



The Diversity of Asthma Care Beliefs and Practices

The Findings of the
Asthma Caregivers and
Children Project

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- Asthma disproportionately impacts children who are Black and live in neighborhoods characterized by residential segregation, environmental injustices, and lack of medical providers.
- Asthma treatment in the U.S. largely focuses on self-management.
- However, high healthcare costs, long distances to healthcare providers, and inadequate insurance coverage make it challenging for people to have close relationships with doctors.

Diversity and Asthma

We want to expand our thinking of asthma-related diversity to include:

- How do caregivers think and feel about their child's asthma?
- How do these thoughts and feelings influence how they manage asthma?
- How do children themselves experience and manage asthma in their everyday lives?
- What challenges and opportunities do differences in opinions on asthma create?



We conducted our study in two cities marked by racism, poverty, and environmental injustices that shape asthma trends: Gainesville, FL and St. Louis, MO



Gainesville, Florida



St. Louis, Missouri



- 60 minute narrative interviews with caregivers of children with asthma
- In depth interviews with healthcare providers
- Household visits and online interviews with children
 - Zoom interviews after the onset of the COVID-19 pandemic

Caregivers

- 41 caregivers: 25 in St. Louis, 16 in Gainesville
- Most were women (83%), Black (80%), and/or had low incomes (78%)



Providers

- 12 providers: 7 in St. Louis, 4 in Gainesville
- Pediatricians, school nurses, pulmonologists, asthma coach, ER resident



Children

- 24 children: 10 in St. Louis, 14 in Gainesville
- 6-16 y/o, most were Black (71%) and boys (58%)



Findings

Healthcare providers, caregivers, and children can all have different views of what asthma management can and should involve.



Children's asthma was often undertreated

- Many of the children in our study had not received sufficient medical treatment for their asthma.
- Three types of disconnects that helped explain why children's asthma was undertreated:
 - System disconnects
 - Resources disconnects
 - Interpersonal disconnects





shifting posture

avoiding triggers

asthma controller medication

socioeconomic contexts

children's independence

negotiation

resting

controlling home environment

emotional management

preventive medication

bodily experiences

medication adherence

risk perception

social comparison

home remedies

symptom management

drinking water

allergies

breathing exercises

biomedical model of disease

Caregivers

Challenges with housing influenced how caregivers managed asthma



- Many caregivers and their families lived in housing conditions that made asthma worse.
- Families cared for asthma across several households
- Families dealt with multiple medical issues in the home at the same time.

Caregivers understood and made decisions about asthma based on comparisons to other people

- Caregivers compared their child's asthma with other people's asthma.
- Social comparisons influenced caregivers' thoughts, feelings, and decisions related to asthma



Caregivers and children used their bodies to understand asthma



- Caregivers and children experienced asthma at the same time as other bodily sensations.
- Severe symptoms of asthma were more noticeable than other features of asthma.
- Asthma was both physical and emotional.

Children



Children were central to asthma management

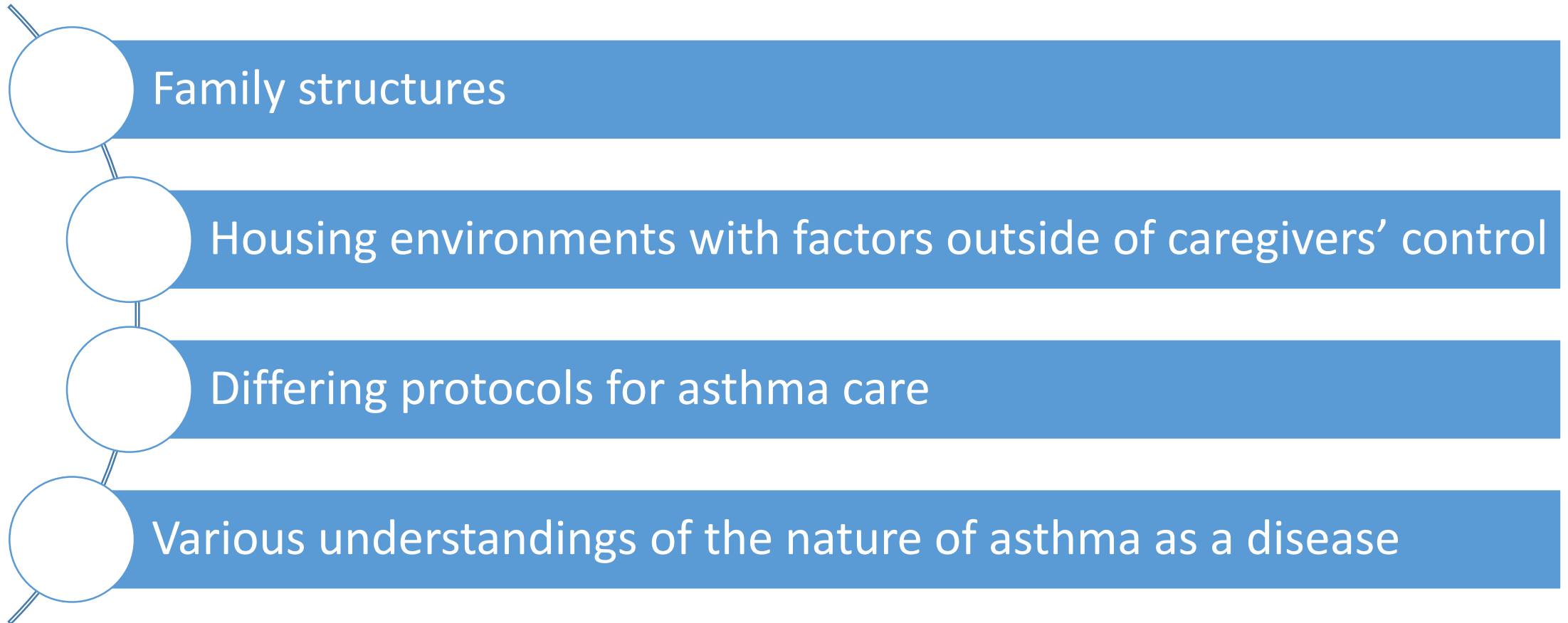
- Detecting and identifying symptoms of asthma
- Deciding when to slow down or take a break
- Bringing asthma medications when they left the house
- Remembering to take daily controller medications
- Avoiding triggers
- Using alternative strategies for relieving symptoms (for example, resting, calming, drinking water, stretching)

Children's asthma management strategies were often shaped by challenges outside of their control.

- School policies shaped children's access to inhalers.
- Children felt that their inhalers were important but also stressful.
- Children used water for diagnosing asthma, intervening in asthma symptoms, or as part of preventing asthma.



We must recognize diversity in:

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- Family structures
 - Housing environments with factors outside of caregivers' control
 - Differing protocols for asthma care
 - Various understandings of the nature of asthma as a disease

How can providers use this information?

Acknowledge that caregivers are living in challenging situations

Proactively seek information about the child's asthma

Affirm the individuality, ambiguity, and uncertainty of asthma

Acknowledge caregivers' asthma management practices

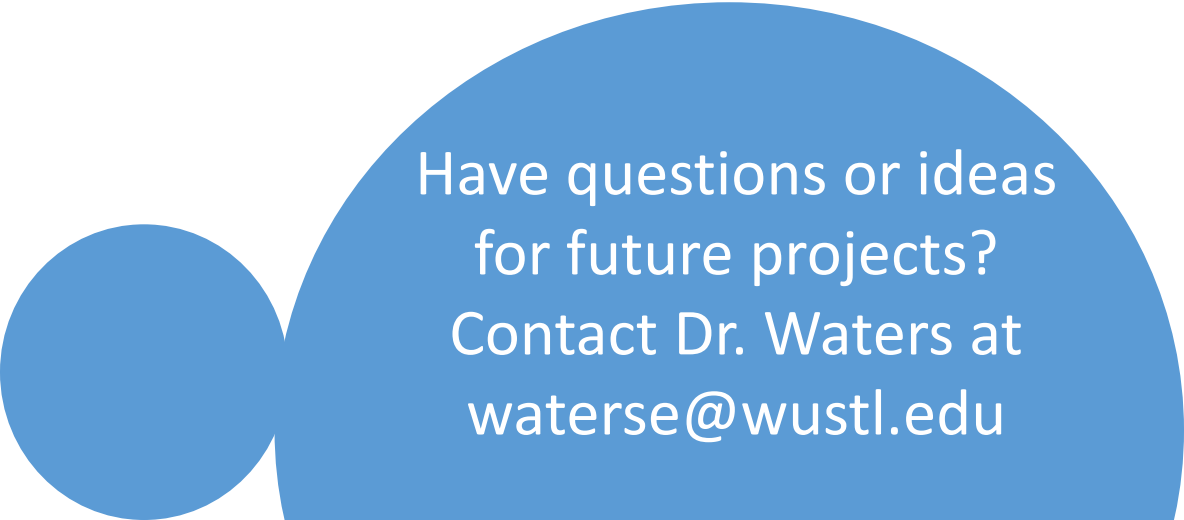
Validate children's roles in their own asthma management

Recognize the need to support and educate multiple caregivers

Support research on children's participation in their healthcare

Next Steps

- Recruiting providers, caregivers, and children for a community advisory board
- Intervention planning
- Disseminating results

Two overlapping blue circles of different sizes are positioned in the bottom right corner of the slide. The larger circle is partially behind the smaller one.

Have questions or ideas
for future projects?
Contact Dr. Waters at
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Published Works

Spray, J., Carter, C., Waters, E.A., Hunleth, J. 2021. "Not Breathing Easy: 'Disarticulated Homework' in Asthma Management." *Medical Anthropology Quarterly*. <http://dx.doi.org/10.1111/maq.12628>.

Hunleth, J., Spray, J., Ruiz, S., Maki, J., Fedele, D., Prabhakaran, S., Forsyth, R., et al. 2020. "Situating Household Management of Children's Asthma in the Context of Social, Economic, and Environmental Injustice." *Journal of Asthma*. <https://doi.org/10.1080/02770903.2020.1837159>.

Spray, J., Hunleth, J., Ruiz, S. Maki, J., Fedele D. A., Prabhakaran, S., Fectel, H., Shepperd, J. A., Bowen, D. J., Waters, E. A. (2022). How do embodied experiences of asthma influence caregiver conceptual models? *Social Science and Medicine*, 294:114706. doi: <https://doi.org/10.1016/j.socscimed.2022.114706>

Spray, J., & Hunleth, J. (2022). Breathing Together: Children Co-constructing Asthma Self-Management in the United States. *Culture, medicine and psychiatry*, 1–28. Advance online publication. <https://doi.org/10.1007/s11013-022-09766-5>

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Thank you!

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Funding: This research was funded by the National Heart, Lung and Blood Institute, which is part of the U.S. National Institutes of Health (Grant number R01 HL137680).

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