

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

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Introduction: The process of self-management knowledge, behavior, and skill development in children with asthma from families with low income is understudied.

Method: Fifteen mothers of children with uncontrolled asthma participated in semistructured interviews exploring the transfer of asthma self-management responsibilities from parent to child. Team members performed thematic analysis of written transcripts.

Results: All participants were all the biological mothers and were impoverished, with most (73%) reporting an annual family income of less than \$30,000. Their children ranged from 5 to 15 years old, were African American (100%), and had uncontrolled asthma based on national guidelines. Themes showed that child asthma

self-management is difficult to achieve, that the transfer of asthma responsibility from mother to child is variable, and that mothers overestimate their child's developmental capacities for independent asthma self-management and have poor understanding of what well-controlled asthma means.

Discussion: Ongoing assessment and tailored guidance from health care providers are critical to support the pivotal role of mothers in their child's self-management development process. *J Pediatr Health Care.* (2019) XX, 1–10

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Asthma, self-management, poverty, health beliefs

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Asthma affects more 8% of all children younger than 18 years, making it one of the most common pediatric conditions in the United States (Centers for Disease Control and Prevention, 2018). However, morbidity and mortality rates disproportionately affect children of racial minorities. Asthma prevalence is nearly twice as high in African American children (15.7%) compared with the overall national rate (Zahrán, Bailey, Damon, Garbe, & Breyse, 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 that of non-Hispanic White youths (Gergen & Togias, 2015).

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 (Rand et al., 2012; USDHHS, 2007). 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 (Butz et al. 2017; Bruzesse et al., 2012; Rohan et al., 2010). A range of factors associated with residing in disadvantaged communities are thought to heighten the risk for ineffective asthma self-management including poverty, exposure to violence in the home and community, multigenerational trauma, housing instability, poor communication with school staff and administration, and caregiver psychological distress (Bellin et al., 2017a, 2017b, 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). More than two decades ago, Eggleston et al. (1998) observed that by age 9 years, more than half of African American children were self-administering asthma medication without adult supervision. Similar alarming findings were noted in research by Winkelstein et al. (2000), who found that nearly all 6- to 14-year-old youths of racial minorities in their sample (93%), and a quarter of children between the ages of 4 and 6 years (25%), were taking asthma medications without adult supervision, despite the fact that only 7% of these children demonstrated the ability to appropriately administer their inhalers. More recent studies suggest that this pattern continues, with children as young as 7 years old assuming at least a portion of the 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 nonminority 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 with their peers with controlled asthma. Caregiver and child concerns about the adverse 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 of whether treatments were followed) have also been noted (Bellin et al., 2017a; Laster et al., 2009; Martin, Beebe, Lopez, & Faux, 2010).

More recent focus group research with African American adolescents aged 14 to 18 years and their caregivers extended the 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 youths 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 African-American children with poorly controlled asthma from families with low income. This focus may ideally help inform the development of effective interventions that support the strengths of these families and address their challenges.

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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 (Butz et al., 2017). 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, and asthma-related ED visits and hospitalizations (U.S. Department of Health and Human Services [USDHHS], 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 serious other respiratory conditions such as cystic fibrosis. All children received serologic testing for common environmental allergens and exposure to secondhand smoke during an ED visit for asthma. Children were randomly assigned to 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 Butz et al., 2017 for more detailed information). The RCT was approved by the institutional review boards of the associated universities.

Institutional review board approval was obtained to send follow-up study letters to 40 caregivers who completed the RCT and 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 semistructured interviews that followed a script based on preliminary data from the larger RCT and team members' clinical practice experiences of delivering care to children of racial minorities 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 the following:

- *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 subthemes. The coding scheme and definitions for the themes and subthemes were evaluated and revised in data analysis meetings held over the course of 6 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 subthemes against the original transcripts (Padgett, 2008; Patton, 1999). Discrepancies in code classification, theme and subtheme conceptualization and definitions, and exemplar quotes were resolved through consensus decision.

RESULTS

All participants were the child's biological mother (100%); their average age was 33 years, and most were 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 to 15 years (mean = 9.13 years), and had uncontrolled asthma (very poorly controlled [VPC] asthma = 53%, not well-controlled [NWC] asthma = 47%) based on national guidelines (USDHHS, 2007; Table 1). However, two-thirds (67%) of the participants perceived their child's asthma to be well-controlled. Most 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 3 months (standard deviation = 0.99) and nearly two-thirds (60%) using rescue medications on a daily basis.

Two themes and six subthemes 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 subthemes. 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 mothers with low income 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 use, 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.

Subtheme: Child has difficulty recognizing asthma symptoms

Participants reflected that their children generally know that they are not feeling well when asthma symptoms

TABLE 1. Family demographics (N = 15)

Family	Child age, years	Mother history of asthma	Asthma control level	Caregiver perception of whether child's asthma is controlled ^a
1	11	Yes	Not well-controlled	Not controlled
2	12	Yes	Very poorly controlled	Controlled
3	15	No	Very poorly controlled	Controlled
4	8	Yes	Very poorly controlled	Controlled
5	6	Yes	Very poorly controlled	Controlled
6	12	No	Very poorly controlled	Controlled
7	10	Yes	Not well-controlled	Controlled
8	8	No	Not well-controlled	Controlled
9	12	Yes	Very poorly controlled	Not controlled
10	8	Yes	Not well-controlled	Controlled
11	10	Yes	Not well-controlled	Controlled
12	5	Yes	Very poorly controlled	Not controlled
13	8	Yes	Not well-controlled	Controlled
14	6	No	Not well-controlled	Not controlled
15	6	Yes	Very poorly controlled	Not controlled

Note. Child asthma control level was based on national guidelines (USDHHS, 2007): well-controlled, not well-controlled, or very poorly controlled.

^aCaregivers 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?

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 that 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 8-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 friend’s 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 child, 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 child, NWC, mother perceives control)

Only a few felt that 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 quotation 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 child, NWC, mother perceives control)

Subtheme: Child relies on rescue inhalers rather than preventive asthma medication

Knowing how to prevent symptoms through daily controller medication and when more therapy is needed for symptom exacerbation are core elements of skill building for asthma

TABLE 2. Themes and subthemes

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

self-management. However, 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 use.

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, “All right, you can get it right there,” and he gets a puff or two. (family 15, 6-year-old child, 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 child, VPC, mother perceives control)

Subtheme: *Child beliefs, behaviors, and attitude toward asthma impede effective self-management*

The mothers emphasized the importance of their child accepting the severity of his or her condition, not ignoring symptoms, and seeking health care 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 health care 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, 2-year-old child, 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 child, VPC, mother perceives control)

So when she be dancing, I'll be like, “[Child's name], 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 child, VPC, mother perceives control)

Additionally, as the experience of one mother of a 12-year-old highlights, a child's negative attitude toward his or her 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 child, 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, nonadherence.

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 child, 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 child, 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. Not a single participant described receiving guidance from health care providers in the decision to transfer asthma responsibility to the child nor how to prepare for that process. Instead, participants relied on their own judgment 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 3 to 5 years of age and taking responsibility for administering treatments around age 6 to 10.

About three [years of age]! Yeah, she would say, my chest hurts I gotta go to the hospital. (family 5, 6-year-old child, 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 child, NWC, mother does not perceive control)

In contrast, some mothers did not feel comfortable transferring responsibility for medication administration until the early teen-age 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 child, 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 the treatment devices, and showed 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's name] 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 child, 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)

Subtheme: Mothers have primary oversight but lack full understanding of what well-controlled asthma is and how to achieve it

Participants' reflections also showed heterogeneity in the nature of the roles and responsibilities that 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,

Not a single participant described receiving guidance from health care providers in the decision to transfer asthma responsibility to the child nor how to prepare for that process.

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 child, 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 child, 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 child, 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 that the child's asthma was uncontrolled. The following quotations are from two different mothers who considered their child's asthma to be under control but, in actuality, the child was characterized as having NWC asthma 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-year-old child, NWC, mother perceives control)

[Child's name] 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 child, NWC, mother perceives control)

Subtheme: 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 5-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 child, VPC, mother does not perceive control)

Another mother of a 6-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 child, VPC, mother does not perceive control)

Subtheme: 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 maintain 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 although 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 child, 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 child, 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 child, 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 use, 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. Although the timing and steps to transfer 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" (p. 19) 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 the child. It was particularly concerning that mothers depicted their children taking a reactive rather than proactive or preventive approach to asthma management, which is critical 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 mothers with low income of youths with uncontrolled asthma, we found that mothers' health beliefs profoundly affected asthma self-management; however, the role of the mother's own history of asthma did not emerge in that study (Bellin et al., 2017a). 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 affects 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. 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 (USDHHS, 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 have 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 (Bellin et al., 2017a, 2018).

Our findings further suggest that this sample of mothers of children with poorly controlled asthma may not fully understand child development processes, particularly 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; Winkelstein et al., 2000). Focus group research by Laster et al. (2009) with African American youths (8–17 years) from families with low income and their caregivers showed 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 to prepare them for success in a chaotic and underresourced social and physical environment (Garbarino, 1998; Halpern, 1990; McLoyd, 1990; Ogbu, 1981). However, 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 ecologic 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 health care 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 health care providers as having vital roles in the transition of asthma self-management from mother to child. However, two decades ago Zimmerman, Bonner, Evans, and Mellins (1999) 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” (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. The Reasoning About Asthma Scenarios tool (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,

We observed a striking discrepancy between perceived and objective measures of asthma control level.

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 use, 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., 2010), Self-Management and Transition to Adulthood (STARx; Cohen et al., 2015; Ferris et al., 2015), TRANSITION-Q (Klassen et al., 2015), the Transition Readiness Assessment Questionnaire (TRAQ; Wood et al., 2014), and the University of North Carolina TR(x)ANSITION Scale (Ferris et al., 2012).

Limitations

There are several potential limitations associated with this study. First, our sample was composed solely of mothers and not the children with asthma themselves. The findings may have been enhanced by including the children's perspectives on how they develop asthma self-management knowledge, behaviors, and skills, because their viewpoints may differ from those 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 because our sample was primarily composed of urban mothers with low income 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-racial minority families, or families of children with well-controlled asthma.

Recommendations

Despite these limitations, study findings extend understanding about when and how mothers with low income decide to transfer asthma management responsibilities to their children with uncontrolled asthma. Based on the themes emerging from our data, health care providers working with this population need to continually (a) 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, (b) explore the beliefs and attitudes of the child and caregiver about the asthma self-management process, (c) assess the caregiver's understanding and perception of the child's level of asthma control and knowledge of national guidelines, and (d) screen youth for the level of symptom recognition to provide interventions

that promote accurate symptom assessment and preventive care behaviors (Rhee, Belyea, Hunt, & Brasch, 2011). These ongoing assessments will ideally inform individualized asthma plans and tailored guidance and education about proper asthma control to children with asthma and their caregivers. Health care 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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