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Experiences, Functioning and Needs of Low-Income African American Mothers of Children With Asthma¹

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The purpose of this proposed study was to explore experiences, needs and functioning of low-income, African American caregivers of children with asthma in order to better understand symptom management.

Method: A qualitative, descriptive design was used. A purposive sampling technique was used to screen 32 caregivers of children with asthma, and 15 caregivers agreed to participate.

Results: Three main themes were identified: managing the symptoms; cultural beliefs and values; and culturally competent health care provider.

Conclusion: For the caregivers culture disparity is not just about access to health services but instead the healthcare providers' understanding of the complexity of symptoms management.

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ASTHMA IS ONE of the most common chronic diseases in African American children. Morbidity associated with asthma is the leading cause of school absences, emergency department visits, and hospitalizations (Pedersen et al., 2011). This disproportionate morbidity is caused, in part, by limited resources in the management of symptoms and access to care (Looman & Lindeke, 2005). Low-income African American families with chronically ill children are less likely than other families to have or visit a primary care provider. As a result, these families cannot benefit from the preventive health care that may decrease the frequency of emergency room visits (Canino, 2012; Lara et al., 2003; Pedersen et al., 2011; Tapp, 2011). Asthma management interventions in the United States (US), such as educational programs and follow-up plans post emergency room visits, have been effective (Baren, 2006; Sidora-Arcoleo, 2012; Zorc, 2003). Yet despite their success, there continues to be a disproportionate level of morbidity in low-income African Americans.

There also continue to be disproportionate barriers to health services for African American children with asthma. These disparities may be shaped by the complex interactions between caregivers, healthcare providers, social, cultural, behavioral, emotional, educational, and financial factors (Riera & Walker, 2010). Low-income African American mothers of children with asthma are faced with complex environments that increase the challenges of symptom management, placing the child with asthma at risk for poor health outcomes.

Researchers have reported that low-income African American caregivers of children with asthma experience a tremendous amount of uncertainty, which may affect their behaviors and decisions in managing asthma symptoms (Fiese, Winter, Anbar, Howell, & Poltrock, 2008; Garro, 2011; Raymond, Fiese, Winter, Knestel, & Everhart, 2012; Rydstrom, Dalheim-Englund, Segesten, & Rasmussen, 2004). A caregiver coping with uncertainty about symptom management may develop fear for the child with asthma. The caregiver may then become overprotective of the child, which may further impede the child's development.

Decisions about how to manage children with asthma symptoms at home, and when and how to access health care

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services often involve extended family and community support. African American families have been known to depend on family and faith to carry them through stressful times, for example having a chronically ill child. Few studies, however, have examined asthma symptom management by low-income African American caregivers (Koenig, 2007; Riley-Jacome, Parker, & Waltz, 2014; Thakur et al., 2013; Walker, 2013). Indeed, Thakur et al. (2013) report that there continues to be limited information on the relationship between socioeconomic status and childhood asthma, including symptom management. A better understanding of low income African American children with asthma and their caregivers' experiences, functions, and needs may help to improve symptom management (Walker, 2013).

The purpose of this study therefore was to explore the experiences, needs, and functions of low-income African American caregivers of children with asthma in the context of their environment, and to examine the impact of their culture on symptom management. Using the revised 2012 Federal Poverty Guidelines, low-income individuals were those whose family's taxable income for the preceding year did not exceed 150 percent of the poverty level amount (<http://www.ssa.gov/policy/docs/ssb/v68n3/v68n3p79.html>). This US family of four with two adults and two children and an annual income below \$23,283, was considered low-income.

Method

A qualitative, descriptive emergent design was used to explore the experiences, functions, and needs of low-income African American mothers of children with asthma. This design made it possible to also explore the cultural beliefs and values of these mothers, and examine their day-to-day lives (Patton, 2002).

Participants and Setting

Recruitment for the study took place in two locations in a central North Carolina county: a child development center and an allergy and asthma clinic. The county population was 26% African American, 62% White and 12% Hispanic. Over 600 households received services at the child development center; their ethnic breakdown was 42% African Americans, 29% Hispanics, 14% Whites, 7% Asians, and 8% others. Many of the families who received services from this child development center were low-income. Median household income for the county in which the center was located was \$45,570 per 2.49 persons per household (Ekim & Ocakci, 2013). The percentage below the poverty level in the county was 15.5%.

Sample

The inclusion criteria for the study were low-income, African American mother or primary caregiver as legal guardian (e.g., grandmother) of a child aged 2 to 14 years who had been diagnosed with asthma within the past 5 years.

Children who were enrolled in the Child Development Center (CDC), or had a sibling enrolled in the center, or were patients at the asthma clinic; and were able to speak and read English were recruited. Diagnoses were confirmed through medical records at the Child Development Center or by the primary health care provider in the asthma clinic. A social worker at the CDC who was trained in the inclusion criteria identified and recruited participants. An asthma and allergist specialist physician who was also trained in the inclusion criteria identified and recruited participants from the clinic. This process was designed to assure integrity.

A purposive sampling technique was used to recruit mothers of children with asthma. While an approximate sample size of 20 was targeted, sampling continued until data saturation was reached (i.e., no new themes emerged). The final sample consisted of 15 African Americans who agreed to participate in the study.

These low-income African American mothers had children with asthma. All had at least a high school education, and nine mothers had 1–2 years of college education. Half were employed; a few were unemployed and receiving subsidies, and one mother reported no income. The mean age of the mothers was 32.4 years (8.38 SD) (Table 1).

Data Collection

Each mother participated in a semi-structured interview with a set of questions that allowed the interviewer to guide the conversation. An interview guide was developed to explore and describe, explain, and generate ideas/theories about caregivers' experiences with chronically ill children (Table 2). The interview guide was developed by the author and reviewed by child research expert and allowed mothers some control over the direction of the interview. The interviews began by asking the mother to tell the story of

Table 1 Demographic of African American mothers.

Race	AA	Mean	SD
Age of mom	22–52 (mean and SD)	32.4	11.6
Income	\$0–\$25,000 (mean and SD)	\$10,077	\$6224
Age of Child(ren) with asthma	2 years–18 years		
Age of all children	2 years–21 years		
Highest education level	60% college education & 40% finished high school		
Employed	53 % employed 47% unemployed		
Marital status	27% Married, 27% NM, 20% divorced, 13% LWP & 13% separated		

SD = standard deviation; NM = non-married; LWP = living with partner.

Table 2 Interview guide.

Semi-structured interview

1. Tell me the story of how you and your child came to know about asthma.
2. Can you tell me how this may have changed your family's way of life?
3. Please describe how you manage the care of your child's asthma.
Areas to explore:
 - a). How do you know when your child is doing well with her/his asthma?
 - b). Do you see a health care provider when your child is doing well with his/her asthma?
 - c). What medications is he/she on? How do you get these medications? How easy/hard is it to give these medications to your child?
 - d). How do you know when your child with asthma is getting sick?
 - e). What do you do when he/she is sick?
 - f). How do you decide when it is time to see a health care provider? Describe how you get access to a health care provider?
 - g). What worries or concerns do you have about your child's asthma care?
4. Tell me about how you cope with having a child with asthma?
PROBE: Effect on your life? Any change over time? Your health related problems? Stress? Depression? Anxiety? Physical symptoms (sleepless nights)?
5. Can you tell me about an experience with your child's asthma that was very stressful for you?
6. Can you tell me an experience with your child's asthma that was very rewarding for you?
7. Tell me about some challenges that have been unique for you and your child with asthma.
PROBE: transportation? Appointment? Explaining to the doctor your needs?
8. Tell me about some of your family influences in caring for your child with asthma.
PROBE: Any changes in daily customs or routine?
9. Please describe for me your experience with visiting a health care provider when your child is well?
10. Please describe for me your experience with visiting a health care provider when your child is sick?
PROBE: Talk about the health care provider understands of you and your child's needs.
11. What about the communication between you and the health care provider?
12. Is there anything else that you would like to share with me about being a mother caring for a child with asthma?

- Can you tell me an experience with your child's asthma that was very stressful for you?
- Can you tell me an experience with your child's asthma that was very rewarding for you?
- Tell me about some of your family influences in caring for your child with asthma.
- Please describe for me your experience with visiting a health care provider when your child is sick.
- What about the communication between you and the health care provider?

Procedure

Approval from Duke University Institutional Review Board (IRB) for Human Subjects Research was obtained for the study. Written informed consent for audio taping was obtained from all of the caregivers who participated. All interviews were face-to-face and conducted by the author in the home or a preferred place of the mother. Preferred places included McDonalds, the public library and their homes. Interviews lasted from 60 to 90 minutes. In addition, the author made detailed field notes immediately following the interview to capture information not obtained by the audio tape, such as responses to the interview and setting. One of the ways, in which the author confirmed the information and results from these mothers was by paraphrasing. The author and a child research expert met at intervals between interviews to debrief and review possible unique encounters in the field. These meetings allowed the author to discuss any feelings or personal beliefs and values.

Data Analysis

The digitally recorded interviews were transcribed into an electronic text and analyzed using content analysis techniques, with the aid of a text-based analysis computer software program (ATLAS.ti v 7 Scientific Software, 2013). The goal was to study the caregiving experiences, functions, and needs of low-income African American mothers of children with asthma. An open category style was used. To look for patterns that connected various themes related to contextual and cultural symptom management, the analytic strategy used was guided by the Miles, Huberman and Saldana method for data management (Miles, Huberman, & Saldana, 2013). The interview data were analyzed to identify and discover regularities and categorize patterns (Miles et al., 2013). Each transcribed interview was first read as a complete whole. The goal of this first read was to understand the mothers' contextual and experiential stories of caregiving within their social world. On the second read of the interviews, line-by-line coding was done to break the narratives into small areas of data that could stand alone and be labeled with code names. To establish reliability during code development, the author and a second child health researcher initially each coded 25% of the transcripts. After several meetings, the researchers resolved differences in coding by discussing the codes and their meanings. Once the two had reached consensus, the codes developed were used to

how her child was diagnosed and how she managed her child's asthma. Sample questions included these:

- Tell me the story of how you and your child came to know about asthma.
- Can you tell me how having a child with asthma may have changed your family's way of life?
- Please describe how you manage the care of your child's asthma.

code the remaining transcripts. Any new codes developed were added to the code list during this second stage of coding. Once all transcripts had been coded, general categories were developed by grouping together codes with similar patterns of meaning. The categories developed were then systematically examined for specific configurations that generated meaning. The content analysis provided a rich description of the caregiving experiences of low-income, African American mothers of children with asthma. The author followed rigorous techniques to assure validity. One technique, known as communicative validity for qualitative research, included having a child health expert researcher review the data collection and holding discussions with that expert to understand meaning through dialog (Hesse-Biber & Leavy, 2006). The author and the expert reviewed transcribed data and coded data.

Results

Three main themes emerged from the interviews: managing the symptoms; cultural beliefs and values; and culturally competent healthcare providers (Table 3).

Managing the Symptoms

These low-income mothers of children with asthma described their experiences in providing care, including medication management, symptom assessment, and parenting. Mothers experienced the management of symptoms for their child with asthma in a “*moment-by-moment*” fashion. For example, a mother spoke of living her life moment-to-moment:

I'm just dealing with it at the moment you know, and I know as the seasons change it's still going to act up, so. My biggest thing; stay by the phone you know or keep my doctor on call you know?

For these mothers, day-to-day experiences drove their ability to cope and intervene with their child's asthma symptoms, and they described having to be aware and flexible every moment.

...it's not really different than the other, one day at a time, that's how I think about it. You can take it one day at a time, don't rush it and live a year from now but you just....I don't want him to go through that so, I really want to nip it in the bud so to speak.

One mother described having to make quick decisions about whether to take her child to the primary care physician late one day. The mother explained how she had to make decisions:

One bad experience with him when he had asthma was when he had a real bad cold. And boy, we went to the emergency room, I took him to the emergency room because we lived in Randolph county and that doctor didn't open on Fridays so it was on a Thursday night, so he was sick; so he I ended up going to the emergency room. And we stayed in the emergency room until Friday morning so he didn't go to school. And they had to put him on oxygen because he couldn't breathe.

Table 3 Themes that emerged.

Managing the symptoms as a parent	Cultural beliefs & values of the mother influence day to day management	Professional/Clinical competence of the health care provider
Time/Moment-by-moment	Generational faith	Personal knowing
Ensuring the help of others	Watchful eye for fear of impending death	Engagement in the child's care
Use of emergency services	Sense of self-efficacy	Having an open ear
Take control	Family social support	Understanding the need
Knowing my child	Family influence in relation to symptom management	Trust in PCP
Acceptance in the moment	Faith	Personal interest
Informing others	Fear of losing the child	
Speed dial	Mother's health	
Acknowledge the seriousness	Impact on the child's future	
Family life changes	Fear of loss	
Rationalizing daily events		

Another mother described sending the child with the father for a weekend trip in which the mother forgot to pack the inhaler. She said the moment she realized the child was without the inhaler, “*Just hurry up and on the phone trying to get someone to fill the inhaler real quick; you are in panic mode.*” As noted earlier, low-income African American mothers often rely on others to assist in the management of asthma symptoms. These mothers often worked, and the children spent most of the day in the public schools. Thus, it was essential for the mothers to be assured that everyone involved with the child was aware of the child's medical needs. For example, one mother stated:

Well when M., every time M. has an outbreak or she misses a couple days at school I make sure that they know that her asthma flare up and they ask me do I need to bring a machine so they're very helpful as far as that goes....

Mothers talked about “*ensuring the help of others*”. For these families, the community took an active part in the day-to-day experiences of the mothers. It was the community that needed to know about the children with asthma. Another mother stated,

...Pretty much I have to make sure everybody is aware in my circle, aware of what's going on.

“Taking control” was extremely important for the caregivers, especially with symptom management. These mothers had to have some control over the health of their child. One of the mothers said that

I must have control over my home because there is no one else.

...I just try to educate myself as much as I can on asthma so anything that I have around him or anything that may be in our house that could trigger him to have an asthma attack that I don't know about I try to make myself aware of it.

These mothers often said that they needed to know their child's symptoms for healthcare management. Most mothers repeated throughout the interview the importance of "knowing their child":

So most of the time, she just says it but if she's laying around and really not talking that much because she likes to talk, if I know she's not doing it then I know something is wrong so...that's about it, that's how I really can tell because her whole, she's just a happy person all around like she's so sweet.

These mothers' greatest concern was two different kinds of fear, "loss of the child" and "inability of the child to participate in sports". Over 75% of the mothers reported these fears. Mothers kept a "watchful eye for fear of impending death". Low-income mothers with a child who is ill are often in constant stress and anxiety, not knowing whether the child will develop worsening symptoms. These mothers would even check their child's heart rate frequently. For example, two mothers expressed their experiences in this way:

I don't want to see my baby die in his sleep because he can't breathe....I usually let him sleep with me but I'm scared that it might happen while he's sleeping one day.

The mothers reported that their constant fear and anxiety even affected their own health. Mothers also reported depressive symptoms, and some were under medical treatment. Other mothers reported feeling tired from a lack of sleep watching the child all night.

Yes...um...my second child, yes I was depressed I was on depression pills...and I was stressed for over I think like what I think for like probably a month yes...cause I was going through a lot.

For some African American mothers, their child's best future was sports. The only way to enable their children to have a better life was through participation in sports and education. For the African American family, participation in sports is thought to have an effect on socialization and to lift the family out of poverty (Beamon, 2010; Gustafsson, Bjorksten, & Kjellman, 1994; Robertson, 2010). Participation in sports is thought to provide greater opportunities, i.e. education. Thus, these mothers lived their dreams through their children, hoping for a way of removing the family from poverty or isolation.

*It won't be something that will stop her from being able to play sports or interact with other kids.
...so whether he has to be restricted or whether he's going to start you know playing football.*

Cultural Beliefs and Values

The cultural beliefs and values of low-income African American mothers of children with asthma influence their day-to-day management of their child's health. A major finding of the interviews was "generational faith"; that is, the faith of these mothers was passed down from one generation to another. There were also several family influences in the management of day-to-day asthma symptoms.

My aunt....instilling in us that you can do it there's no such thing as you can't do it. In the summertime they go from the hip hop, from vacation Bible school to instill in you yes you can do it. You get this blessing, yes you can do it.

Cultural influences such as community and church were an important part of day-to-day living for these mothers. One said,

...my brother was preaching....she had an asthma attack...so everybody started praying, they started praying ...

Another mother said:

Like but...I deal with it you know? I have back up family, if I have to leave work, go get them sometimes I have to take them to primary care. But my grandmother, she has always been there, that's my rock you know if I call and say my kids need anything or you know they need some medicine, she's there, her and her husband.

Professional/Clinical Competence of Healthcare Providers

These low-income African American mothers described needs related to accessing care and health care provider cultural competence for their children with asthma. A major finding was the desire for culturally competent health care providers, including personally knowing the mother and her child. Knowing the name of their child was important to these mothers. This provided them assurance that their child was not just another patient, but a human being with needs that were unique. These low-income mothers of children with asthma believed that a healthcare provider should have the ability to communicate, understand their needs and engage them in the healthcare of their child. The idea of "personal knowing" was important. Mothers wanted to feel a sense that the healthcare provider knew their child and the family on a personal level.

Yeah-uh, Everybody in there, they're family I consider them being the, the receptionist, some of them are a little older than me so I consider them as a you know, a mother figure because I can see, I talk to them and their one doctor is younger than me but the rest of them are a little older than me and I can sit down and talk to them and you know more about when they tell me something's wrong when I just have to ask more questions to get a better understanding of it. They get it, because they're parents too so you know they're always-these guys, they love what they do. ...they are-the sweet, they talk to you like they know you personally you know.

Overall, any healthcare provider was expected to have the skills to engage individuals in a conversation about health. This became very clear during the interviews with the mothers. They spoke of mother–physician communication and engaging the mother in the child’s healthcare.

*Help me and I can help my kids.
Give me step plan and goals.
And then they’ll ask me before I ask them is there
anything else that we can check on her, and if I say yeah
they’ll do it for me.*

Mothers wanted to feel that the healthcare provider was listening to them. They also wanted providers to listen to the needs of the mother. For example,

*He actually understands our cultural needs very well, he
knows that different people, people are different and
react different ways you can’t treat everybody the same.
So he takes his time and listens to us very well.*

One mother described this as “*having an opening ear*”:

*Well when I go, when I tell them that they’re sick they
pretty much um...they listen, they look; they understand
and they because of the fact that my mom is an LPN.....
..first indication of her (PCP) being in tune even out in
hallway and hearing his cough and coming in and
saying something to me about that I feel pretty confident
that she’s pretty in tune.*

Discussion

Management of Symptoms

Managing symptoms for these mothers involved the ability to have control over the situation. They also wanted to ensure that others knew. These caregivers sought normalcy in their day-to-day life, meaning that the children could play outside or the mothers could go to work without the school calling. Some of the mothers even spoke of wanting to go on vacation but were in fear of an attack occurring. Mothers reported motivation and interest in managing the symptoms of asthma. Several mothers revealed that they monitored their child’s symptoms. Mothers felt that predicting their child’s symptoms would help them manage the asthma. Mothers also spoke of their own health and well-being, which was influenced by the actions taken for the benefit of their child. These mothers internalized their goals, for the health of the child and themselves. They used problem-solving or coping skills to gain control (Baumeister, Vohs, DeWall, & Zhang, 2007; Fenton, Keating, & Plosker, 2003; Kjellman & Gustafsson, 2002; Kopel, Phipatanakul, & Gaffin, 2014).

Mothers' Beliefs and Values

Awareness of cultural differences may provide an understanding of contextual barriers, support, and opportunities for improving health care delivery for children with

asthma. Mothers who have faith in God, family and community faith support are more likely to be active in the health outcomes of their child (Cohen, 2004). They are also more likely to adhere to treatment of the asthma (Smeeton, Rona, Gregory, White, & Morgan, 2007; van Olphen et al., 2003).

Culturally Competent Healthcare Providers

Researchers have shown that physician behaviors influence health outcomes (Clark et al., 2008). This includes the communication between the physician and patient or caregiver (Clark et al., 2007). The mother and healthcare provider relationship is essential to the health outcomes of the child. These mothers mentioned personal knowing, understanding their needs, trust, engagement of the mother in care, and listening to their needs. An earlier study that examined patterns of family caregivers and their child’s utilization of health care systems found that children from all racial, income, and practice setting groups received suboptimal treatment (Yoos et al., 2006). In the current study, it was very clear to mothers that health care providers needed to work with their belief systems. In addition, they felt it was important for the primary care provider to know them on a personal level.

Conclusions

Clearly, for low-income African American caregivers, culture is not just about access to health services; it is also about healthcare providers’ understanding of the complexity of their environment and symptom management for children with asthma. Cultural competence involves interpersonal relationships, understanding the environment, and shared decision making between healthcare provider and caregivers. This study has provided information on many of the beliefs and values of this sample of mothers. This information can provide a foundation for further research on symptom management and shared decision making that includes children, caregivers and primary care providers.

Limitations

This study included only African American mothers in one county in North Carolina, and thus the findings may not be generalizable to others. Further research is needed to explore the experiences of caregivers from other cultures. Exploring links between culturally competent healthcare providers, their delivery of health services, and pediatric asthma health outcomes will also further the science.

Implication for Nurses

Cultural awareness and its importance for patients and caregivers will be key to the delivery of high-quality health services. The unique needs of low-income African American caregivers of children with asthma, include management of symptoms from moment to moment, beliefs and values related to faith and support, and the role of culturally

Table 4 Pathway model for mother's symptom management, PCP & child health outcome.

	Mother internal context	→	PCP internal context	→	Child health outcomes
Essential factor	Take control	→	Engages the mother in the care of the child	→	Less frequent night time exacerbation

PCP = primary care provider.

competent HCP is building interpersonal relationship and shared-decision making. Despite its limitations, the study provides insight into the low-income African American mothers of children with asthma. However, nurses need to be culturally aware to deliver appropriate health services to patients. Those who are sensitive to the needs of diverse population can play a particularly important role in achieving positive health outcomes for children with asthma (Table 4). The Institute of Medicine (IOM) has suggested that nurses will have a great impact on the quality of healthcare in the future. Thus, nurses need to have knowledge about the needs of these children and their caregivers. As children with asthma from diverse backgrounds become more involved in self-management, pediatric nurses will need to apply interventions that are individually tailored for these children.

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