Caregiver Experiences, Functioning and Needs of Low-Income African American and Latino Mothers of Children with Asthma

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“We are called to join in a dance whose steps must be learned along the way. Improvisation and new learning are not private processes; they are shared with others at every age. Even in uncertainty, we are responsible for our steps.”
Mary Catherine Bateson

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Background & Significance

- African American and Latino families are disproportionately affected by Asthma in USA

- In 2011, 10 million U.S. children under the age of 18 diagnosis with asthma (14%) and 7 million (10%) still have asthma.
- African Americans (21%) were more likely to be diagnosis and (16%) still have asthma to Hispanic (15% & 10%) than non-Hispanic Whites (12% & 8%) children.
- Children in fair or poor health (42%) were three and one-half times as likely to have ever been diagnosed with asthma and almost five times as likely to still have asthma (38%) as children in excellent or very good health (12% & 8%).
- In 2009, African Americans were three times more likely to die from asthma related causes than the White population.
Background & Significance

- Children from low income families are less likely to utilize primary care services
  - Primary care providers have limited cultural experiences with diverse population
  - There is distrust with the primary care provider
- Access to preventative health services
  - African Americans had asthma-related emergency room visits 4.5 times more often than Whites in 2004.
  - Latino families often visit the ER due to language barriers
- Fragmentation of family
  - Asthma attacks often occur at night without extended family support
Aims

Explore experiences, functioning & needs of minority mothers of children with asthma.

**Aim 1.** To examine the caregiving experiences of AA and Hispanic/Latino mothers.

**Aim 2.** To explore how the cultural beliefs and values of AA and Hispanic/Latino mothers influence the management of their child’s healthcare.

**Aim 3.** To identify AA and Hispanic/Latino mothers’ perceptions of health care provider cultural competence when accessing care.
Methods

- Qualitative descriptive design
- Narrative style interviews

Sampling

- Purposive sampling design
- Recruitment
- Sample:
  - African American mothers  N=15
  - Latino Mothers N=15
# Sample Demographics

<table>
<thead>
<tr>
<th>Race</th>
<th>AA and Latino</th>
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<tbody>
<tr>
<td>Age of mom</td>
<td>22-52</td>
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<tr>
<td>Income</td>
<td>$0-$25,000</td>
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<tr>
<td>Age of Child (ren) with asthma</td>
<td>2y-18y</td>
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<tr>
<td>Age of all children</td>
<td>2y-21y</td>
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<tr>
<td>Education level</td>
<td>60% college education &amp; 40% finished high school</td>
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<tr>
<td>Employed</td>
<td>53 % employed 47% unemployed</td>
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<td>Marital status</td>
<td>27% Married 27% NM 20% Divorced 13% LWP</td>
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Data Collection

- IRB
- Subject Recruitment & Compensation
- Interviews
  - Semi structured
  - Conducted in mothers’ home
  - Digitally recorded
Data Analysis

- **Transcription**
  - PI proofed the transcripts against digital recordings

- **Data Management**
  - Imported the proofed transcriptions into HU (ATLAS.ti Software v7.8)

- **Intercoder reliability**
  - PI and a second child health researcher initially code 25% of the transcripts

- **Data Analysis**
  - Content analysis procedure
Results

Managing the symptoms

Time

- Moment–to–moment
  - “….it’s not really no 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 take it one day at a time, and that’s how I do it.”
  - “…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”.
  - “I can’t really think of one right now at the moment”.

Ensuring the help of others

- “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…”
- “…Pretty much I have to make sure everybody is aware in my circle, aware of what’s going on”.

Managing the symptoms

Use of Emergency Services

- “I call 911…cause I didn’t know what to do…so that was the hardest thing for me to ever see in my life that was the hardest thing to deal with.”
- “…what happen was she, I guess like caught a cold. Because in the midst of it all I seen was my baby turning purple and blue and if I didn’t call the police, you know the ambulance then they were saying that you know she probably would have died on me…”
- “My biggest thing; stay by the phone you know or keep my doctor on call you know”.

Take Control

- “….I don’t want him to go through that so, I really want to nip it in the bud so to speak”.
- “…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 I don’t know about I try to make myself aware of it”. 
Managing the symptoms

Knowing my child

- “….when they’re playing, the possibilities of an attack based on how hard they’re playing. I try to make sure before she even gets out there to do that she takes her inhaler”.

- “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.”
Cultural belief & values

Generational faith

- “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”.

Watchful eye for fear of impending death

- “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.”
- “..just the scare of seeing them or just the fear of losing them”.

Impact on my child’s future

- “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 belief & values

Sense of self-efficacy

- “..I probably would not have made those life changing events for myself or for my kids if they hadn’t been diagnosed I’d probably still be smoking. I’d probably you know, my kids would still be exposed to second hand smoke and it would have just gone down a different path versus a bad habit. And they got it early it had to stop me and change my outlook on my life and how I just looked at myself as a parent. So it just forced me to grow up a lot”.

- “Me taking him to the hospital all the time because his, his oxygen level that’s what his oxygen level had dropped…and it kept on getting low, and that’s when he was in the eighties and he had woke up and said he couldn’t breathe, that was one of them, that’s that time. And I didn’t have to think about it not one time I got straight up and took him to the emergency room”.
“…my brother was preaching….she had an asthma attack…so everybody started praying, they started praying …”

“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”.
Personal knowing

- “Yeah mhm. 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”.
Cultural competence of the PCP

Engagement in the child’s care

- “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”.

Having an open ear

- “He actually understands our cultural needs very well he knows that 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…”.
- “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 being in tune with her 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”.
Pathway model for mother’s symptom management, PCP & child health outcome

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<th>Essential Factors</th>
<th>Mother internal context</th>
<th>PCP internal context</th>
<th>Child Health Outcomes</th>
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<td>Take control</td>
<td>Engages the mother in the care of the child</td>
<td>Less frequent night time exacerbation</td>
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Discussion

- Management of symptoms
- Mothers’ belief and values
- Cultural competent PCP
HCP Cultural Competent Conceptual Model

- Healthcare provider that has a trusting relationship; Engages the mother in the care; & having an open ear

- Acknowledge the Mother ability to manage the symptoms such as:
  - Time/Moment-to-moment
  - Ensuring for the help of others

- Identifying mothers’ own cultural belief & values such as:
  - Self-efficacy
  - Social support system

- Cognitive Behavioral Factor
  - Practice Behavioral Factor
  - System Level Behavioral Factor

- Pediatric Asthma Health Outcomes

Cultural Competent
Implications

- **Practice**
  - Having cultural awareness will ensure appropriate delivery of health services

- **Research**
  - Further research is needed to explore experiences of mothers from other cultures
  - Explore link between cultural competence of healthcare provider / delivery of health services and pediatric asthma health outcomes
Acknowledgement

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