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
• 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
avoiding triggers
asthma action plan
shifting posture
risk perception
controller medication
socioeconomic contexts
children's independence
social comparison
negotiation
home remedies
symptom management
resting
controlling home environment
limiting physical activity
drinking water
allergies
emotional management
breathing exercises
biomedical model of disease
preventive medication
bodily experiences
medication adherence
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:

- 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

Have questions or ideas for future projects? Contact Dr. Waters at waterse@wustl.edu
Published Works


Scan here for community reports and publications:
Thank you!

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