
< 4 mo	2	40%
4-6 mo	0	0%
> 7mo	3	60%
Primary Care (first care for asthma exacerbations)		
Single provider	1	20%
Shifting multiple providers in single facility	3	60%
ER use for all crisis care	1	20%
Frequency of ER visits		
< 3 per month	2	40%
≥ 3 per month	3	60%
Total hospitalizations		
1-3	2	40%
4-9	2	40%
10 or more	1	20%

Table 4
Pseudonyms of Mothers and Children Cited

Family	Mother	Child
1	Lisa	Patricia
2	Jessica	Daryl
3	Lucia	Janine