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Fostering Effective Asthma Self-Management Transfer in High-Risk Children: Gaps and Opportunities for Family Engagement

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Abstract

Introduction—The process of self-management (SM) knowledge, behavior, and skill development in low-income children with asthma is understudied.

Method—Fifteen mothers of children with uncontrolled asthma participated in semi-structured interviews exploring the transfer of asthma SM responsibilities from parent to child. Team members performed thematic analysis of written transcripts.

Results—Participants were all the biological mother and impoverished with most (73%) reporting an annual family income of less than $30,000. Their children ranged from 5–15 years, were African-American (100%) and had uncontrolled asthma based on national guidelines. Themes revealed child asthma SM is difficult to achieve, the transfer of asthma responsibility from mother to child is variable, mothers overestimate the child's developmental capacities for independent asthma SM and have poor understanding of what well controlled asthma means.

Discussion—Ongoing assessment and tailored guidance from healthcare providers are critical to support the mothers' pivotal role in their child's self-management development process.

Keywords

asthma; self-management; poverty; health beliefs

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Asthma affects over eight percent of all children under the age of 18 making it one of the most common pediatric conditions in the United States (CDC, 2018). However, morbidity and mortality rates disproportionately impact racial minority children. Asthma prevalence is nearly twice as high in African-American children (15.7%) compared to the overall national rate (Zahran et al., 2018). African-American youths with asthma are more likely to have poorly controlled asthma and to experience more Emergency Department (ED) visits and hospitalizations (Akinbami, 2006). African-American children also experience asthma-related deaths at a rate that is nearly eight times higher than non-Hispanic white youths (Gergen, 2016).

Effective asthma self-management, defined as the problem-solving actions that individuals and families take to prevent, monitor, and manage asthma symptoms, is critical to achieving and maintaining well-controlled asthma (U.S. DHHS, 2007; Rand et al., 2012). Poor asthma self-management is thought to contribute to the observed disparities in asthma morbidity for African-American children, particularly those residing in low-income and urban settings (Laster, Holsey, Shendell, McCarty, & Celano, 2009). Specifically, inconsistent and low daily controller medication use and lack of preventive care measures such as primary care visits have been regularly observed among families of African-American children (Bruzzesse et al., 2012; Author et al., 2017a; Rohan et al., 2010). A range of factors associated with residing in disadvantaged communities are thought to heighten risk for ineffective asthma self-management including poverty, exposure to violence in the home and community, multi-generational trauma, housing instability, poor communication with school staff and administration, and caregiver psychological distress (Author et al., 2017b, 2017c, 2018; Kub et al., 2018).

Premature transfer of asthma responsibility from parents to young children is also associated with suboptimal asthma self-management and, in turn, contributes to negative child health outcomes (McQuaid, Kopel, Klein, & Fritz, 2003). Over two decades ago, Eggleston and colleagues (1998) observed that by age nine, more than half of African-American children were self-administering asthma medication without adult supervision. Similar alarming findings were noted in research by Winklestein et al. (2000) who found that nearly all 6 to 14-year-old racial minority youths in their sample (93%), and a quarter of children between the ages of four and six years (25%), were taking asthma medications without adult supervision, despite the fact that only seven percent of these children demonstrated the ability to appropriately administer their inhaler. More recent studies of racial minority and non-minority children with asthma suggest this pattern continues with children as young as seven years old assuming at least a portion of responsibility, if not full responsibility, for taking their daily asthma medications without parental supervision (Klok, Lubbers, Kaptein, & Brand, 2014; Orrell-Valente, Jarlsberg, Hill, & Cabana, 2008).

Caregiver and child health beliefs have also been identified as factors eroding effective asthma self-management, and in particular, adherence to recommended therapies. Mammen, Rhee, Norton, and Butz (2017) interviewed a mixed sample of racial minority and non-minority adolescents (13–17 years) and their parents to explore asthma self-management knowledge, beliefs, and behaviors. A major finding was that adolescents with uncontrolled asthma were more likely to view asthma symptoms as normal compared to their peers with

controlled asthma. Caregiver and child concerns about the side effects of daily controller medication use, perceptions of invincibility (i.e., child believing nothing negative could happen when not taking medications as recommended) and feelings of resignation (i.e., child believing that asthma exacerbation would occur regardless if treatments were followed) have also been noted (Author et al., 2017b; Laster et. al, 2009, Martin, Beebe, Lopez, & Faux, 2010).

More recent focus group research with African-American adolescents aged 14–18 years and their caregivers extended understanding of how asthma self-management goals and behaviors may increase risk for asthma morbidity in racial minority youths (Gibson-Scipio, Gourdin, & Krouse, 2015; Gibson-Scipio & Krouse, 2013). The adolescents typically formed short-term self-management goals in response to active asthma symptoms as opposed to more long-term goals related to preventive care (Gibson-Scipio et al., 2015). However, the goals differed from those expressed by caregivers who wanted their children to be more independent (i.e., less reliant on others for medication administration), proactive (i.e., recognize symptoms), and responsible for their own asthma management (Gibson-Scipio & Krouse, 2013).

In summary, a growing body of research has illuminated caregiver and youth perceptions of asthma self-management in the home context, including the critical role of health beliefs as a barrier to optimal asthma self-management among urban, African-American youth with asthma. However, the process of how self-management knowledge, behaviors, and skills develop in this vulnerable population is understudied, especially in younger children with uncontrolled asthma. Even less is known about when and how caregivers decide to begin transferring asthma management responsibilities to their children. The purpose of this study was to extend understanding of how asthma self-management responsibilities are transferred from parent to child in a sample of low-income, African-American children with poorly controlled asthma. This focus may ideally help inform the development of effective interventions that support the strengths of these families and address their challenges.

Methods

This qualitative study was part of a randomized controlled trial (RCT) testing the efficacy of a behavioral environmental control intervention for children with uncontrolled asthma and frequent ED visits (Author et al., 2017a). Inclusion criteria for the RCT included a) physician diagnosed child asthma that was uncontrolled based on national asthma guideline criteria including symptom frequency, asthma rescue medication use, activity limitation, asthma-related ED visits and hospitalizations (U.S. DHHS, 2007); (b) two or more child ED asthma visits or at least one hospitalization over the past 12 months; and (c) residence in the large mid-Atlantic metropolitan area that was the site of the trial. Children were excluded if they had significant other respiratory conditions such as cystic fibrosis. All children received serologic testing for common environmental allergens and exposure to second hand smoke during an ED visit for asthma. Children were randomized into either an intervention or control group. The intervention consisted of nurse home visits for home environmental control combined with a clinic visit for follow-up asthma evaluation and education. The control group in the study received standard asthma education during three nurse home visits

(see Author et al., 2017a for more detailed information). The RCT was approved by the Institutional Review Boards (IRB) of the associated universities.

IRB approval was obtained to send follow-up study letters to 40 caregivers who completed the RCT agreed to be contacted for future asthma research. Fifteen caregivers contacted the study office and consented to be interviewed face-to-face after receiving additional information about the study. Caregivers were compensated $30.00 for their time participating in the interview and received a packet of information about community resources for psychosocial supports. Trained study staff conducted semi-structured interviews which followed a script based on preliminary data from the larger RCT as well as team members' clinical practice experiences of delivering care to racial minority children with high-risk asthma in an urban setting. The questions were designed to elicit the caregiver's perception of factors associated with the transfer of asthma self-management responsibility to their child and included questions such as:

- How do you decide when your child is ready to be more independent in managing his/her asthma?
- Is there a certain age that you think that children with asthma should be able to take their medicine on their own?
- Is there a particular discussion that happens with your child?
- What problems/difficulties have you noticed with your child's ability to recognize and manage his/her own asthma symptoms?

All of the interviews were audiotaped and professionally transcribed. The lead interviewer reviewed all transcripts to confirm content accuracy.

Data Analysis

Thematic analysis of the written transcripts was conducted by three team members. First, the team members independently performed open coding of the transcript data to begin to identify constructs and conceptualize themes and sub-themes. The coding scheme and definitions for the themes and sub-themes were evaluated and revised in data analysis meetings held over the course of six months. To increase the validity of findings, two outside reviewers with research and clinical expertise in high-risk pediatric asthma evaluated the codes, themes and sub-themes against the original transcripts (Padgett, 2008; Patton, 1999). Discrepancies in code classification, theme and sub-theme conceptualization and definitions, and exemplar quotes were resolved through consensus decision.

Results

Participants were all the biological mother (100%), averaged 33 years in age, single (87%), and impoverished with most (73%) reporting an annual family income of less than $30,000. The children of interview participants were African-American (100%), ranged in age from 5–15 years (M=9.13), and had uncontrolled asthma (Very Poorly Controlled [VPC] asthma = 53%; Not Well Controlled [NWC] asthma = 47%) based on national guidelines (U.S. DHHS, 2007) (Table 1). However, two thirds (67%) of the participants perceived their

child's asthma to be well controlled. A majority of participating mothers reported having a personal history of asthma (73%). Asthma morbidity was high, with the youths averaging 1.5 ED visits for asthma over the prior three months (SD=0.99) and nearly two-thirds (60%) using rescue medications on a daily basis.

Two themes and six sub-themes were identified in the analysis (Table 2). Results were consistent across mothers who completed the control arm of the RCT and those assigned to the intervention arm. To add context, exemplar quotes from participants are used to highlight the themes and sub-themes. Each is labeled with child age and asthma control level based on national guidelines.

THEME 1: *Child asthma self-management is multifaceted and difficult to achieve*

This sample of low-income mothers of African-American children with uncontrolled asthma identified a number of factors that, from their perspective, are critical components of child asthma self-management: symptom recognition, medication usage, and understanding the consequences of nonadherence and delayed treatment. However, based on their mothers' descriptions, most children lacked evidence of achieving independence in these areas.

Sub-theme: Child has difficulty recognizing asthma symptoms—Participants reflected that their children generally know that they are not feeling well when asthma symptoms flare but often have more difficulty understanding the nuances of their symptoms (i.e., an asthma cough rather than a common cold cough; inability to catch breath from extreme physical exertion vs. asthma exacerbation). The mothers felt their children struggled to describe their symptoms clearly, and in some cases, the child was unable to recognize that an acute asthma exacerbation was imminent. A mother of an eight-year-old with VPC asthma offered the following description of her daughter's inability to distinguish between asthma and non-asthma symptoms:

> Yeah, coughing for her, she seems to just "Oh I'm coughing" but it's a different kind of cough and I don't think she can recognize the two yet until she's actually like in pain. When I say pain it's like her chest is hurting and she's extremely tired and that's when she realizes it. And when you're extremely tired and your pain in your chest is hurting, that mean okay, you delayed it a long time. So she don't know the difference yet between her coughs and she don't understand that when she gets a cold, how come her cold is a little bit more than her friends cold and why she has to stay home or why she can't be around sick children. So she don't understand that yet. Family # 4, 8-year-old, VPC, Mother perceives control

Another mother of a 10-year-old with NWC asthma similarly illustrated the lack of nuance in her child's symptom recognition:

> He'll just say that he's not feeling well. He won't – and I'll just look at him and can see it. But, I mean, he won't say, 'I can't breathe.' He'll just say, 'I'm not feeling good.'" Family # 7, 10-year-old, NWC, Mother perceives control

Only a few felt their child was attuned to symptoms, but at the same time, most of these parents incorrectly perceived their child's asthma to be controlled. The following quote from a mother of an 8-year-old characterized with NWC asthma exemplifies this disconnect:

> She can recognize them [symptoms] now and she's only eight. Anybody knows their body and knows when something is not right." Family # 10, 8-year-old, NWC, Mother perceives control

Sub-theme: Child relies on rescue inhalers rather than preventive asthma medication—Knowing how to prevent symptoms through daily controller medication, as well as when more therapy is needed for symptom exacerbation, are core elements of skill building for asthma self-management. Yet, these mothers depicted their children with poorly-controlled asthma as relying more heavily on rescue medication as a means to address symptoms rather than proactively implementing measures to avoid symptoms by using daily preventive medications. When discussing their child's understanding of when to use asthma therapies, caregivers were apt to point out reliance on rescue medication usage.

> He tells me, because he plays a lot of sports. He plays football, basketball. So, he can be – like, I can be home and he might be outside playing football or something and he comes in and says, "Ma, I need a [inhaler]. You know, I need a puff or something," and I say, "Alright, you can get it right there" and he gets a puff or two. Family # 15, 6-year-old VPC, Mother does not perceive control

> She would tell me she's wheezing, she'll hook up her machine and get on the machine. Family # 3, 15-year-old, VPC, Mother perceives control

Sub-theme: Child beliefs, behaviors and attitude toward asthma impede effective selfmanagement—The mothers emphasized the importance of their child accepting the severity of their condition, not ignoring symptoms, and seeking healthcare for asthma when needed. However, child resistance, which resulted in delayed treatment, was common in their reflections. One mother described her child as being reluctant to seek healthcare for asthma:

> He doesn't like to go to the hospital but I've told him if you're really bad off you can get brain dead, you can lose oxygen and whatever…You need to get help, because sometimes I don't have the stuff here to help and you gotta get help quick" Family # 9, 12-year-old, VPC, Mother does not perceive control

Participating mothers' often voiced concern that their children—in particular, adolescents—had difficulty accepting the seriousness of their condition which often led them to ignore or minimize symptoms:

> I think he tries to go as far as he can without it [medications]…We just had an incident at school--he was coughing and whatnot. He took his Flovent that morning, but he didn't take his Albuterol. The teacher kept asking him if he was okay. He kept saying yeah until about second period. The next teacher was like, "No. Go to the Health Room." The nurse called and said, "Yeah, he has to go." So brought him home and made him take his medicine. So I think he's at that stage

where he feels like, “I can be without it.” Family # 2, 12-year-old, VPC, Mother perceives control

So when she be dancing, I’ll be like, “[Child], you better sit down, you know your asthma. She’s like, “I know”, but then, she likes to dance, and that’s what she wants to be. Family # 3, 15-year-old, VPC, Mother perceives control

Additionally, as the experience of one mother of a 12-year-old highlights, the child’s negative attitude toward their asthma can result in behavioral challenges, such as defiance, that further undermine effective asthma self-management:

And then like I was saying they got behavioral problems as well, they always want to act out because they’re like why did this have to happen to me, why do I have it bad, why do I have to take all these pills? You’re dealing with all of that also. Family # 9, 12-year-old, VPC, Mother does not perceive control

Finally, limitations that asthma placed on the children’s social and recreational activities likewise generated frustration and, in some cases, non-adherence.

With her being in the [dance group], I’m like “Okay time for you to get out.” and she’s like “Oh no I’m not done.’ Then she’ll get out and it’s like, you know what I mean, it’s too late, I told you to get out. Family # 4, 8-year-old, VPC, Mother perceives control

That, I think he’s just stubborn and wants to be able to try to control it without taking the medicine. I think he’s really at that stage where he’s like, “It’s frustrating I gotta keep taking it…Having to take time out, maybe not participating as much as he would want. Sometimes myself and his stepfather will tell him – he’ll want to go out and play basketball early throughout the day, and it’s like, “Well, it’s a little too hot right now. You’ve got to wait until it cools down,” while all the other kids are still out…He gets limited sometimes as far as when he can go and how long. Family # 2, 12-year-old, VPC, Mother perceives control

THEME 2: *Transfer of asthma responsibility from parent to child is variable*

There was no uniform age that mothers believed children should be participating in asthma self-management. Interestingly, not a single participant described receiving guidance from healthcare providers in the decision to transfer asthma responsibility to the child nor how to prepare for that process. Instead, participants relied on their own judgement about the child’s capacity for self-management. Most participants reported that their child started becoming involved in asthma management by recognizing symptoms as early as three to five years of age and taking responsibility for administering treatments around age six to ten.

About three [years of age]! Yeah, she would say, my chest hurts I gotta go to the hospital. Family # 5, 6-year-old, VPC, Mother perceives control

Well, I think he was about seven or eight, and he was – I think I went to the store or something, or I was downstairs, and I came back upstairs, and he wasn’t feeling good, and I asked him was he okay. And then I looked. He was putting the machine on. Family # 1, 11-year-old, NWC, Mother does not perceive control

In contrast, some mothers did not feel comfortable transferring responsibility for medication administration until the early teenage years.

> For me personally, I'd probably say, probably not till like 14, 15 years old. But even at that age I feel like they need to be watched at least medicating themselves. Because sometimes they can overdose, they don't count the breaths in between the pumps. And just making sure that they get the proper medication that they need using the spacer even at 14 because sometimes the medicine might not get directly through to your lungs. Family # 4, 8-year-old, VPC, Mother perceives control

The mothers reported the most confidence in transferring some asthma management responsibility when their child stopped treating medications/treatments as toys, knew how to administer medication and treatments independently, could clean and maintain their treatment devices, and demonstrated understanding of proper medication dosage (i.e., how many puffs) and use (i.e., take breaths between puffs; use of spacer).

> When they stop playing with the pump and pumping out all the medicine. Or they think it's really cool when they put the asthma pump in their mouth and they just blow the asthma mist out. When they stop doing that. I don't even have, for [Child] I don't give him the option to carry his medicine around with him in school because he plays with it. Family # 13, 8-year-old, NWC, Mother perceives control

> When they're having an asthma attack and I'm not around and they know to go and get their spacer and inhaler, how to put the mask on, and they do everything step by step and how I taught them. That's how I know they're ready to handle the medication on their own. Family # 10, 8-year-old, NWC, Mother perceives control

Sub-theme: Mothers have primary oversight but lack full understanding of what well controlled asthma is and how to achieve it—Participants' reflections also revealed heterogeneity in the nature of roles and responsibilities the mothers and children held in asthma self-management in the home. Mothers' roles included assessing their child's readiness for self-management, teaching, demonstrating, monitoring, supervising, reminding, and checking. Most depicted themselves as having primary responsibility for asthma management and monitoring their children as they began to learn about asthma medications and administer treatments.

> Probably around last year, towards winter. I started letting him take more responsibility so that he can learn and feel more responsible about it. I still monitor him and make sure, but I kind of say, "Go ahead and make you take your medicine," and then I'll watch or whatever. And then later I'll say, "You didn't take your pump. Take it now," or something. Family # 2, 12-year-old, VPC, Mother perceives control

However, their reflections suggest that asthma management guidelines are not always followed as evidenced by medication sharing by mother and child and inconsistent use of recommended therapies (i.e., spacer devices).

> If I'm cooking dinner and I'm not able to [administer medication] at that time, she'll go in my purse and get my inhaler. She'll shake it and she'll show me that

> she's about to take it. And I'll tell her to go ahead. Family # 10, 8-year-old, NWC, Mother perceives control

> Well, right now she's ten, so I try – right now with her inhaler, we use a spacer for her, but there's been times when I didn't have her spacer that I try to help her to try to do without the spacer. I try to – even though like most of the time I know she need the spacer, but there's times that I don't have it at the time, and I'll hear her wheezing. And I'm like – I try to direct her how to do it. And most of the time I hold the inhaler, and I'll be like I'm going have you to breathe out. And then I'm going to count to three. And then once I spray the inhaler, then I want you to inhale it and hold it. And once I count to see how she hold, then I tell her that I will do it again. So I try to get her to get familiar of how to do to it, too. But I try – I usually want her to do with it the – like, she know how to do it with a spacer, but then I try to show her how to do it without the spacer too, it makes it easy. Family # 11, 10-year-old, NWC, Mother perceives control

In other cases, mothers have turned over asthma management responsibilities to the child, but they continue to remain involved through prompting and monitoring. However, the expressed confidence in the child's ability to be independent was often in conflict with objective data indicating the child's asthma was uncontrolled. The following quotes are from two different mothers who considered their child's asthma to be under control but, in actuality, the child was characterized as NWC based on the national guidelines:

> Now they have where it tells you on the back of the pump how many pumps are left. I used to monitor that with her, like how many pumps she was taking a day, if she was even taking it. I recently stopped doing that, because I think she's good now. Family # 13, 8 years, NWC, Mother perceives control

> [Child] knows if he gets a steady cough – he'll come right in the room and grab a pump. And take his two puffs. They know what to do. And he knows how to set up his nebulizer. Family # 8, 8-year-old, NWC, Mother perceives control

Sub-theme: Maternal history of asthma influences child asthma self-management—A majority of participants reported having a personal history of asthma. Their knowledge, skills, and behaviors related to asthma self-management often came from their own experiences with asthma and did not necessarily reflect the national guidelines. For example, one mother decided to allow her five-year-old son with VPC asthma to use his inhaler by himself based on her own experience as a child, rather than assessing her son's capacity:

> Well, I know from experience, when I was little, my mom made me use my inhaler when I was five, like five on up. She would teach me only twice, like when needed, and stuff like that. I would try to train my son. Like he's five now, so I want to get him to learn how to use his own inhaler, without overusing it. Family # 12, 5-year-old, VPC, Mother does not perceive control

Another mother of a six-year-old described experiencing an acute asthma exacerbation because managing her own asthma was secondary to caring for her child's asthma:

> I took her to the clinic to get her follow-up from when she went to the emergency room…They had to call code red on me because I couldn't breathe...it didn't dawn on me that I had asthma[exacerbation] too, didn't dawn on me that maybe I can't be running in the heat. So, at the same time, it was like an eye-opener for her [daughter], because now she's probably like, "Okay, that's what I go through. That's what my mama keeps telling me about. This is what happens when you can't breathe or you don't take your medicine or…" you know, things like that. I take my medicine, but – like I said, when it comes down to the kids, I don't think about my asthma. I just up and go, and because she had to be to the clinic, dealing with her asthma. Family # 15, 6-year-old, VPC, Mother does not perceive control

Sub-Theme: Mothers overestimate child developmental capacities for asthma self-management—Mothers of young children often described them as being eager and motivated to take on asthma responsibility, but in most cases, the children were not developmentally ready for the complex asthma management protocols. Asthma self-management requires certain executive functioning skills such as the ability to tell time and keep on a scheduled medication regimen, the knowledge and ability to prepare and administer treatments, and an awareness of how much medication to take and when. Additional executive functioning skills include remembering to carry medications and not misplacing treatments. This group of mothers often perceived their child's asthma to be controlled, but this was in contradiction to their actual symptoms, further suggesting that while children might be eager to take on more responsibility, from a developmental perspective, they are not yet capable of fully executing self-management skills on their own.

> He's very hands on with his medication. If he goes to stay with my grandmother or my aunt or something, he'll be like 'I need my medicine. I get this, this and this.' He knows all of the medications that he gets. He knows what time he gets them, so he'll never let anybody forget to give him his medication." Family # 14, 6-year-old, NWC, Mother does not perceive control

> He just wants to always say, I can do it. I can do it, but I didn't think he shook it enough. So, now he really shakes it. He's seven now, and like I say, he can do that, and he can do the nebulizer. But I prefer to still watch him with the nebulizer, even though my husband said he really, really told him what to do. Family # 8, 8-year-old, NWC, Mother perceives control

> She manages her own medicine, well, she don't manage it on a regular [schedule]. But I mean, like I say, if I sit her somewhere she knows, she'll tell you, hey I need my pump or she'll know…She just doesn't know the timing of it. If I say take it at 3:00, no she don't know that [telling time on clock]. Family # 5, 6-year-old, VPC, Mother perceives control

Discussion

This study elucidated several factors associated with the transfer of asthma responsibility from parent to child in a sample of urban poor families of youths with uncontrolled asthma. Child asthma symptom recognition, proper medication usage, and understanding of

consequences associated with nonadherence and delayed treatment were all described by the mothers as core components of effective asthma self-management. However, most children lacked evidence of achieving independence in these areas. While the timing and steps to transfer of responsibility for self-management from caregiver to child were variable, findings consistently indicated that the mothers held critical roles in assessing their child's capacity for asthma responsibility as well as teaching, demonstrating, supervising, reminding, and checking self-management behaviors.

Similar to the work of Garnett, Smith, and Ormandy (2016) who described a conceptual model for asthma management decision-making as a "dynamic, shifting, and shared" experience, our participating mothers viewed asthma self-management as a process that develops over time. We found that mothers imparted knowledge about symptom awareness, treatment adherence, and medication administration directly through instruction, role modeling, and prompting. At the same time, children learned vicariously by observing how their mothers' enacted asthma management behaviors for themselves and for their child. It was particularly concerning that mothers depicted their children taking a reactive rather than proactive or preventive approach to asthma management, which is imperative given the important role of parental modeling of behavior in the development of self-management skills (Bandura, 1986; Clark & Zimmerman, 2014).

Interestingly, the majority of mothers in the study had their own personal history with asthma. As a result, these mothers had entered into the role of caring for a child with asthma using existing asthma self-management knowledge, behaviors, and skills that they had acquired over the years. Caregiver management of the child's asthma was informed by their own personal experiences with asthma and did not generally reflect the national guidelines. In our previous focus group research with low-income mothers of youths with uncontrolled asthma, we found that mothers' health beliefs profoundly impacted on asthma self-management; however, the role of the mother's own history of asthma did not emerge in that study (Author et al., 2017b). In fact, to our knowledge, few studies have explored the influence of the mother's own asthma on how the child's asthma is managed in the home context or how it impacts decisions regarding the transfer of asthma responsibility from caregiver to child.

Additionally, we observed a striking discrepancy between perceived and objective measures of asthma control level. Notably, two-thirds of mothers considered their child's asthma to be well-controlled, but based on national guidelines, all children were categorized as having NWC or VPC asthma (U.S. DHHS, 2007). This discordance raises significant concerns about the mothers' understanding of what asthma control means, how to achieve it through asthma self-management in the home, and the nature of asthma knowledge, skills, and behaviors they are teaching their children. At the same time, even when mothers do understand asthma control and possess the knowledge, skills, and behaviors required for optimal asthma self-management, other qualitative and focus group research has shown that living in poverty creates barriers that impede the ability to manage asthma according to national guidelines (Author et al., 2017b; Author et al., 2018).

Our findings further suggest that this sample of mothers of children with poorly-controlled asthma may not fully understand child development processes, in particular executive functioning skills and other cognitive and behavioral abilities, which can lead to an overestimation of their child's capacities to properly engage in asthma self-management activities. Consistent with previous studies, the children of our participants were assuming responsibility for asthma medication administration at a very young age (Eggleston et al., 1998; Winklestein et al., 2000). Focus group research by Laster et al. (2009) with low-income, African-American youths (8–17 years) and their caregivers revealed that premature transfer of asthma management responsibility from caregivers to young children may be due to parents feeling overwhelmed by the myriad financial, social, and emotional challenges they experienced related to living in poverty. Additionally, African-American parents living in poverty may promote early independence and self-reliance among their children in order to prepare them for success in a chaotic and under-resourced social and physical environment (Garbarino, 1998; Halpern, 1990; McLoyd, 1990; Ogbu, 1985). Yet, cognitive development continues through adolescence, which likewise has implications for older children in their efforts to be independent in asthma self-management. For example, it has been noted that although adolescents with asthma have reasonable trigger awareness, they often were unable to identify life-threatening symptoms, tell if their asthma was controlled or uncontrolled, or understand the long-term consequences of uncontrolled asthma (Mammen, Rhee, Atis, & Grape 2018). It is critical that future interventions with this population attend to the psychosocial and ecological barriers that may prevent these mothers from accurately assessing their children's developmental capabilities to manage a chronic health condition.

One notable finding was the apparent lack of participant references to partnerships with healthcare providers in the shared decision-making of transferring asthma responsibility from parent to child. Not a single mother discussed receiving guidance or support from providers on how or when to prepare for that transition process. If this discussion did occur, the mothers did not explicitly recognize healthcare providers as holding vital roles in the transition of asthma self-management from mother to child. Yet, two decades ago Zimmerman and colleagues emphasized that collaborations among providers, parents, and youths are "essential because self-management of complex medicines and devices, such as spacer inhalers, depends on high levels of consultation and planning." (1999, p. 69). Indeed, providers should regularly assess the knowledge, capacities, beliefs, and attitudes of both the parent and child while incorporating discussions about the transfer of responsibility into all clinical encounters to facilitate the gradual progression of asthma responsibility among children with high-risk asthma.

There are a number of asthma-specific and generic measures of self-management that providers may use to facilitate assessment and guide transition planning. *Reasoning About Asthma Scenarios* (Kintner, 2007) examines how adolescents with asthma use their knowledge and personal experiences to problem-solve and make decisions around symptom recognition, severity, medication use, and general asthma management. The *Decision-Making Involvement Scale* (Miller & Harris, 2012), developed for children and adolescents with cystic fibrosis, diabetes, and asthma, also measures how involved children and adolescents are in decisions related to self-management. In addition, there are scales

available that measure both parent and child self-efficacy regarding medication usage, attending appointments, trigger avoidance, severity awareness, and attack prevention and management (Bursch, Schwankovsky, Gilbert, & Zeiger, 1999). Finally, several generic self-management instruments may be useful for providers to assess and monitor growth in skills, knowledge, and behaviors over time such as the *Self-Management Skills Assessment Guide* (Williams et al., 2011), *Self-Management and Transition to Adulthood* (STARx) (Ferris et al., 2015; Cohen et al., 2015), *TRANSITION-Q* (Klassen et al., 2015), the *Transition Readiness Assessment Questionnaire* (TRAQ) (Wood et al., 2014), and the *UNC TR(x)ANSITION Scale* (Ferris et al., 2012).

Limitations

There are several potential limitations associated with this study. First, our sample was comprised solely of mothers and not the children with asthma themselves. The findings may have been enhanced by including the child's perspective on how they develop asthma self-management knowledge, behaviors, and skills, since their viewpoint may differ from that of their mothers. Similarly, it would have been useful to add more specific follow-up probes on how the mothers define well-controlled asthma to better understand discrepancies between recommendations from the national guidelines and parent perspectives. Furthermore, drawing on the expertise of an advisory group of Asthma Express enrolled caregivers to inform the development of questions used in this study would have been helpful. Our findings may not reflect the broader population of caregivers of children with asthma due to the fact that our sample was primarily comprised of low-income, urban, mothers of African-American youths with poorly-controlled asthma. Caregiver perceptions of factors associated with the transfer of asthma self-management responsibilities from parent to child may differ in families of higher socioeconomic status, non-minority families, or families of children with well-controlled asthma.

Recommendations

Despite these limitations, study findings extend understanding about when and how low-income mothers decide to transfer asthma management responsibilities to their children with uncontrolled asthma. Based on the themes emerging from our data, healthcare providers working with this population need to continually 1) assess the child's cognitive and developmental capacities and the caregiver's perception of the child's capacities for self-management and individualize interventions accordingly, 2) explore the beliefs and attitudes of the child and caregiver about the asthma self-management process, 3) assess the caregiver's understanding and perception of the child's level of asthma control and knowledge of national guidelines, and 4) screen youth for the level of symptom recognition to provide interventions that promote accurate symptom assessment and preventive care behaviors (Rhee et al., 2011). These ongoing assessments will ideally inform individualized asthma plans as well as tailored guidance and education about proper asthma control to children with asthma and their caregivers. Healthcare providers are well positioned to support caregivers in their pivotal role in their child's self-management development process, which may ultimately help improve asthma outcomes for this vulnerable population.

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Table 1.

Family Demographics (N=15)

Family ID	Child Age	Mother History of Asthma	Asthma Control Level	Caregiver perception of whether child's asthma is controlled*
Family 1	11	Yes	Not well controlled	Not controlled
Family 2	12	Yes	Very Poorly Controlled	Controlled
Family 3	15	No	Very Poorly Controlled	Controlled
Family 4	8	Yes	Very Poorly Controlled	Controlled
Family 5	6	Yes	Very Poorly Controlled	Controlled
Family 6	12	No	Very Poorly Controlled	Controlled
Family 7	10	Yes	Not well controlled	Controlled
Family 8	8	No	Not well controlled	Controlled
Family 9	12	Yes	Very Poorly Controlled	Not Controlled
Family 10	8	Yes	Not well controlled	Controlled
Family 11	10	Yes	Not well controlled	Controlled
Family 12	5	Yes	Very Poorly Controlled	Not Controlled
Family 13	8	Yes	Not well controlled	Controlled
Family 14	6	No	Not well controlled	Not Controlled
Family 15	6	Yes	Very Poorly Controlled	Not Controlled

Note. Child asthma control level was based on national guidelines (US DHHS, 2007): Well controlled; Not well controlled; Very Poorly Controlled.

*Caregivers responded (yes, no, or unsure) to the following question: In the past 4 weeks, do you believe that your child's asthma was well controlled?

Table 2.

Themes and sub-themes

Theme 1	**Child asthma self-management is multifaceted and difficult to achieve**
Sub-theme	Child has difficulty recognizing asthma symptoms
Sub-theme	Child relies on rescue inhalers rather than preventive asthma medication
Sub-theme	Child beliefs, behaviors and attitude toward asthma impede self-management
Theme 2	**Transfer of asthma responsibility from parent to child is variable**
Sub-theme	Mothers have primary oversight but lack full understanding of what well controlled asthma is and how to achieve it
Sub-theme	Maternal history of asthma influences child asthma self-management
Sub-theme	Mothers overestimate child developmental capacities for asthma self-management