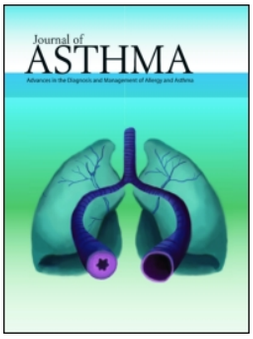

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Situating household management of children's asthma in the context of social, economic, and environmental injustice

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ABSTRACT

Background: Structural determinants of health are social, economic, and environmental forces that generate unequal opportunities for resources and unequally distribute exposure to risk. For example, economic constraint, racial discrimination and segregation, and environmental injustice shape population-level asthma prevalence and severity. Structural determinants are especially relevant to consider in clinical settings because they affect everyday household asthma management.

Objective: To examine how structural determinants shape everyday household management of pediatric asthma and offer a framework for providers to understand asthma management in social context.

Design: Qualitative interviews of caregivers for children with asthma.

Participants: Participants included 41 caregivers in two U.S. cities: St. Louis, Missouri ($n = 25$) and Gainesville, Florida ($n = 16$). Most caregivers were women (83%), Black (73%) and/or had low socioeconomic status (SES; 78%). Caregivers cared for children with asthma aged 0–4 (32%), 5–11 (68%) and 12–17 (54%).

Approach: We carried out narrative interviews with caregivers using an adapted McGill Illness Narrative Interview and using qualitative analysis techniques (e.g. inductive and deductive coding, constant comparison).

Key Results: Caregivers highlighted three ways that structural determinants complicated asthma management at home: 1) housing situations, 2) competing household illnesses and issues, and 3) multi-household care.

Conclusions: By connecting social, economic, and environmental injustices to the everyday circumstances of asthma management, our study can help providers understand how social contexts challenge asthma management and can open conversations about barriers to adherence and strategies for supporting asthma management at home. We offer recommendations for medical system reform, clinical interactions, and policy advocacy.

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Introduction

A challenge for pediatric asthma clinicians is attending to the social and environmental contexts that affect their patients' asthma. In the U.S., asthma affects approximately 6 million children. Asthma prevalence is higher among children living below the federal poverty line and among Non-Hispanic Black children (1), particularly in urban settings (2,3). These inequities originate from structural determinants: the social, political, and economic forces that generate unequal opportunities for resources (4). Known structural determinants of asthma risk and outcomes include economic constraint (5), racial discrimination and segregation (6,7), and environmental injustice (8,9). Pathways include housing (10,11), neighborhood contexts (12), psychosocial stress (13), and pollution (14,15). Contextual factors (e.g. residential crime rates (16), inconsistent insurance coverage (17), maternal or family stress (18,19), and financial and other constraints (17,20)) also affect asthma treatment adherence (21,22).

It is critical to understand how structural determinants shape care at the household level (23–25).

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Without such understanding, treatment plans may be untenable, miss important issues that affect asthma control, or lead physicians to blame caregivers for their (in)action (even unintentionally) (26,27). Thus, the objective of our study is to examine how structural determinants shape everyday household management of pediatric asthma and offer a framework for providers to understand asthma management in social context. In this article, we report on qualitative, narrative interviews with predominantly low-income caregivers of children with asthma, which were part of a larger, two-phased, mixed-methods (qualitative, ethnographic, quantitative) and multi-sited study (St. Louis, Missouri and Gainesville, Florida) on asthma caregiving in context.

Structural determinants of asthma in St. Louis and Gainesville

Historical and present-day processes in St. Louis and Gainesville contribute to social, economic, and environmental injustices that affect the health of residents in both cities. In St. Louis, decades of "redlining," restrictive housing covenants, and urban disinvestment have resulted in a hyper-segregated North-South divide (28) characterized by stark differences in median income, poverty rates, and life expectancy (29–31), and increased exposures to poor housing conditions, high-stress environments, and environmental risks for asthma (e.g. mold, lead, and air pollution) (32). Gainesville is also economically and racially segregated (33). Black families of low economic status disproportionately occupy distinct geographical areas in Gainesville (e.g. East Gainesville). These areas lack access to basic needs, adequate public transportation, and primary care facilities. In St. Louis and Alachua county (where Gainesville is located), 58.2% and 52% of children are on Medicaid respectively (34,35). Since 2016, national and state policy decisions, including a failure to expand Medicaid, have resulted in a three-fold increase in uninsured rates for children younger than 6 years old in Missouri and Florida (36).

In both cities, such injustices affect asthma. Between 2010–2015 in St. Louis, rates of asthma-related emergency department (ED) visits were 8.5 times higher for Black residents than White residents (37), and a recent geographic information system study located every "hotspot" for asthma in predominantly Black North St. Louis (30). Similarly, investigators identified the greatest pediatric asthma hotspot in the low-income area of East Gainesville (LeFave, 1/8/20, personal communication). In Alachua county, age-adjusted asthma-related hospitalization rates were nearly three times higher and ED visits were six times higher for Black residents than for White residents in 2018 (38). Although the effects of social, economic, and environmental injustices on asthma outcomes are apparent, the implications of these broader structural determinants for everyday household asthma management activities remain unknown and are the focus of our study. We carried out our research in these two regions because the economic and racial segregation identified in St. Louis and Gainesville is more the norm than the exception across the U.S. In addition, a comparative approach to asthma increases the research generalizability to other cities and regions.

Methods

After approval from the university review boards, we recruited participants via several strategies, including community recruitment experts, research participant registries, in person outreach, and posting flyers in public locations. Interested individuals were screened by phone for eligibility: age $\geq$ 18, caring for a child ($<$ 18) with asthma, and speaking English. We added eligibility criteria for socio-economic status (SES) after beginning recruitment. Forty-one caregivers participated (Table 1) and received $50 gift cards for participation.

Two interviewers (JH, JM, RF, DF) in each location conducted one-hour, audio-recorded, face-to-face interviews between December 2018 and May 2019. We based our interview guide on the McGill Illness Narrative Interview (MINI) (39). We adapted the MINI to elicit narratives about asthma management, exacerbations, treatment, and the effects of asthma on everyday life. Our thematic data analysis included initially identifying overarching themes in each interview and making connections among these themes as we continued interviewing. After uploading transcribed and de-identified transcripts into NVivo 12, we constructed a thematic codebook based on our observational notes, memo-ing, and transcript review. We double-coded all transcripts, and discussed discrepancies. To assist interpretation, we compiled summaries that allowed us to examine caregivers' narratives as a whole and compare the narratives with our themes. We assigned caregivers and children pseudonyms for interpretation and reporting.

We used several strategies to ensure rigor (40): (1) purposeful sampling, including adjusting eligibility criteria; (2) in-depth interviews based on the MINI guide and adapted by researchers with expertise in

Table 1. Participant Characteristics ($N = 41$).

Caregivers	N (%)
Site	
Gainesville, Fl.	16 (39)
St. Louis, Mo.	25 (61)
Gender	
Female	34 (83)
Male	7 (17)
Age	
18–25	2 (5)
26–30	2 (5)
31–35	10 (24)
36–40	6 (15)
41–45	11 (27)
46–50	8 (20)
50≤	2 (5)
Racial background*	
Black/AA	30 (67)
White	11 (24)
Asian	1 (2)
AI/AN	3 (7)
Economic-status†	
Low	32 (78)
Not-low	9 (22)
Insurance	
Private-Employer paid	7 (17)
Private-marketplace	2 (5)
Medicaid	29 (70)
No insurance	1 (2)
Did not state	1 (2)
Education	
Graduate, professional, or bachelor's degree	11 (27)
Associate's degree or vocational/technical school	11 (27)
High school degree or equivalent	14 (34)
Less than high school	5 (12)
Relationship to child	
Parent	39 (95)
Grandparent	2 (5)
Households	
Total household occupants	
2–3	13 (32)
4–6	23 (56)
7≤	5 (12)
Number of adults in household	
1	17 (42)
2	14 (34)
3≤	10 (24)
Asthma child age/s‡	
0–4	9 (22)
5–11	24 (59)
12–17	18 (44)

*Some participants identified with more than one category. One caregiver (2%) also identified as Hispanic ethnicity.
†Based on reported financial status and/or ability to pay an unexpected $500 medical bill not covered by insurance.
‡Calculated as percentage of households reporting at least one child with asthma in a given age bracket. 16 families (39%) included more than one child with asthma.

qualitative research and in clinical asthma care; (3) clarification of researcher biases and reflexivity using multiple modes including debriefings, field notes, and presentation of initial findings and interpretations in a full-team retreat. To check our framings and interpretations, we repeatedly discussed the disciplinary differences that shaped our perspectives (our team includes clinicians, anthropologists, and psychologists), and our personal experiences with caregiving, asthma, and structural advantages and disadvantages.

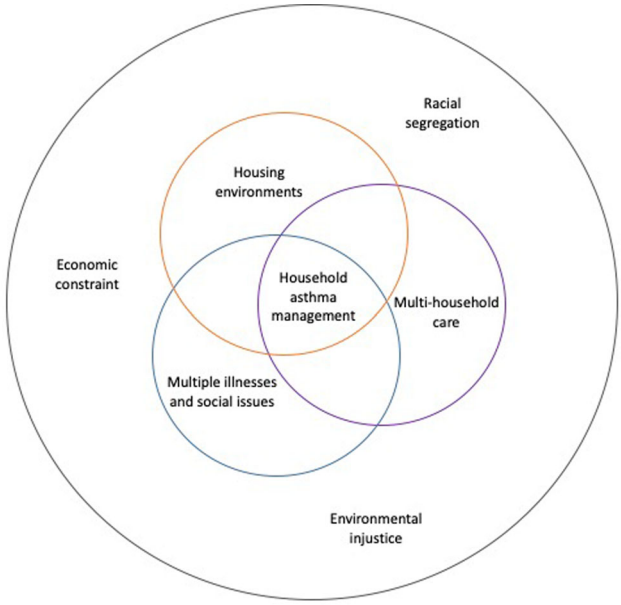

Figure 1. Conceptual framework for the structural determinants that influence household asthma management.

Results

Conceptual summary

We developed a conceptual model to visualize the three household-level situations that shaped caregivers' experiences and management of childhood asthma. As the primary respondents, we place the caregivers at the center of overlapping circles that represent the three situations: (1) housing environments, (2) multiple household illnesses and social issues, and (3) multi-household care. We further place these household situations within the broader context of economic constraint, environmental injustice, and racial segregation (Figure 1).

Housing environments

Caregivers described substantial effects of housing conditions on their children's asthma. They struggled with mold, dust, flaking paint, holes in the walls, pests, and other conditions of older, unmaintained housing. Caregivers also reported catastrophic events related to substandard conditions. For example, Latoya, a Black mother in St. Louis, described a neighbor's ceiling falling in, allowing rain to soak her apartment and cause mold. Building maintenance was too overwhelmed with other tasks to address the issue. Three participants reported house fires within the 1.5 years prior to our interviews. More common in older housing in low SES neighborhoods in the US (41), these house fires impacted asthma management through the smoke that remained in belongings, the

initial loss of asthma medications or nebulizers, and overall financial and social strain.

In such acute and persistent circumstances, caregivers had limited options: either invest effort into controlling what household environments they could, or move. Eliminating triggers entirely (e.g. mold removal) was often beyond family means or their control as renters (42). Efforts instead centered around environmental management activities (e.g. cleaning) that were energy intensive but not necessarily effective given the situation (e.g. a collapsed roof). One caregiver described buying "five bottles of mold spray" to combat the mold in her leaking apartment. Tasha, a Black and Native American mother in St. Louis, could not prevent the fire that destroyed their home, but she described cleaning her new rental for dust and pollen and her vigilant attempts to manage the air. She opened windows, used fans and vents, boiled "sage, onion, and garlic" to clean the air, and used humidifiers. Another caregiver, Ruth, a Black mother in St. Louis, cleaned her apartment with Lysol wipes her mother won at bingo because she could not afford a vacuum cleaner.

Factors in the wider community could also limit possibilities to escape indoor triggers. Caregivers mentioned a range of outdoor threats, including violent crime, tensions with neighbors, proximity to highways, and allergens (e.g. trees) that prompted them to keep children indoors. Nine-year-old Marcus "was suffocatin' every time he walked through the door [to his house]." However, his mother Amber, a Black woman in Gainesville, worried about letting him outdoors because "you can't even sit out the—out the door without a person starin' at you—sendin' their kids at you tryin' to fight your kids or somethin' like that."

Caregivers expressed desires to move because of their child's asthma but new homes could simply introduce new challenges to asthma management. Tuana, a Black mother in Gainesville, described how her previous moldy apartment had affected her five-year-old son Connor so badly that as "soon as we step in the house… he can't breathe." Recognizing that the home environment was untenable, she moved to a new apartment, only to find "we have roaches now," which made Connor cough. While evidence associates roaches with asthma (43), Tuana found that the chemicals she used to kill the roaches also triggered Connor's asthma. Tuana concluded, "I'm always in a win-lose situation."

Providers did not always recognize or understand the difficult circumstances and genuine efforts of caregivers and could assume non-adherence. Tuana was upset when her pulmonologist called social services with accusations of medical neglect because Connor was often sick, assuming Tuana "wasn't giving him his medicine." Tuana explained that when the social worker came to her house, "[she] seen my house was clean. My kids have food. They had places to sleep […] she was like, 'I don't understand why they called [social services]' … And that was that."

Consequently, Tuana no longer trusted Connor's pulmonologist, and disengaged from conversation about anything beyond Connor's symptoms and medications; as she explained: "I talk, but I don't talk." The pulmonologist's actions, though likely well intended, led to a breach of trust, closing future opportunities to understand Tuana's situation and support her asthma management efforts.

Multiple illnesses and social issues

Caregivers contextualized asthma management within a number of complex physical or social issues at the household, rather than individual level. Most caregivers disclosed at least one other health issue affecting the child with asthma or another household member, including autism, ADHD, complications from prematurity, Crohn's disease, sickle-cell, hydrocephaly, COPD, heart disease, dementia, and cancer. Caregivers managed these simultaneous health conditions in the context of other social issues, including drug addiction, family violence, incarceration, sexual assault, and caregivers' own health issues.

The demands of other illnesses and issues often swamped caregivers' ability to maintain asthma control. For example, Nicki, a Black mother in St. Louis, cared for five children. Nicki oriented her household management around protecting 11-year-old Nathan, who had ADHD and autism alongside asthma, from his older brother Liam following an attempted sexual assault. Both boys were now in therapy, but Nicki had to constantly watch Liam around Nathan. Nicki described how, after rushing Nathan to the hospital by ambulance for an asthma attack, the following month Liam body-slammed Nathan, returning him to the hospital for a neck-brace. Amongst these events, Nicki tried to remain vigilant about Nathan's asthma, but described how he would become distracted and remove the nebulizer mask while she was occupied with other family needs.

Competing family needs complicated household asthma management. Many caregivers were single parents of multiple children, some had additional care responsibilities for older family members, and some personally suffered from illness (e.g. asthma, epilepsy, cancers, mental health issues). Nicki described a life revolving around "picking up medicines, doctor's

appointments" for her five children, including ten appointments that week, all requiring travel via public transport and costing about $30 per day. Tuana, a single parent, described how she sometimes missed pulmonologist appointments for her five-year-old's severe asthma, because "when they set my appointments… we're always there for hours and hours on top of hours" preventing her from collecting her other four children from school. Monique, a Black mother in Gainesville, had epilepsy, anxiety, and migraines, and cared for her mother and her brother, who had suffered a stroke. Monique described her life as a "day-to-day situation" in which she had to "make sure we can pass this [crisis so] we can get to the next [one]." Consequently, her 14-year-old daughter Zoe's asthma was often a low priority for Monique.

While other family or caregiver illnesses could entail more contact with medical professionals, caregivers often prioritized pressing illnesses during doctor's visits. This prioritizing meant that asthma received attention only when symptoms were acute in an ED or urgent care center. While EDs often referred patients back to their primary care physicians following an exacerbation, once symptoms had subsided, caregivers again prioritized other issues at doctor visits. After Shonda, a Black mother in St. Louis, took four-year-old Jackson to the hospital three days in a row for exacerbations, the ED doctor told her to follow up with her primary care physician, but:

> "every time I go to my doctor's office, I forget to say it. I don't be writin' it down. A lotta times when I go to the doctor's office, I be havin' so much different problems that I wanna ask them, but then I forget to ask 'em really about that until I get home. Then I'm like, "Uh, too late."

However, providers who found opportunities to ask about asthma during non-asthma visits could improve asthma management. Liz, a Native American mother in Gainesville, described how 12-year-old Courtney's asthma was poorly controlled until "while she was being treated for her Crohn's disease, the doctor […] was like—ask questions about her asthma and stuff as well, and she was like realizin' it didn't sound like it was under control." That physician referred Courtney to a pulmonologist who prescribed controller inhalers that greatly improved her symptoms.

Multi-household care

The environment in which caregivers managed was often not *one* household, but several, either sequentially or simultaneously. Participants in Gainesville spoke of histories of living in several different states, and with different family members. In St. Louis, children also moved between multiple households. However, an intergenerational history of living in deprived and segregated areas of St. Louis and limited social and economic capital meant that even when they wished to, families often could not leave the area. Across sites, mobility disrupted relationships with medical providers, complicated insurance, and led to discontinuity of care. Multi-household living also required caregivers to negotiate children's asthma care in domestic spaces that were not their own, where they were not physically present, and with multiple caregivers.

Medicaid, unlike private insurance, helped families significantly with the cost of asthma medication. However, issues of cost and insurance coverage particularly appeared in relation to the mobility of family life. Insurance coverage limited the number of inhalers caregivers could fill. Lacking sufficient inhalers for all the spaces in which children's asthma was managed, caregivers and children had to remember to bring medication to their other residences. These additional burdens could lead to medication sharing or improvization with other medical techniques (e.g. using a grandparent's CPAP machine for a child's asthma symptoms).

Caring for children across multiple households required caregivers to give up control and hope that other caregivers and the child would appropriately manage the asthma. For example, 13-year-old Devonte spent whole summers at his grandparents' house, which meant that responsibility for his asthma management shifted entirely to a caregiver who was not the one who saw the physician. This redistribution of responsibility caused caregivers concern when co-caregivers had different views of and experiences with asthma. For example, Liz described how her daughter Courtney's father and stepmother:

> "wouldn't make sure she did her inhalers, and they wouldn't make sure she did her Flonase, and they wouldn't make sure she took her Singulair and she would come back and … she'd be struggling."

Caregivers also expressed desires to avoid conflict within family relationships. Denise, a Black mother in St. Louis, worried about the cigarette and cannabis smoke that her 16-year-old daughter Summer encountered when she moved in to assist her grandmother after frequent falls. Summer had experienced three asthma exacerbations within two months, but Denise had little control over the smoke, which came from a nephew under house arrest and also staying with his grandmother. Although Denise connected Summer's

wheezing symptoms to the smoking, she felt unable to address it with her nephew because:

> "Whatever happened to him in prison, he's a little … I don't want no conflict. He like to carry around guns and … I can't deal with him."

Other caregivers expressed worry that interceding about others' environments or caregiving would damage their relationships. For many, the interdependence among households and co-parenting demands required that they "say nothing" or develop alternative strategies such as increasing their child's medication upon return or handing their child responsibility for asthma management. Some families received support from school nurses who administered children's daily medication at school.

Discussion

This study traces the consequences of structural determinants of asthma to provide insights into household asthma management from the perspective of caregivers. We focus on three aspects of household circumstances that caregivers emphasized (Figure 1).

First, we identify the housing environment. Under the constraints of financial pressures and geographic residential segregation, caregivers expressed being trapped in unhealthy housing and in neighborhoods that worsened their children's asthma. Caregivers had little opportunity to move to neighborhoods and housing with better conditions, so they went to great lengths and spent substantial resources on managing their environments. *Physicians can use this information to acknowledge caregivers' situations and efforts, cultivate trust, and identify assistance.* Provider recognition of and empathy for caregiver situations could help caregivers trust providers. This recognition can lead to a positive cycle where caregivers are more open about barriers and stressors they face. Practitioners could familiarize themselves – perhaps with the assistance of social workers – with local resources to assist with unmet needs (44). Better-resourced primary care clinics could offer patient/family advocacy interventions (45).

Second, the same social and environmental injustices that produce asthma disparities also contribute to numerous other health inequalities (46,47). Caregivers identified that asthma was not the only or most important illness or issue they faced. The competing demands of other household issues meant that the child's asthma received attention primarily when children had symptoms or exacerbations, rather than the daily routine maintenance of the clinical ideal. *Physicians might proactively seek information about asthma and remain mindful that non-acute asthma checks may be deprioritized when patients seek care for other issues.* In the context of more acute health issues or exacerbations, caregivers and children may also view symptoms that indicate uncontrolled inflammation as normal or tolerable. Asking specific questions and continuing to follow NHLBI guidelines (48) for routine assessment of asthma control may help physicians identify needs that families themselves do not recognize.

Finally, a normative view of the family and household in which one main caregiver cares for one child in one house does not match reality for caregivers in our study. Caregivers managed their child's asthma across multiple households and with multiple caregivers, including children who cared for themselves or others. Distributed care is an unavoidable feature of interdependent households and represents, in part, a means of coping with economic insecurity, health needs of others, and acute crises (e.g. house fires). *Physicians might recognize the need to support and educate multiple caregivers, rather than assume that one caregiver bears sole responsibility.* Current health systems and policies likewise need to recognize such mobility and distributed care. For example, there is a need to increase the ability of various electronic medical record systems to communicate with each other (i.e. "interoperability") (49). This will benefit caregivers and children when they seek care at the emergency room or from other providers, and will also support children who may see providers with different caregivers and when living in different locations.

We acknowledge the limits on clinicians. All three categories we identified in our figure show that support is needed beyond the clinic. Making asthma care accessible before a crisis occurs, and outside of ED and urgent care settings, requires multiple strategies. Such strategies might include using mobile asthma vans, medico-legal partnerships (50), or community health workers (51–53). School nurses could also play a pivotal role in asthma management for families living in adverse circumstances (54); their long-term, on-site relationships with children and their families make them well-positioned to follow up on exacerbations that happen at school.

As with many conditions, emphasizing pharmaceutical responses in absence of addressing structural determinants can amplify disparities (55). Many environmental conditions that contribute to asthma disparities are largely unmodifiable through individual behavior—particularly in circumstances of economic

constraint—and require collective structural change (4,42). Macro-level processes (e.g. racial segregation, environmental injustice, and economic disadvantage) are currently under-recognized by asthma policies and guidelines. This lack of recognition constrains the actions of children, their caregivers, and providers. Providers might support their relevant organizations (e.g. the American Academy of Pediatrics) to advocate for local and national policy change directed at structural determinants, including more equitable housing (42), pollution (8,15), or public transit (30) policy.

Limitations

Interviewing only one caregiver per family narrows our understanding by excluding the views of other people who provide care in and across households. It also excludes children, who play roles in asthma management but whose involvement is underestimated by caregivers and physicians (56,57). Because all primary interviewers were white, nonwhite caregivers may have felt uncomfortable addressing certain issues that shaped asthma management, such as the extent of the racial injustices they experienced. Despite these limitations, our narrative interview methods provide insight into caregiving situations that is unavailable within the most commonly used approaches (e.g. quantitative, structured qualitative, focus group). This understanding helps identify implications for asthma care.

Conclusions

This study fills a critical gap in the literature by drawing together two bodies of research—the structural determinants of asthma disparities, and caregiver experiences with household asthma management—to illustrate the importance of understanding asthma management across multiple levels of analysis. Although these two areas are well researched separately, few studies have examined the ways broader structural determinants influence how caregivers manage care in households. Our findings show that, in such constrained circumstances, caregivers often had no easy solution to environmental circumstances known to make children sick or keep them unhealthy (4,10,42). Put simply, situations caused by structural forces require multi-level and structural solutions (24,30).

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Declaration of interest

The authors declare that they do not have a conflict of interest.

Compliance with ethical standards

Ethical approval was obtained from the Washington University School of Medicine and University of Florida Institutional Review Boards.

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