Published in final edited form as:

J Pediatr Health Care. 2018 ; 32(4): 387–398. doi:10.1016/j.pedhc.2017.12.009.

Improving Care of Inner-City Children With Poorly Controlled Asthma: What Mothers Want You to Know

Melissa H. Bellin, PhD, LCSW¹, Angelica Newsome, MSW¹, Cassie Lewis-Land, MA², Joan Kub, PhD, RN³, Shawna S. Mudd, DNP, CRNP⁴, Rachel Margolis, MSW¹, and Arlene M. Butz, ScD, RN²

¹University of Maryland School of Social Work

²Johns Hopkins University School of Medicine, Division of General Pediatrics and Adolescent Medicine

³University of Southern California School of Social Work-Department of Nursing

⁴Johns Hopkins University School of Nursing, Medicine and Public Health

Abstract

Introduction—Low-income caregiver perspectives on asthma management are understudied but may illuminate strategies to improve care delivery and child outcomes.

Method—Purposive sampling methods were used to recruit 15 caregivers of children with frequent asthma Emergency Department (ED) visits. Interviews explored how poverty and stress impact asthma management. Grounded theory coding techniques were used to analyze the data.

Results—Participants were the biological mother (100%) and poor (75% \$30,000 annual income). Their children (Mean age = 6.9 years) were African-American (100%), enrolled in Medicaid (100%), and averaged 1.5 ED visits over the prior three months. Four themes emerged: (1) deplorable housing conditions, (2) allies and adversaries in school-based asthma management, (3) satisfaction with asthma healthcare delivery, and (4) prevalent psychological distress.

Discussion—Impoverished caregivers of children with frequent asthma ED visits describe stress that is multifaceted, overwhelming, and difficult to eradicate. Their experiences underscore the need for improved school-based asthma management and family-centered approaches to healthcare delivery.

Keywords

asthma; caregiver, stress; poverty; asthma management; provider relationships

Corresponding author: Melissa H. Bellin, PhD, LCSW, Associate Professor, Chair, Health Specialization, University of Maryland School of Social Work, 525 West Redwood Street, Baltimore, MD 21201, mbellin@ssw.umaryland.edu, 410-706-4409.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Introduction

Poorly controlled asthma is a major cause of morbidity and mortality in children (Normansell et al., 2017; O'Byrne et al., 2013). Although nearly 50% of youths with asthma experience an acute exacerbation annually (Akininbami, 2009), low-income, minority youths are disproportionately at higher risk for uncontrolled asthma and asthma-related Emergency Department (ED) visits (Zhang, Lamichhane, & Diggs, 2016). The causes of poorly controlled asthma are multifactorial and include environmental exposures to triggers in the home and community (e.g., second hand smoke, rodents, mold, dust mites), poor condition knowledge and self-management skills, access to care barriers including difficulties with medication administration in the school, and hardships associated with poverty (Authors, 2014 Authors, 2017a; Borowsky et al., 2013; Bruzesse et al., 2012; Camacho-Rivera et al., 2014; Lang et al., 2013; Ungar, Cope, Kozyrskyj, & Paterson, 2010). Caregiver psychosocial factors such as life stress and depressive symptoms further heighten risk for child asthma morbidity (Authors, 2015; Clawson et al., 2016; Feldman et al., 2011, 2013; Lim, Wood, Miller, & Simmens, 2011; Martin et al., 2013; Tibosch, Verhaak, & Merkus, 2011). To improve asthma control and reduce asthma health disparities, a range of home, community, and ED based interventions have been developed (Pinnock et al., 2017; Welsh et al, 2011), but the suboptimal outcomes for low-income, minority children persist.

Designing and implementing effective interventions for this population requires greater understanding of how social inequities stemming from family poverty and caregiver stress impact asthma management (Clouteir, 2008). Qualitative methodologies may be particularly fruitful in shedding light on caregiver experiences and, in turn, informing responsive asthma programs (Searle, Jago, Henderson, & Turner, 2017). For example, a mixed-method investigation of daily life stress in a sample of 40 urban poor caregivers of children with asthma found that semi-structured interviews offered deeper insights into family, financial, and caregiving-related stressors compared with quantitative measures (Sampson et al., 2013). Qualitative research with urban, low-income families likewise revealed important findings related to barriers to asthma management such as financial constraints impeding effective home environmental control, concerns about asthma medication side effects resulting in non-adherence to guideline-based care, and profound psychological distress in caregivers (Authors, 2017; Laster, Holsey, Shendell, McCarty, & Celano, 2009; Water et al. 2017). Other qualitative interviews and focus group research with caregivers of children with asthma highlighted the need for increased sharing of asthma information in clinical encounters (Kieckhefer & Ratcliffe, 2000) and, more specifically, improved provider sensitivity to the sociocultural context of minority families (Riera et al., 2015; Tumiel-Berhalter & Zayas, 2006). In-depth interviews with parents further identified strained family relationships and roles due to the intensive nature of asthma caregiving and asthma knowledge deficits as other potential sources of stress (Archibald et al., 2015; Rydström, Dalheim-Englund, Segesten, & Rasmussen, 2014).

In summary, a growing body of research offers some insight into the magnitude of stress experienced by caregivers of children with asthma, as well as the need for enhanced caregiver-provider relationships in the shared management of childhood asthma; however, the experience of impoverished caregivers of minority children with poorly controlled

asthma remains understudied but is critical to understand in light of persistent asthma health disparities. The current study aims to build on these previous studies by examining caregiver perspectives on how stress and poverty impact asthma home management and exploring how asthma management in the community may be improved from the unique caregiver lens.

This qualitative study was part of a larger, IRB approved randomized controlled trial (RCT) testing the efficacy of an ED and home-based environmental control intervention for young children with frequent asthma ED visits (Authors, 2017b). Inclusion criteria for the RCT included: (a) physician diagnosed persistent and uncontrolled child asthma based on current national asthma guidelines (U.S. Department of Health & Human Services, 2007), (b) 2 or more child ED asthma visits or 1 hospitalization over the past 12 months, and (c) residence in the Baltimore metropolitan area. Children were excluded if they had significant other non-asthma respiratory conditions (i.e., cystic fibrosis). Purposive sampling methods were used to recruit caregivers who had completed the RCT and agreed to be contacted for future asthma studies. Since maternal depression and life stress are associated with greater risk for child asthma morbidity and impaired caregiver quality of life (Authors, 2015; Clawson, Borrelli, McQuaid, & Dunsiger, 2016; Martin et al., 2013; Otsuki et al., 2010; Pak & Allen, 2012; Shalowitz, Berry, Quinn, & Wolf, 2001), study staff sent letters inviting 37 caregivers who reported clinically significant depressive symptoms (CES-D score ≥ 16 ; Radloff, 1977) or high life stress scores (Visual Analogue Scale of daily life stress score ≥ 6 where stress 1=no stress, 10=highest possible stress) at 12-month follow-up to participate in the individual interviews. Interested caregivers (n=12) contacted the study office, received additional details about the purpose of the study, and consented to be interviewed. Three additional caregivers with low depressive and life stress scores at 12-month follow-up were also interviewed to ascertain whether asthma management experiences differed as a function of psychological state (Patton, 1999). All caregivers received \$30.00 compensation for their time participating in the interview and an informational packet inclusive of community resources for psychosocial support and home services.

The interview script and associated questions were informed by preliminary data from the larger RCT as well as study team members' clinical practice in high-risk, inner-city pediatric asthma. The questions were designed to draw out caregiver reflections on how poverty and stress impact asthma caregiving experiences and to elucidate perspectives of asthma management in the school and healthcare settings from the unique caregiver lens (Appendix A). Trained study staff conducted the interviews from August 2016 to February 2017, all of which were audiotaped and professionally transcribed. The lead interviewer reviewed all transcripts to confirm content accuracy.

Data Analysis

Grounded theory coding techniques were used to analyze the data in a series of iterative steps. First, two research team members independently performed open coding of the transcript data for preliminary construct identification and conceptualization of themes and sub-themes. The coding scheme and definitions for the themes and sub-themes were evaluated and revised across a series of data analysis meetings held bi-weekly over a six-month period. The final coding scheme was then applied to all transcripts, with agreement

on thematic classification surpassing ninety-five percent across raters. Data collection and analysis continued until data saturation was achieved (Walker, 2012). Additional techniques to increase the validity of findings included member-checking with three participants (tentative findings were reviewed with three mothers to confirm accuracy of their experiences) and the use of a outside reviewer with clinical and research expertise in high-risk pediatric populations who evaluated the themes and sub-themes against the original transcripts (Padgett, 2008; Patton, 1999).

Results

Interview participants [Mean age= 32.9 (SD8.2) years] were the biological mother (100%), single (87%), and living in poverty, with most (73.3%) reporting an annual household income \$30,000 (Table 1). As expected based on study design, the majority of caregivers reported elevated levels of depressive symptomology (score of 16 or higher on CES-D) or daily life stress (score of 6 or higher). The children of participating caregivers were African-American (100%), enrolled in Medicaid (100%), and had significant asthma morbidity and high rates of healthcare utilization for asthma. The youths averaged 6.3 symptom days over the previous two weeks (SD=5.2), 10.2 symptom nights over the prior four weeks (SD=11.4), and had a mean of 1.5 ED visits over the prior three months (SD=0.99), indicating poorly controlled asthma. Nearly all mothers (73%) reported limitation of child activity due to asthma.

Four themes illuminating caregiver experiences with asthma management in the home and broader community were identified in the analysis (Table 2). No differences in thematic results were observed between participants who completed the control arm of the RCT (n=7, 46.7%) or those in the intervention group (n=8, 53.3%).

Theme 1: Deplorable Housing Conditions

Sub-Theme: Rodent Infested and Moldy Dwellings—Comprehensive care for children with poorly controlled asthma requires providers to have an understanding of how poverty and social inequities experienced by families may undermine treatment adherence and effective home environmental control. This group of low-income mothers described extreme housing conditions, including rodent infestation and mold exposure, which are known triggers for asthma. Yet, most lacked the financial resources needed to change their dire circumstances.

Where we all live – it's like it's infested [with mice], like, in the walls, the basement...and the environment is not a good environment for my children. I feel like there's mold on my walls and no one has never took the time out to come check it out, fix it, remove [it]. I felt the more I'm in my house, the more my daughter [with asthma] will be at the hospital. You would think that you could go in your room and get some air, try to relax, but you're breathing in whatever's in the walls. (Participant O)

If you go to my cabinet and with my pots and stuff will be, yes, you will see them [roaches] there... we just all bombed together, all four of my neighbors, and Lord

Jesus I don't know what happened. I guess they [roaches] were so powerful it just didn't [work], they just decided they wasn't going nowhere. (Participant E)

Every time [it rains], it rains in the basement. So I constantly have to buy the products to make sure no mold is growing and clean and check every day. It has to be dry everywhere, because that would be a trigger. It flows through the air, so it can flow from the basement through the vents or air. (Participant I)

Mothers who described living in more hygienic housing conditions were generally more likely to report better psychological health (e.g., were below cut-points on depressive symptoms and life stress).

I have adequate housing, and I have a job and an income. (Participant G)

Sub-Theme: Lack of Responsiveness from Landlords—Participating mothers often expressed frustration about how landlords appeared to lack concern for their child's welfare and the poor housing conditions experienced by the family.

The type of landlord that I have is just, "Oh okay, you have mold, okay. Maybe we oughta find somebody If we don't, we don't. We do, we do." That's the type of landlord. I don't know how many work orders I put in for them to come patch something up....They didn't test it. They just painted it over it and they, like, if you go to her room, you can see white marks of them painting over something, and then you can also see how the wetness of the mold is still coming through. (Participant O)

I don't think they [landlords] take it seriously and I think that's frustrating for me too because she's allergic to mice and that's a trigger for her as well...maybe landlords as well need to be educated on children and asthma, children and allergens and maybe that would help them be better management for their rental properties. (Participant D)

Only one participant described a responsive landlord, but even in that case, home repairs did not occur until the neighbors collectively advocated for change.

My neighbor that lives downstairs from me, her son also has asthma too, so we were just very adamant about him [landlord] coming out with a inspector because they have asthma and that's [mice] a trigger for both of them. I felt like he [landlord] took time to do it, but when we both just kept saying stuff to him, he did it. (Participant N)

Sub-Theme: Few Options for Change—This sample of impoverished mothers of children with poorly controlled asthma typically had few options or resources to move the family to safer home and community settings. A sense of helplessness was evident in their futile efforts to improve the family's circumstances.

I put in for another place. They haven't called me yet....Because I'm in public housing, it's like I'm on their time. They gonna move me when they're ready to move me. (Participant O)

When we first moved in there it was rats. I have to save the rent now. There's a lot I just go through...So, I just say it, it's gonna get better one day and I'm gonna figure it out, and I'm gonna put this together...I don't want handouts I need help. (Participant E)

They [children] want to move from around here. We want to move, but we can't move right now, you know? A lot of times, she'll [daughter with asthma] get upset and, once she gets upset, her asthma kick in, so I'm trying to keep her as calm as I can. (Participant F)

In addition to concerns about poor housing conditions, participants expressed alarm about violence and drug exposure in their neighborhoods when asked about sources of stress in their lives.

The drugs, the gang shootings and stuff like that [is stressful]. (Participant B)

Especially now it is [stressful] because you're afraid to take your kids outside. You're afraid to do certain things in Baltimore because there's so much going on... So yeah so if he's not with me, I wouldn't feel comfortable with him just going outside to play by himself. (Participant N)

Theme 2: Perceived Allies and Adversaries Encountered in School Asthma Management

Sub-Theme: Caregivers Trust and Collaborate with School Nurses—Mothers valued and actively pursued partnerships with school personnel in the shared responsibility of managing their child's asthma. Their reflections generally depicted positive interactions with school-based nurses, with mothers especially appreciating regular communication about the child's health status.

Each year, I go there [to the school] and I speak with the nurse. Make sure that she [nurse] has her [child's name] Albuterol, the tube, the spacer. Make sure they have that...so they already knew who I was and the routine of the asthma, and I love it. They still call me and let me know if she has an accident or if they had to give her a treatment. So, that way, I already would be on top of what they've given her or something like that, and then they also sent a letter home saying, "Hey! She was in the nurse's office the day. I gave her this and one of those." And I love it, it's so— Things like that is so much of a reliever for me, it is. (Participant O)

The nurse there handled it [asthma exacerbation] very well. She even gave him pointers on how to take his pump...And that was one of the things that made me feel good as far as the nurse in the school because she was on top of that, like, "You're supposed to use the spacer." That's the first time I heard a nurse in the school say that. (Participant B)

Sub-Theme: Lack of Teacher Awareness and Sensitivity to Child's Asthma—In contrast, mothers perceived school administrators and teachers as unresponsive and not understanding of the complexity and severity of their child's health condition.

They [teachers] never think a child's serious. I see that all the time. Like when a child gotta go to the bathroom, they don't take them serious. And if he was – like I

said having an attack, some teachers don't take him serious. They be thinking that he's playing. He's joking. (Participant A)

I had one teacher that didn't [understand]. That's when [child's name] went and told her she was sick, she didn't feel good. She [teacher] told her, "Go back to your seat." So she's smart. She goes in the bathroom and called me on her cell phone. She said, "Ma, you need to come up here. I'm feeling really weird." I went up there and that's what it was. She was going to have an asthma attack. (Participant F)

I'm pretty much worried because a lot of people would take it [request for help] as a joke. And then of course it's becomes a conflict because now I'm upset...I expect them to do better but they don't, and it's more so the teachers than it is the nurse... If [child's name] says "Hey I need to go to the nurse." The teachers like 'Oh no that can wait.' And that becomes frustrating for me because she can't wait. But it seems like the staff is not fully aware or is like maybe to them it's an interruption for all of the other students (Participant D)

Only one mother described positive relationships with teachers yet cautioned that most were not cognizant of asthma triggers or how to manage an acute exacerbation.

I think the teachers and everybody at the schools are doing their part.... But I don't know if they [teachers] know how it affects their asthma. Like I said, they can only tell if a child is not feeling good, then they'll send them to the nurse's office. (Participant K)

Sub-Theme: Recommendations to Improve Asthma Care in the School—In the interview process, participants were asked to nominate strategies to improve school-based management of their child's asthma. Recommendations were diverse in scope and emphasized the need for: (a) increased asthma knowledge among teachers and school staff, (b) policies allowing for self-carry of asthma medications, (c) enhanced school environmental control measures to reduce trigger exposures, (d) greater trust in children when they express need for medicine, and (e) increased screening and monitoring of their child's asthma.

The nurse has to have it [inhaler], but like I told him, "Keep it in your pocket," because half the time, the nurse is not even there. You never know when your child's gonna have a asthma attack... They should be able to wear it [inhaler] around their neck, keep it in their pocket. They should be able to have it. (Participant A)

[School administration] had [the children] in the trailer part of the school, and I think they said it was like mold and stuff in there...when she was home and on the weekend she wouldn't have it [symptoms]. As soon as she'd go to school, it was like something was triggering her asthma. (Participant C)

I think they [school administration] should have classes on asthma... They should know the symptoms. Have a poster up about the symptoms and stuff like that so they would know if they're having a episode or something because, like I say, some teachers don't know. (Participant L)

One day they could look fine, but when they check them, they could be wheezing... because like I said, you know, a parent is not always around their child when they're in school, so a parent doesn't know what's going on until last minute...it would be good if like every two weeks to a month that they check them to see if it's controlled. (Participant K).

Theme 3: Satisfaction with Asthma Healthcare Delivery

Sub-Theme: Characterization of an Ideal Encounter with Providers—As expected, interactions with healthcare providers were frequent in this group of caregivers of children with high ED utilization. In the process of the interview, participants were asked to identify provider competencies that strengthen confidence in their child's asthma care delivery. Their experiences indicate that mothers value: (a) asthma education that is reinforced in each clinical encounter, (b) comprehensive asthma assessments that include questions directed to their child, (c) tailored guidance on asthma management in the home, and (d) a caring attitude that supports their experience as a caregiver.

They [providers] always was trying to teach me something, like how to do certain things different, what to give her. Every time, they always was giving me some more knowledge of asthma. (Participant O)

They show us the right way to do the—to use the spacer. She [child] was using it wrong. They took time out to show us the importance of a spacer. (Participant C)

They [providers] asked all kinds of stuff. They asked me am I still smoking in the house. At that time, I didn't think that it would hurt if she was upstairs and I was down in the kitchen smoking. Oh no, they [providers] really got upset. They said, "Oh no, Mrs. [name], we can't have that." (Participant F)

She [healthcare provider] asks him [child] a lot of questions and stuff. (Participant A)

Say I call her [provider] about something and she's not in the office, she always return my calls. If I call her about something, she'll ask me in full detail what's the problem...She's just like she cares about them and she cares about their well-being. (Participant N)

Sub-Theme: Perceived Differences in Asthma Care Experiences across Contexts—For some caregivers, the nature and quality of healthcare encounters differed based on the context of practice. Asthma care received in the ED was sometimes portrayed more negatively compared to healthcare delivery in primary care or specialty care settings.

I really don't like going to the emergency room, only because it's different doctors and we don't know that doctor. I don't always trust every doctor, so that's very stressful for me, because sometimes I don't agree with some of the doctors calls. (Participant M)

Sometimes I feel like emergency room doctors, they try to push them out a little too soon. Like if he's still wheezing...there's been times I had to go home and bring him back [to ED]...The specialist helped because he actually put him – He's the

one that put him on the Flovent. He put him on the Flovent and he put him on another allergy med that was very helpful. (Participant N)

Sometimes I just feel like they brush it off or if they really don't know, they just discharge you because they really don't know and say follow up with your primary care. "We got him as stable as we can get him." (Participant I)

Sub-Theme: Caregiver Perspectives on Enhancing Asthma Healthcare

Delivery—Although parents generally expressed satisfaction in healthcare interactions, they also suggested several provider practice behaviors that could be improved. Specifically, participants recommended that providers: (a) be more responsive to parent concerns about a potential asthma diagnosis, asthma medication side effects, and the need for prescription refills, (b) increase child involvement in clinical encounters, and (c) show greater sensitivity to the emotional and financial stressors of the family.

When I found out my son had asthma for the first time, they [healthcare providers] were nonchalant at first because he was under nine months and he was wheezing... So I was like, "I'm not leaving until you give him a treatment." When they gave him his treatment, then they understood that it cleared up from the treatment. So that's when they found out that he had asthma. (Participant L).

If I could give training to a doctor, I would say get to know the patient first not just the parent. I would say talk to the child, ask them how they're feeling, ask them how would they, how do they feel, are they even aware of why they take medication?...So I would say if they could train in that, getting to know their patient first, spend a little bit more time with their patient versus just an appointment where you come in, it's paperwork, questionnaires and things that's all of the same, it would be a little bit more easier for the child. (Participant D)

I would want them to let me know like is it different medications? Instead of using the strong ones, is it less strong medications that can control it instead of using the real strong, strong ones and stuff like that? (Participant L)

I get that they feed the kids [in the hospital], but they should have to give for single parents, like food. I guess sometimes they give us drinks, but like half the time people don't have money to buy food. (Participant K)

Make the patients feel more like family instead of what they are, patients...we go in [to primary care], pass the security guard, and then you go into the med care area. Then after that, you're rarely greeted. So you just feel like okay I'm here at the doctors' office instead of okay I'm really relaxed here. You become more irritated because you don't know how long your wait's gonna be or whether they even acknowledge that you're there. (Participant J)

Theme 4: Prevalent Psychological Distress

Sub-Theme: Fear and Frustration About Lack of Symptom Control—

Participating mothers consistently described a deep emotional impact of raising a child with high-risk asthma. Their reflections illuminate profound stress, chronic worry, and a

perceived lack of control in their efforts to manage their child's asthma. This chronic state of heightened alarm about their child's breathing negatively impacted their quality of life and was especially evident in social and employment restrictions.

The toughest part is, I think it's just not being able to control it. That's the toughest part because when you think you have it under control, when you give them something and you say, "Okay, that's gonna work," and it don't work, what's next? What to do? I rush her to the hospital. Every time I rush her to the hospital, they always say, "You just made it. Thank God. Good thing you brung her." (Participant O)

I have to constantly go back and forth and make sure his breathing is okay. That's the one thing I'm really worried about because when he's in his room by himself, I don't want him to not –stop breathing, you know? ... Like I cry and I have to cry while I'm trying to figure out what to do because it's like it is stressful. (Participant L)

I would say the hardest probably would be of course worrying...Because if I felt that everyone was aware or could take of her like I would, then I can go out and probably gain more finances on the weekend or I the evening or overnight. (Participant D)

If he's in school and if he's outside running around playing, will he go into an asthma attack...Because you feel like, I feel like nobody can watch him like I can. (Participant M)

It's a scary thing for a child to have [asthma] so you just worry if they're gonna be okay you know. Some kids die from asthma, so that's a worry that you have. (Participant N)

Sub-Theme: Financial Stress Accentuates Worry and Helplessness—As shown in Table 1, nearly all mothers were living in extreme poverty. The lack of resources and financial insecurity amplified their worry and feelings of distress in managing their child's asthma. The following exchange between a study team member and parent reflects this dynamic:

Interviewer: What is the toughest part of taking care of a child with asthma? Parent: When I don't have money to go to the clinic or to the emergency room and I don't have any medicine. Sometimes I ask people, "Can I borrow money?" in order to get it and stuff like that or I would limit my things that I had to do just in order as far as catching the bus because the medicine is like the same amount as riding the bus. It's like \$4.00... I will still have to limit my bus ride in order for me to have money to get inhalers and stuff like that. (Participant L)

Other participants similarly acknowledged how financial hardship and concerns about employment stability with a sick child exacerbated their daily life stress.

Mostly paying bills [is stressful]. Like, paying rent, that's difficult. And then I work, but like the money that I'm bringing home is really not covering it all, or my expenses...If she's very sick with asthma, and you have to take a couple days [off

of work] – she got sent to the emergency room, and they have to keep her, it's hard to have to take all them days off of work to try to take care of your sick child. It's very difficult because not only is it a stressing for your child, but then you got to wonder if you're going to have a job the next day. It's very stressful. (Participant K)

If you're a working parent, taking off can just be stressful. I'm lucky enough that they [employer] understand. But that doesn't have anything to do with missing a day's work of pay or whatever. (Participant B)

I've been at my job for 13 years. We don't get benefits, no nothing like that to that extent, so I work straight, straight, we don't get time-and-a-half, we don't get anything to that extent. So, if she gets sick I don't have off, you know what I mean. So, if she's in the hospital for three days, I'm off three days, three days of pay.... There was a time that she had an asthma attack and I was all the way out the door and it was, I was actually, literally, in a decision of I have to go to work or I'm gonna be fired. (Participant E)

Sub-Theme: Unmet Mental Health Needs—Given the study design, it was not surprising that the majority of participants described living with psychological distress. Their candid reflections depict unresolved anxiety, sadness, anger, and depression, as well as poor coping strategies, which all underscore the critical need for enhanced family-centered assessment and engagement in asthma care delivery.

I started getting anxiety thing when I'm stressed. I just started going through that. It's really weird– Talk to God. I say, “God, I'm giving this to you. I can't take it. I can't do it.”(Participant A)

I do suffer with depression now. I have to take medicine because I get anxious and depressed because it's a lot on you. So I see a therapist and a doctor to help me because when you're depressed, it messes with your body. So if they [children] come to me and I need to respond you gotta be able to jump up, and if you're depressed even though your mind is telling you to jump up your body is not allowing you to. You have to get up because this is a life or death matter...And then if they're really sick or if it's really a bad [allergy] season and you get anxious it doesn't make it better for you. (Participant I)

I smoke a lot of cigarettes. I get stressed out, the first thing I do is I get my purse and go outside and have a cigarette. That's not a good habit, but that's what I do... I suffer from post-traumatic stress disorder and depression and anxiety...I'm looking for a counselor. Right now I'm not in any counseling. (Participant M)

Even the mothers who were not categorized as having high levels depressive symptoms or life stress reported feeling overwhelmed at times, particularly during the early stages of their child's asthma diagnosis and treatment. This sub-group appeared to have developed effective coping mechanisms and social supports to help them process and successfully navigate stress over time, as illustrated by the following reflection:

I don't worry now because he's had it [asthma] since he was a baby. So now I know what to do to not be stressed. So it's just I don't know it's just life now. But at first,

it was very stressful... I just basically try not to let myself get stressed and, if I do, I just take a minute, breathe.... I mean I think everybody sometimes have their times when they're overwhelmed with life or things happen. So things can happen to make you sad or you know? But you just have to pull yourself out of it. (Participant N)

Discussion

A major finding to emerge from the interviews with impoverished caregivers of children who have frequent ED usage for asthma suggests that the psychological stress they experience is multifaceted in nature, deeply overwhelming, and difficult to eradicate. The extreme housing conditions that most families reside in is a major driver of their distress. Although home environmental control is a core component of pediatric asthma management recommended by the NAEPP guidelines (USDHHS, 2007), participating caregivers were generally unable to effectively control their child's environment and had to rely on landlords to address leaky roofs, moldy walls, and rodent infestation, which contributed to their distress and feelings of helplessness. Further, mothers highlighted the detrimental effects of neighborhood safety concerns, including violence and drug exposure, on their stress level. This relationship is noteworthy since neighborhood concerns may divert attention away from the child's asthma management (Coutinho, McQuaid, & Koinis-Mitchell, 2013). Our data also indicate significant financial concerns related to lack of parental capacity to pursue or maintain employment when the child is experiencing symptoms. The intensive monitoring and managing of the child's uncontrolled asthma symptoms required frequent visits with providers, leaving some mothers having to decide between receipt of hourly work wages or asthma care for the child. This vicious dilemma exacerbated the experience of psychological distress in caregivers.

The prevalence of self-reported unmet mental health needs is an alarming finding that negatively impacts both caregivers and their children. Previous research suggests that caregivers who are depressed or anxious may not be as attuned to the child's asthma symptomology, resulting in greater healthcare utilization and poorer child outcomes (Feldman et al., 2013; Otsuki et al., 2010; Pak & Allen, 2012). Although we purposively recruited caregivers with elevated life stress and depressive symptoms, earlier research with similar caregiver populations identified similarly high rates of psychological distress, with one third of low-income, inner-city caregivers experiencing clinically significant depressive symptoms based on standardized measures (Kub et al. 2017). The chronic nature of stress noted in this study underscores the need for family-centered models of asthma care delivery that are responsive to the caregiver's psychological state, the family's living circumstances, and the pervasive challenges associated with extreme poverty. Comprehensive assessments and case management services may both lessen the stress experienced by caregivers and lead to reduced asthma ED visits and hospitalizations.

Another notable finding from the interviews reveals complex relationships between caregivers and school-based staff in the shared responsibility of asthma management. Interactions with school nurses were generally positive and reassuring to mothers but most schools, particularly those located in under-resourced communities, lack full-time onsite

nurses to provide consistent asthma oversight that parents desire (Hanley Nadeau & Toronto, 2016; Lineberry & Ickes, 2015; McClanahan & Weismuller, 2015). Yet, research suggests when schools add full-time nurses to provide comprehensive education, care coordination, prevention and follow-up services, school absenteeism and ED visits for asthma decrease (Rodriguez et al., 2013). Increasing asthma education for school administrators and teachers was another common request made by caregivers in this study, most of whom perceived teachers and school staff as lacking sensitivity to the high acuity needs of their child with asthma (e.g. the potential for a rapid decline in a child with asthma symptoms). Asthma education interventions have shown some promise in advancing teacher knowledge (Kawatha & Tawalbeh, 2015) yet several barriers exist including ineffective communication across school staff and inadequate access to asthma medications (Cain & Resnick, 2016; Hanley Nadeau & Toronto, 2016). Additionally, participating parents expressed frustration with school-based indoor exposures needing remediation; however, schools in low-income communities may not have resources to adequately remove mold and other triggers.

In contrast, asthma management in healthcare settings was generally considered to be comprehensive, but context dependent. Recommendations to improve care reflect parents' desire for more family-centered health services in which providers acknowledge the stress associated with caring for a child with poorly controlled asthma, are sensitive to how poverty shapes asthma management in the home including the inability to relocate despite deplorable housing conditions, and increase engagement of the parent and child in clinical encounters. Although other research likewise found low provider engagement of children during asthma care visits (Carpenter et al., 2014), evidence suggests that caregiver and child outcomes, including quality of life and satisfaction with care, are enhanced with increased provider-child communication (Carpenter et al., 2013; Sleath et al., 2011).

Limitations

Study findings are to be interpreted with caution due to several methodological challenges. Only three of the twelve index participants (e.g., those with psychological distress) were reachable in the member-checking process. Although the presented study findings were consistent with their experiences, confidence in the themes and sub-themes generated in the analysis would be strengthened by member-checking with more participants. Also, findings may not be reflective of the broader population of caregivers of children with asthma. The sample was primarily comprised of low-income, inner-city mothers who self-reported high psychological distress. Experiences of asthma caregiving in the home and community may differ in families of higher socio-economic status or who reside in rural or suburban settings.

Despite these limitations, the study findings advance understanding of several less recognized aspects of asthma management for children and caregivers residing in extreme poverty. The chronicity and multi-faceted nature of stress experienced by caregivers, deplorable housing conditions with few opportunities for amelioration, and unmet mental health needs of caregivers are critical areas to screen for in clinical encounters. It is essential that providers identify these sources of stress, link families to community agencies for housing assistance and other psychosocial supports, and collaborate with school systems to improve school-based asthma management.

Acknowledgments

This study was funded by the National Institute of Nursing Research, National Institutes of Health (NIH), with the grant number R01 NR013486. The study is registered with ClinicalTrials.gov with number NCT01981564. This publication was made possible by the Johns Hopkins Institute for Clinical and Translational Research (ICTR) which is funded in part by Grant Number UL1 TR 000424-06 from the National Center for Advancing Translational Sciences (NCATS) a component of the National Institutes of Health (NIH), and NIH Roadmap for Medical Research. We thank the caregivers who participated in this research.

References

- Akinbami LJ, Moorman JE, Garbe PL, Sondik EJ. Status of childhood asthma in the United States. 1980-2007. *Pediatrics*. 2009; 123(Suppl 3):S131-145. [PubMed: 19221156]
- Archibald MM, Caine V, Ali S, Hartling L, Scott SD. What is left unsaid: An interpretive description of the information needs of parents of children with asthma. *Research in Nursing and Health*. 2015; 38:19-28. [PubMed: 25557981]
- Authors. The influence of community violence and protective factors on asthma morbidity and healthcare utilization in high-risk children. *Journal of Urban Health*. 2014; 91(4):677-689. DOI: 10.1007/s11524-014-9883-6 [PubMed: 24889008]
- Authors. Stress and quality of life in urban caregivers of children with poorly controlled asthma: A longitudinal analysis. *Journal of Pediatric Health Care*. 2015; 29(6):536-546. DOI: 10.1016/j.pedhc.2015.04.018 [PubMed: 26036621]
- Authors. Characterization of stress in low-income, inner-city mothers of children with poorly controlled asthma. *Journal of Urban Health*. 2017a; epub ahead of print. doi: 10.1007/s11524-017-0162-1
- Authors. Factors associated with poor controller medication use in children with high asthma emergency department use. *Annals of Allergy, Asthma & Immunology*. 2017b; 118(4):419-426. DOI: 10.1016/j.anai.2017.01.007
- Borowsky B, Little A, Cataletto M. Determining the relative burden of childhood asthma at the local level by surveying school nurses. *Pediatric Allergy, Immunology, and Pulmonology*. 2013; 26:76-80.
- Bruzzesse JM, Stepney C, Fiorino EK, Bornstein L, Wang J, Petkova E, Evans D. Asthma self-management is sub-optimal in urban Hispanic and African American/black early adolescents with uncontrolled persistent asthma. *Journal of Asthma*. 2012; 49:90-97. [PubMed: 22149141]
- Cain A, Reznik M. Asthma management in new york city schools: A classroom teacher perspective. *Journal of Asthma*. 2016; 53(7):744-750. DOI: 10.3109/02770903.2015.1135946 [PubMed: 27031532]
- Camacho-Rivera M, Kawachi I, Bennett GG, Subramanian SV. Associations of neighborhood concentrated poverty, neighborhood racial/ethnic composition, and indoor allergen exposures. *Journal of Urban Health*. 2014; 91:661-676. [PubMed: 24771244]
- Carpenter DM, Ayala GX, Williams DM, Yeatts KB, Davis S, Sleath B. The relationship between patient-provider communication and quality of life for children with asthma and their caregivers. *Journal of Asthma*. 2013; 50(7):791-798. DOI: 10.3109/02770903.2013.808347 [PubMed: 23730868]
- Carpenter DM, Stover A, Slota C, Ayala GX, Yeatts K, Tudor G, et al. Sleath B. An evaluation of physicians' engagement of children with asthma in treatment-related discussions. *Journal of Child Health Care*. 2014; 18(3):261-274. DOI: 10.1177/1367493513489780 [PubMed: 23818146]
- Clawson AH, Borrelli B, McQuaid EL, Dunsiger S. The role of caregiver social support, depressed mood, and perceived stress in changes in pediatric secondhand smoke exposure and asthma functional morbidity following an asthma exacerbation. *Health Psychology*. 2016; 35:541-551. [PubMed: 26867039]
- Clouteir MM. Considerations in culturally directed asthma disease management programs. *Disease Management Health Outcomes*. 2008; 16:95-105.

- Coutinho MT, McQuaid EL, Koinis-Mitchell D. Contextual and cultural risks and their association with family asthma management in urban children. *Journal of Child Health Care*. 2013; 17(2):138. [PubMed: 23455872]
- Feldman JM, Acosta Pérez E, Canino G, McQuaid EL, Goodwin RD, Ortega AN. The role of caregiver major depression in the relationship between anxiety disorders and anxiety attacks in island Puerto Rican youth and young adults. *Journal of Nervous and Mental Disease*. 2011; 199:313–318. [PubMed: 21543950]
- Feldman JM, Steinberg D, Kutner H, Eisenberg N, Hottinger K, Sidora-Arcoleo K, Warmna K, Serebrisky D. Perception of pulmonary function and asthma control: The differential role of child versus caregiver anxiety and depression. *Journal of Pediatric Psychology*. 2013; 38:1091–1100. [PubMed: 23873703]
- Hanley Nadeau E, Toronto CE. Barriers to asthma management for school nurses. *Journal of School Nursing*. 2016; 32(2):86. [PubMed: 26656476]
- Kieckhefer GM, Ratcliffe M. What parents of children with asthma tell us. *Journal of Pediatric Health Care*. 2000; 14:122–126. [PubMed: 10823971]
- Kub J, Bellin MH, Butz A, Elizabeth Bollinger M, Lewis-Land C, Osteen P. The chronicity of depressive symptoms in mothers of children with asthma. *Western Journal of Nursing Research*. 2017; 193945917705858-193945917705858. doi: 10.1177/0193945917705858
- Lang JE, Dozor AJ, Holbrook JT, Mougey E, Krishnan S, Sweeten S, Wise RA, Teague G, Wei CY, Shade D, Lima JJ. Biologic mechanisms of environmental tobacco smoke in children with poorly controlled asthma: results from a multicenter clinical trial. *Journal of Allergy and Clinical Immunology: In Practice*. 2013; 1(2):172–180. [PubMed: 24565456]
- Laster N, Holsey CN, Shendell DG, McCarty FA, Celano M. Barriers to asthma management among urban families: Caregiver and child perspectives. *Journal of Asthma*. 2009; 46:31–739.
- Lim J, Wood BL, Miller BD, Simmens SJ. Effects of paternal and maternal depressive symptoms on child internalizing symptoms and asthma disease activity: Mediation by interparental negativity and parenting. *Journal of Family Psychology*. 2011; 25:137–146. [PubMed: 21355653]
- Lineberry MJ, Ickes MJ. The role and impact of nurses in American elementary schools: A systematic review of the research. *Journal of School Nursing*. 2015; 31(1):22–33. [PubMed: 24972802]
- Martin MA, Thomas AM, Mosnaim G, Greve M, Swider SM, Rothschild SK. Home asthma triggers: Barriers to asthma control in Chicago Puerto Rican children. *Journal of Health Care for the Poor and Underserved*. 2013; 24:813–827. [PubMed: 23728047]
- McClanahan R, Weismuller PC. School nurses and care coordination for children with complex needs: An integrative review. *Journal of School Nursing*. 2015; 31(1):34–43. [PubMed: 25266887]
- Normansell R, Kew KM, Stovold E. The Cochrane Database of Systematic Reviews. 2017; 4:CD012226.doi: 10.1002/14651858.CD012226.pub2 [PubMed: 28417456]
- O'Byrne PM, Pedersen S, Schatz M, Thoren A, Ekholm E, Carlsson LG, Busse WW. The poorly explored impact of uncontrolled asthma. *Chest*. 2013; 143:511–523. [PubMed: 23381316]
- Otsuki M, Eakin MN, Arceneaux LL, Rand CS, Butz AM, Riekert KA. Prospective relationship between maternal depressive symptoms and asthma morbidity among inner-city African American children. *Journal of Pediatric Psychology*. 2010; 35(7):758–767. DOI: 10.1093/jpepsy/jsp091 [PubMed: 19850709]
- Padgett, D. *Qualitative methods in social work research*. 2nd ed. Thousand Oaks, CA: Sage Publications; 2008.
- Pak L, Allen PJ. The impact of maternal depression on children with asthma. *Pediatric Nursing*. 2012; 38:11–19. 30. [PubMed: 22474854]
- Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Services Research*. 1999; 34:1189–1208. [PubMed: 10591279]
- Pinnock H, Parke HL, Panagioti M, Daines L, Pearce G, Epiphaniou E, Bower P, Sheikh A, Griffiths CJ, Taylor SJ. PRISMS and RECURSIVE groups. Systematic meta-review of supported self-management for asthma: A healthcare perspective. *BMC Medicine*. 2017; 15:64. [PubMed: 28302126]
- Radloff LS. The CES-D scale: A self report depression scale for research in the general population. *Applied Psychological Measurements*. 1977; 1:385–401.

- Riera A, Ocasio A, Tiyyagura G, Krumeich L, Ragins K, Thomas A, et al. Vaca FE. Latino caregiver experiences with asthma health communication. *Qualitative Health Research*. 2015; 25(1):16–26. [PubMed: 25185159]
- Rodriguez E, Rivera DA, Perlroth D, Becker E, Wang NE, Landau M. School nurses' role in asthma management, school absenteeism, and cost savings: A demonstration project. *Journal of School Health*. 2013; 83(12):842–850. [PubMed: 24261518]
- Rydström I, Dalheim-Englund AC, Segesten K, Rasmussen BH. Relations governed by uncertainty: Part of life of families of a child with asthma. *Journal of Pediatric Nursing*. 2004; 19:85–94. [PubMed: 15077206]
- Sampson NR, Parker EA, Cheezum RR, Lewis TC, O'Toole A, Zuniga A, Patton J, Robbins TG, Keirns CC. "I wouldn't look at it as stress": Conceptualizations of caregiver stress among low-income families of children with asthma. *Journal of Health Care for the Poor and Underserved*. 2013; 24:275–288. [PubMed: 23377734]
- Searle A, Jago R, Henderson J, Turner KM. Children's, parents' and health professionals' views on the management of childhood asthma: A qualitative study. *NPJ Primary Care Respiratory Medicine*. 2017; 27(1):53–53. DOI: 10.1038/s41533-017-0053-7
- Shalowitz MU, Berry CA, Quinn KA, Wolf RL. The relationship of life stressors and maternal depression to pediatric asthma morbidity in a subspecialty practice. *Ambulatory Pediatrics*. 2001; 1:185–193. [PubMed: 11888399]
- Sleath B, Ayala GX, Washington D, Davis S, Williams D, Tudor G, et al. Gillette C. Caregiver rating of provider participatory decision-making style and caregiver and child satisfaction with pediatric asthma visits. *Patient Education and Counseling*. 2011; 85:286–289. [PubMed: 20971603]
- Tibosch MM, Verhaak CM, Merkus PJ. Psychological characteristics associated with the onset and course of asthma in children and adolescents: A systematic review of longitudinal effects. *Patient Education & Counseling*. 2011; 82:11–19. [PubMed: 20409670]
- Tumiel-Berhalter L, Zayas LE. Lay experiences and concerns with asthma in an urban Hispanic community. *Journal of the National Medical Association*. 2006; 98:875–880. [PubMed: 16775908]
- Ungar WJ, Cope SF, Kozyskyj A, Paterson JM. Socioeconomic factors and home allergen exposure in children with asthma. *Journal of Pediatric Health Care*. 2010; 24:108–115. [PubMed: 20189063]
- U.S. Department of Health and Human Services. The National Asthma Education and Prevention Program. Expert Panel Report 3 (EPR3): Guidelines for the Diagnosis and Management of Asthma. 2007 NIH publication No. 70-4051, August 2007.
- Walker JL. The use of saturation in qualitative research. *Cardiovascular Nursing*. 2012; 22:37–46.
- Welsh EJ. Home-based educational interventions for children with asthma. *Cochrane Database of Systematic Reviews*. 2014; (9)doi: 10.1002/14651858
- Zhang Q, Lamichhane R, Diggs LA. Disparities in emergency department visits in American children with asthma: 2006-2010. *Journal of Asthma*. 2016 Nov.23:1–8. Epub ahead of print.
- Searle A, Jago R, Henderson J, Turner KM. Children's, parents' and health professionals' views on the management of childhood asthma: A qualitative study. *NPJ Primary Care Respiratory Medicine*. 2017; 27:53.doi: 10.1038/s41533-017-0053-7

Table 1
Caregiver Socio-Demographics and Child Asthma Health Status at 12-month Follow-up (N=15)

	CES-D Score	Daily Life Stress	Family Income Baseline	Child Asthma Severity at Baseline	ED Visits/ 3Months	Symptom Days/2 weeks	Symptom Nights/ 4 Weeks	Asthma Control Level
Participant A	21	10	30-39,000	Mild persistent	2	14	30	NWC
Participant B	8	9	30-39,000	Moderate Persistent	1	14	4	VPC
Participant C	2	8	20-29,000	Mild persistent	0	1	0	VPC
Participant D	17	8	10-19,000	Moderate Persistent	1	14	7	VPC
Participant E	12	10	20-29,000	Severe Persistent	1	14	30	VPC
Participant F	37	10	10-19,000	Moderate Persistent	0	2	3	VPC
Participant G	0/0	2	Refused	Moderate Persistent	0	0	0	NWC
Participant H	13	7	20-29,000	Severe Persistent	2	2	2	NWC
Participant I	20	10	10-19,000	Moderate Persistent	2	14	30	VPC
Participant J	16	7	Refused	Severe Persistent	0	14	14	NWC
Participant K	27	9	10-19,000	Mild Persistent	0	0	2	NWC
Participant L	19	9	< 10,000	Moderate Persistent	1	14	30	VPC
Participant M	15	9	10-19,000	Mild Persistent	0	2	30	NWC
Participant N	5	3	20-29,000	Severe Persistent	0	14	15	NWC
Participant O	4	1	10-19,000	Moderate Persistent	1	2	2	VPC

/ A score of 16 or higher on the 20-item Center for Epidemiologic Studies-Depression Scale (CES-D) reflects clinically significant depressive symptoms (Radloff, 1977). Participants reported their perceived level of daily life stress on a scale of 0-10 with "0" defined as no stress at all to "10" reflecting the highest level of stress. A daily stress score in the range of 6-7 is moderate stress and above 8 is high stress. Asthma severity assessed at Baseline only. Asthma control level was ascertained using national guidelines (USDHHS, 2007): NWC=Not well controlled; VPC=Very Poorly Controlled.

Table 2
List of Themes and Sub-Themes

THEME 1: Deplorable Housing Conditions
<u>Sub-Theme: Rodent Infested and Moldy Dwellings</u>
<u>Sub-Theme: Lack of Responsiveness from Landlords</u>
<u>Sub-Theme: Few Options for Change</u>
THEME 2: Allies and Adversaries in School-based Asthma Management
<u>Sub-Theme: Caregivers Trust and Collaborate with School Nurses</u>
<u>Sub-Theme: Lack of Teacher Awareness and Sensitivity to Child's Asthma</u>
<u>Sub-Theme: Recommendations to Improve Asthma Care in the School</u>
THEME 3: Satisfaction with Asthma Healthcare Delivery
<u>Sub-Theme: Characterization of an Ideal Encounter with Providers</u>
<u>Sub-Theme: Perceived Differences in Asthma Care Experiences across Contexts</u>
<u>Sub-Theme: Caregiver Perspectives on Enhancing Asthma Healthcare Delivery</u>
THEME 4: Prevalent Psychological Distress
<u>Sub-Theme: Fear and Frustration About Lack of Symptom Control</u>
<u>Sub-Theme: Financial Stress Accentuates Worry and Helplessness</u>
<u>Sub-Theme: Unmet Mental Health Needs</u>