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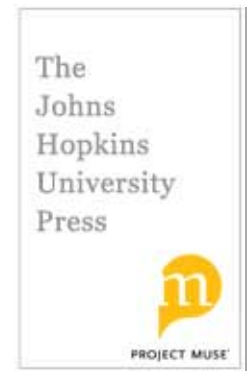
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## Using Concept Mapping to Explore and Engage Parent and Youth Residents of an Economically Underserved Minority Community around Children's Asthma

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### Abstract

**Background.** Asthma continues to disproportionately impact children living in economically underserved urban neighborhoods, and contributes to persistent racial and economic disparities in health. Furthermore, asthma is often exacerbated by the presence of social and environmental factors that are prevalent in, and sometimes particular to, these communities.

**Objectives.** The present study uses a community-based participatory research (CBPR) approach to explore and define the experience and issues around children's asthma in an economically underserved community. These findings will be used to inform the design of a community intervention.

**Methods.** Through a community and academic partnership called Healthy Living, Healthy Learning, Healthy Lives (HL3), we engaged neighborhood youth and adult residents (N = 21) in a concept mapping activity to identify triggers and health care-related factors that influence children with asthma.

**Results.** Findings highlight that the most important triggers of asthma included indoor and outdoor irritants and allergens, as well as violence and fear-related emotions. The most important factors perceived to influence the care of asthma included medical relievers such as asthma medication, appliances such as a humidifier, and supports for asthma like the school nurse. Differences between adults and youth perceptions of factors triggering and influencing asthma are highlighted.

**Conclusions.** Engaging community residents as experts provided a deeper understanding of the issues around children's asthma in the community, which can contribute to the design of a more effective intervention.

### Keywords

Children's health, asthma, community-based participatory research, CBPR, urban health, health disparities

Asthma continues to be an issue in many economically underserved communities where there is a concentration of poverty among children of color. Poor children are 1.5 times more likely than non-poor children to have been diagnosed with asthma, and a much higher percentage of non-Hispanic Black children are diagnosed with asthma (22%) than Hispanic (14%) and non-Hispanic White children (14%).<sup>1</sup> Asthma not only negatively impacts health, but is also related to increases in psychosocial stress exposures and

academic outcomes.<sup>2</sup> In particular, a 2008 study reported that 60% of children with asthma ages 5 to 17 reported at least one asthma-related absence from school.<sup>3</sup>

A growing body of literature acknowledges the social, structural, and environmental conditions that significantly influence the health and well-being of children with asthma. These conditions include access to medical care; physical and psychosocial environmental factors, including elevated exposure to chronic stressors like violence, property vacancy,

and abandonment; lack of local capacity to coordinate and deliver comprehensive asthma care; and limited capacity to identify and reach children who are most at risk.<sup>4–8</sup> These conditions are more prevalent in economically underserved communities, suggesting the need for targeting interventions that address contextual factors within these communities.

In addition to environmental exposures, psychosocial factors such as stress and anxiety have been found to complicate and exacerbate the care and management of asthma, specifically how well asthma is controlled and managed for individuals and children living with asthma.<sup>10,11</sup> The impact of stress on asthma may be greater and more direct than previously thought.<sup>8,12</sup> Psychological stress that is associated with community violence exposure and/or victimization has been linked to asthma.<sup>13–16</sup> Stressors in the home, such as family and relationship violence and economic stress are also associated with asthma.<sup>17,18,19–21</sup>

Several community-based asthma studies, such as the Inner-City Asthma Study, the Seattle-King County Healthy Homes Project, and the Harlem Children's Zone Asthma Initiative, revealed that environmental factors specific to low-income areas contributed to high asthma prevalence rates. These studies also reveal the potential for positive implications and impact of community-based asthma management and education solutions.<sup>22–25</sup>

Translating such research knowledge and experience into practice, however, remains a serious challenge given the complex nature of community settings and the lack of time traditionally taken to integrate interventions with existing organizations and leaders in the community. As Clark<sup>26</sup> explains, this persistent lack of effective translation of new knowledge about interventions into practice necessitates community-based solutions. She argues for a collaborative model of asthma management where children, parents and guardians, teachers, and health practitioners all share the responsibility of caring for children with asthma.<sup>26</sup>

#### USING CBPR TO ADDRESS CHILDREN'S ASTHMA

To inform and implement integrated community and clinical interventions to reduce asthma disparities, it is essential to understand and engage the expertise of youth and caregivers in the community. CBPR is a partnership approach to research guided by principles that respect and integrate

diverse expertise and promotes decision making that involves community members with organizational representatives, and researchers in all aspects of the research process.<sup>9</sup> Using a CBPR approach allowed us to build on existing relationships and community strengths to develop new knowledge around the specific social and environmental influences on childhood asthma with residents of an economically underserved community to inform interventions.<sup>9,27–30</sup>

The academic and community partnership applied the established principles of CBPR throughout the study. For example, the four principal investigators (PIs), including two academic PIs from the University of Pittsburgh (one in the School of Social Work and one in the School of Medicine) and two community PIs from the Homewood Children's Village, worked together to identify the topic of focus for this project. The topic of children's asthma was chosen as a priority community health topic owing to the strong community interest in addressing children's education, and the existing link between asthma and school absenteeism. The two elementary schools serving the community had among the highest chronic elementary absenteeism rates (missing  $\geq 18$  days of school) in the city of Pittsburgh, and the local high school (grades 6–12) had a chronic absenteeism rate of 58%.<sup>31</sup> Research between the academic and community partners revealed that asthma is the leading health-related cause for absenteeism,<sup>32</sup> leading the partnership to focus on children's asthma. In particular, we wanted to understand, document, and address the triggers for children with asthma in Homewood to inform targeted intervention and prevention efforts with residents of the community.

CBPR has been used to guide community-informed, culturally relevant research that may more effectively address social determinants of health, especially in economically disadvantaged and marginalized communities.<sup>23,5,29</sup> These studies highlight that an effective, community-based intervention strategy must speak to and reflect the needs and concerns of children, parents and guardians, and concerned community members who care for children. As part of our larger CBPR partnership to eliminate local disparities in childhood asthma, this study used concept mapping to engage residents in the process of identifying, defining, and prioritizing the social and environmental factors perceived to impact children with asthma, focusing specifically on the triggers and factors related to asthma care.

## METHODS

### Study Setting: Homewood

The present study takes place in Homewood, a 1-square-mile neighborhood located on the east end of the city of Pittsburgh. According to the most recent census,<sup>33</sup> Homewood's population of approximately 6,400 residents is overwhelmingly African American (94.1%) and socioeconomically disadvantaged. More specifically, 45% of Homewood's residents live below the federal poverty line, 72% of its approximately 2,000 children are being raised by single parents, and only 10% of residents 25 years or older have earned a bachelor's degree or more.<sup>33</sup> In addition to the individual- and family-level conditions that place children in Homewood at increased risk for asthma, the neighborhood has a number of environmental and contextual asthma risk factors. These risk factors include the age of Homewood's housing stock (e.g., the average property was constructed around 1920), and property vacancy and abandonment (e.g., 61% of Homewood's properties and land is vacant). Homewood also suffers from poor air quality with Pittsburgh's air quality being among the worst in the nation,<sup>34</sup> and high levels of pollution resulting from the intersection of a major bus transportation hub. Finally, Homewood has among the highest level of community violence in the city of Pittsburgh, with a murder rate eight times higher than the city overall.<sup>35</sup>

### Community and Academic Research Partnership

The HL3 Project is a partnership between the University of Pittsburgh's School of Social Work, School of Medicine, and the Homewood Children's Village, a nonprofit community-based organization that supports children and families who live, learn, and play in Homewood. Coming together to begin this project was a natural progression of relationships established over many years of previous collaboration between the PIs. Together, the PIs applied for and were awarded a grant from the National Institutes of Health's Institute on Minority Health and Health Disparities to begin the project.

The HL3 project used principles of CBPR to understand, investigate, and intervene in preventable factors that contribute to racial disparities in asthma among Homewood's children. Our goal was to document and conceptualize perceptions of community, school, and household factors impacting children with asthma who live, learn, and play in the neighborhood.

All research procedures and the study protocol were reviewed and approved by the University of Pittsburgh's Institutional Review Board (PRO13010601).

The research team included equal membership from the academic and community partners, which provided a balanced representation of both perspectives throughout the project. In addition to the four PIs, there were two study coordinators—one from the academic partner and one from the community partner—as well as additional staff members from the community partner and a graduate student and research associate from the academic partner. We conducted weekly meetings at the community partner's office to discuss and address the project design, outreach, implementation, and dissemination issues, as well as approved a conflict resolution plan to address any emergent issues of concern. In addition, we tapped into our teams' established relationships with additional community groups who worked with local children. Together, the research team was able to quickly learn and exchange new ideas for outreach, to engage relevant community residents in concept mapping, and to share our findings with the community.

### Participants

We used multiple strategies to recruit youth who have been diagnosed with asthma as well as the parents and guardians of children with asthma to participate in the study. Flyers were distributed in a variety of local neighborhood institutions (i.e., school, library, YMCA, and the community health clinic). However, the most effective recruitment occurred through the existing social and organizational connections of the Homewood Children's Village. Inclusion criteria for the study were adults who have children with asthma, or youth between the ages of 11 and 17 with asthma, who live, learn, or play in Homewood. The sampling strategy was one of convenience, in which we used the population to which we had access to identify the participants best able to address the topic of interest, and was not intended to generalize to the whole population.<sup>36</sup> Twenty-one participants (14 adults and 7 youth) were recruited through the existing community ties of the local elementary and high school, community partner agencies, and sports leagues. Participants were asked to attend three unique concept mapping sessions (explained in detail elsewhere in this article).

## Data Collection and Analysis Procedures

We used concept mapping to explore the issue of children's asthma. Concept mapping is a mixed methods approach that uses data that are collected with the community to identify, prioritize, and rank factors impacting children with asthma. More specifically, concept mapping involves three phases of data collection, and uses a series of multivariate analyses to group, weight, and examine comparisons and differences between participants' qualitative responses to a set of open-ended questions on a specific topic.<sup>37,38</sup>

All three concept mapping sessions took place at a local community center on a weekday evening, instead of at the university campus, to be more accessible and comfortable for participants. We provided food and drink, and had time at the beginning for everyone, including both participants and researchers, to eat and mingle. We encouraged participants to bring other family members, specifically younger children, and we offered child care for any younger children attending. The community partner took the lead in recruiting participants, securing the location, and arranging for dinner and child care to be available during the sessions. Both academic and community partners attended each concept mapping session.

Of 21 participants, 9 (approximately 43%) came to all three sessions, 7 (33%) came to two sessions, and 5 (24%) attended one session. Participants received a monetary incentive to attend each session in the form of a cash payment via a bank card (\$20). To encourage participation, we included an extra monetary incentive (\$20) if participants came to all three sessions. The community partner also had regular check-ins with participants, gave reminders, and helped arrange for transportation when necessary.

### Session 1: Brainstorming and Generation of Items

A "brainstorming" session of approximately 1.5 hours was the first step of the concept mapping process. For this session, participants were separated into a group of adults (largely parents) and a group of youth (aged 11–17). Led by a pair of individuals from the research team, including one community partner and one academic partner, participants were asked to address the following focus question: "In your opinion, what things influence your child's experience/ your experience with asthma?" Through open discussion, key terms were clarified for adult and youth participants; for example,

"things that influence" either positively or negatively could include a diverse range of social and environmental factors (objects, entities, situations, emotions, etc.) associated with the home, school, and community settings. All of the concepts or factors were generated organically by the participants themselves, with one exception. The adult group did not directly bring up the issue of violence, which research has shown to be tied to asthma.<sup>8,39–41</sup> Therefore, the facilitators probed for whether this was an issue for triggering asthma among their children. The adults noted that hearing gunshots caused panic, stress, anxiety, and fear, but that it did not necessary induce an asthma attack. Thus, the adults tied gunshots to anxiety, which was a trigger for asthma.

After the session, academic and community members of the research team worked together to consolidate the lists generated from each group's discussion into a single nonduplicative list of factors perceived to influence youth's experiences with asthma. For example, items such as "polluted air," "bad pollution days," and "smog" were consolidated into a single item labeled "pollution in the air." This process is consistent with the traditional concept mapping protocol.<sup>42</sup>

### Session II: Sorting and Rating Items

A second session, conducted with adults and youth approximately 2 weeks after the first session, took approximately 2.5 hours. Each participant individually sorted and rated the final list of 88 unique items generated during the brainstorming session. First, participants were asked to sort the statements into groups or themes that made sense to them and to name each pile created, and then rate on a 1- to 5-point Likert scale the importance of each statement to the triggering of and care of childhood asthma.

The session was described to participants by an academic partner, and members of the research team (both community and academic) were available to assist participants during the process of rating and sorting. The community partner also followed up with participants who could not attend the second session and conducted it with them in a private setting (e.g., participant's home, room in the public library) at a separate time.

After the sorting and rating were complete, members of the research team entered the ratings into the Concept Systems Global software<sup>43</sup> to produce preliminary "concept maps" and rating lists. First, we created a similarity index,

which applies nonmetric multidimensional scaling, a multivariate analysis, to map the points representing the distances and relations between the statements.<sup>38,44</sup> After this step, we produced concept maps, which are made by using hierarchical cluster analysis to divide the map into clusters representing ideas or concepts. In particular, the groupings made by participants in the second session determined how the items were clustered in the map, and the importance ratings for asthma triggers, and management and care factors obtained during the second session were used to determine each statement's average importance rating within the cluster.

### Session III: Data Analysis and Interpretation

In the third and final session, we worked with participants to interpret the concept maps generated using the software.

We combined adult and youth participants into one large group. The focus group began with an introduction of a community partner PI, and was facilitated by an academic partner PI. Additional members of the research team sat in the focus group taking notes, and audio recorded the session for accuracy. In this session, we presented participants with a visual cluster map of their perceptions to allow them to confirm that the items were clustered correctly and to help interpret the map. The facilitator made an effort to elicit responses from both youth and adult participants. The focus group lasted for approximately 1 hour and 20 minutes, with the majority of the time focused on making sure the items were clustered correctly. Although the participants were presented with the adult-youth differences in rankings near the end of the session, this did not generate much discussion.

There were a few important changes that came out of this third group session. For example, participants moved some items from one cluster to another. This included moving items such as air purifier and humidifier from a cluster on medical and other asthma relievers to a cluster on appliances to help with asthma. Also, participants created a new cluster focused specifically on the items related to emotions, such as feeling surprised and school-related issues. As a result, we went from a seven-cluster to an eight-cluster solution.

**Table 1. Descriptive Statistics of Sample Participants (N = 21)**

	Youth (n = 7)	Adults (n = 14)	Total (n = 21)
<i>Gender</i>			
Female	6	12	18
Male	1	2	3
<i>Age (y)</i>			
11-18	7		7
19-34		6	6
39-49		5	5
50-64		3	3
≥65		0	0
Average	14	40	33
<i>Education</i>			
Less than high school	7	2	9
High school diploma or GED		9	9
Some college		2	2
College degree		0	0
Unreported		1	1
<i>Race</i>			
Black or African American	5	11	16
Black and ≥1 other race	1	1	2
White		1	1
Unreported	1	1	2

## RESULTS

### Characteristics of Youth and Adult Participants

Our study sample consisted of 21 participants (Table 1), including 14 adults and 7 youth. On average, adult participants were 40 years of age (range, 22-64) and youth were 14 years of age (range, 11-18). All of the participants were female, with the exception of three males (2 adults and 1 youth). Reflecting the racial demographics of the community, most participants identified as Black/African American (n = 16). Two participants identified as belonging to one more racial/ethnic groups in addition to being Black/African American, one participant identified as White, and two were unreported. Almost two-thirds of adults in the sample reported the highest level of education completed was a high school diploma or GED. At the time of the study, none of the youth had completed high school. Finally, some of the participants were related to the youth. There were three adult caregivers (parents) with



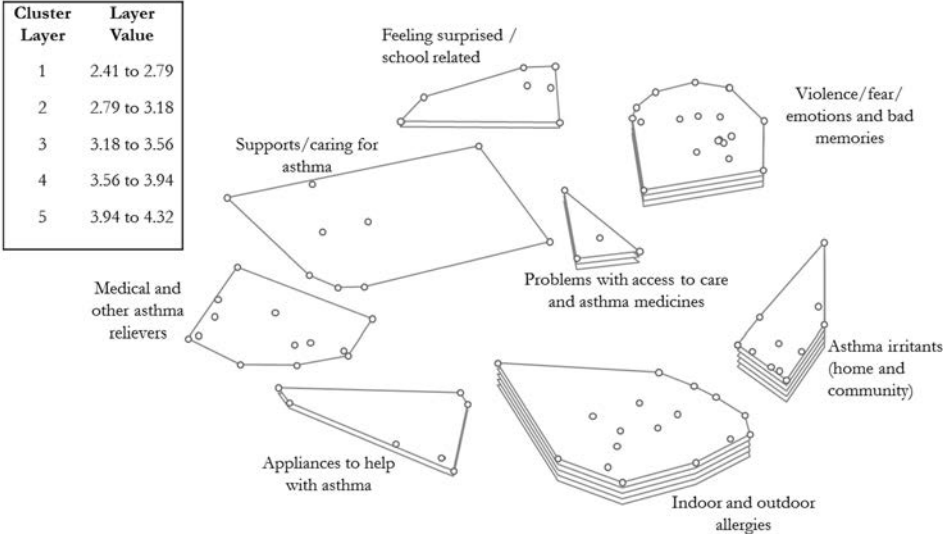
youth in the sample. In addition, there was one pair of youth who were sisters, but did not have an adult in the sample. One youth was not related to any adult in the sample, and 11 adults were not related to any of the youth.

On average, children of parents and youth in the sample

were diagnosed at age 10, had 2.2 emergency visits in the past 12 months owing to asthma, and spent 0.56 nights in the hospital over the past 12 months as the result of breathing problems. Participants also reported that asthma contributed to missing an average of 5 days of school in the past year.

# Influence Rating Map

For all participants, after revisions based on CM3 feedback



# Care Rating Map

For all participants, after revisions based on CM3 feedback

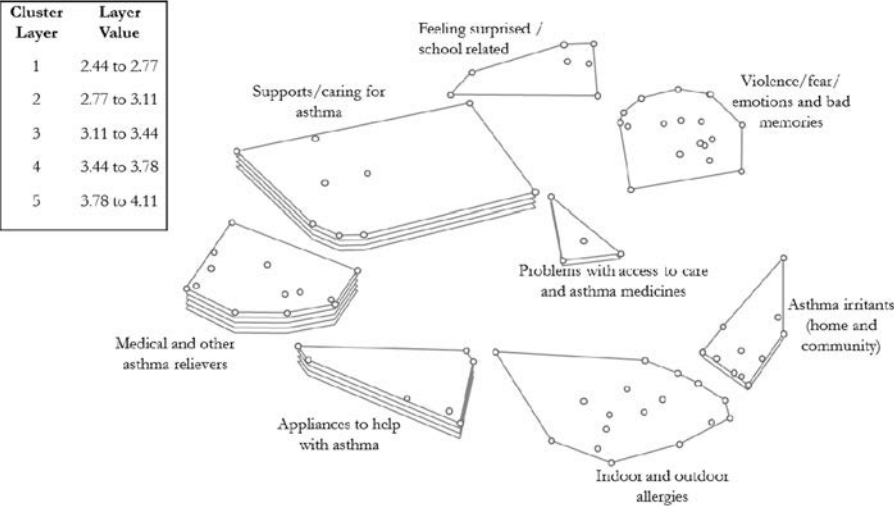


Figure 1. (top) Cluster map for asthma triggers generated by all participants. (bottom) Cluster map for asthma care generated by all participants.

## Influencing Children’s Asthma in Homewood

In the first session, participants brainstormed a total of 88 unique items that influenced children’s asthma in Homewood, which were then ranked for their importance as a trigger or factor related to the care children’s asthma. Figure 1 depicts the final eight cluster solutions generated by the concept mapping sessions and the average cluster rating for each of these two domains. The dots represent items that participants sorted into the same groups, and the number of layers shows the importance of each cluster in relation to influencing asthma.

### Asthma Triggers

Five of the clusters were identified as being important triggers for asthma. The most important cluster of items perceived to influence the triggering of an asthma exacerbation was Asthma Irritants in the Home and Community, in which items averaged 4.32 on a scale of 1 to 5 (Table 2). This cluster was made up of 12 items, with the most highly ranked items being cigarette smoke, construction dust, pollution, and roaches.

The second most important cluster of items for triggering asthma was indoor and outdoor allergies, with an average item ranking of 4.17. This cluster was made up of 17 items, which included dry heat, pet allergies, outdoor allergies, and mold/must in the house as the most highly ranked items.

Participants also identified items related to violence, fear, emotions and bad memories as important for triggering asthma attacks (3.76). This cluster consisted of 19 items, including physical fights and bullying, feelings of rage or anger, and remembering the death of family members who had died.

A cluster of items around problems with access to health care and asthma medicines was also important for understanding asthma triggers (3.42). This fourth most important cluster was made up of only four items. They included when it is hard to get an inhaler, the medicine is out of stock at the pharmacy, you have to pay out-of-pocket because the insurance will not cover the medicine, and nurse is not present at the school.

Finally, a cluster of items related to emotions (feeling surprised and school-related stress) were ranked as somewhat important for triggering asthma exacerbations (2.84). However, it was not ranked highly overall. The seven items in this cluster included emotions that come from having a baby, feeling excited as a result of good things, as well as school-related stresses such as testing and other responsibilities.

### Asthma Care

Three clusters were ranked by participants as being important for the care for asthma. First, participants ranked a cluster of 13 items on Medical and Other Asthma Relievers as the most important with an average rating of 4.11 (out

**Table 2. Final Eight Clusters and the Average Cluster Rating for (1) Triggering an Asthma Attack and (2) Care of an Asthma Attack**

Cluster	Example Cluster Items	Trigger Rating	Care Rating
Asthma irritants (home and community)	Cigarettes, construction, pollution, roaches	4.32	2.90
Indoor and outdoor allergies	Dry heat, pet allergies, outdoor allergies (such as pollen), dust	4.17	2.72
Violence/fear/emotions and bad memories	Physical fights, bullying, rage/anger, remembering the death of a family member that died	3.76	2.44
Problems with Access to Care and asthma medicines	Hard to get inhaler, pharmacy is out of stock of medicine, insurance does not cover medication and you have to pay out of pocket, absence of nurse	3.42	2.82
Emotions: feeling surprised or school-related stress	Having a baby, excitement from good things (such as love crushes), testing/school (PSSAs), school responsibilities	2.84	2.56
Medical and other asthma relievers	Steroid inhaler (prednisone), asthma camp, nebulizer, taking a break/resting	2.53	4.11
Appliances to help with asthma	Air duct filter, humidifier, steam, air purifier (home)	2.91	3.77
Supports/caring for asthma	Indoor sports (such as basketball), music to calm down, school nurse, having friends with asthma	2.41	3.52

Abbreviation: PSSA, Pennsylvania System of School Assessment.



of 5). Examples of the most highly ranked items in this cluster are medications for treating asthma, nebulizers, rescue inhalers (i.e., albuterol), steroid inhalers (i.e., prednisone), the Children's Hospital emergency room, asthma camp, and when other kids are accepting of asthma.

The cluster of seven items, appliances to help with asthma, was the second most important care-related factor (3.77). The most highly ranked item was a humidifier; having an air purifier in the home was also important. Other items perceived as somewhat important for the care of asthma included changing the bed sheets or having clean linens, an air duct filter, steam (either a machine or leaning over steam), and air conditioners.

Finally, participants rated the cluster of nine items related to having supports caring for asthma as important (3.52). The most highly ranked items within this cluster were the school nurse (who has your inhaler), having resources to get medicine like a gift of money, counting to calm down, having friends with asthma, and meeting professional athletes, such as former professional football player Jerome Bettis, who have asthma.

#### Adult Versus Youth Perceptions

Pattern match analysis allowed us to compare the ratings of the clusters generated by the participants' responses of the adults and youth in the sample. Overall, adults and youth had a fairly high level of agreement on what is important for triggering asthma ( $r = 0.67$ ; Figure 2) as well as asthma care ( $r = 0.74$ ; Figure 3).

For example, both adults and youth perceived asthma irritants in the home and community, indoor and outdoor irritants, and exposure to stress and violence as the top three most important clusters for triggering asthma; however, there were also some differences. Youth were more likely to perceive emotions (e.g., feeling surprised by things or stressors relating to school) as more important triggers of asthma than adults. In contrast, adults were more focused on "management" issues, such as access to medication or an air purifier.

With respect to the care of asthma, both youth and adults gave the highest care ratings to medical and other asthma relievers (including inhalers, nebulizers, medications, and the local health clinic). Adults also perceived appliances (e.g., air purifiers, humidifiers, air conditioning, steam, fans) as more effective in caring for an asthma attack than other support and coping techniques. However, youth perceived these other supports

such as having friends with asthma and coping techniques like using music or counting to calm down and access to the school nurse as more important for the care of asthma than adults.

#### DISCUSSION

This study used a CBPR approach to equitably and respectfully engage adults and youth from an economically underserved community to learn what they perceive as the triggers and care-related factors of children's asthma. Our findings confirmed the importance of traditional environmental triggers of asthma both inside and outside of the home, and identified and illustrated additional factors, such as violence, as an important factor for triggering asthma among children in this community. We found that key factors related to the care of children's asthma included not only medicines and appliances, but also people who could offer support.

Although adult and youth rankings followed fairly similar patterns, there were some key differences. For both domains of the trigger and care factors related to asthma, youth ranked items related to social interaction or emotions higher than adults. These included items such as school-related stress, positive emotions, bullying, and painful memories as triggers of an asthma attack, whereas having friends and other supports in school (i.e., a school nurse) were important for the care of asthma. In contrast, adults ranked items related to medical issues and/or monetary resources higher than youth in relation to the care of asthma.

The disparity between youth and adult responses on stress-related factors suggest a lack of knowledge among adult participants of the links between psychosocial factors and asthma. Although youth responses linked asthma exacerbations to stress and cited stress-coping strategies as important asthma care factors, many adult participants rated these items as having little weight in either caring for or triggering an asthma attack. Youth and adult responses also highlighted the confusion over the relationship between physical exercise and asthma, specifically whether it is a trigger of asthma or something that can actually improve asthma symptoms.

#### REFLECTIONS AND LESSONS LEARNED

Although we did not formally solicit feedback from participants on the concept mapping experience, we did receive informal feedback at the last session. Some participants noted

challenges in the second session, in which they were asked to sort the items brainstormed in the first session into categories and rank them with respect to importance. In particular, they felt that it was difficult to sort such a large number of items (88 items) into groups. Participants spoke positively about the final session. Some participants said they learned a lot from hearing from other participants' experiences dealing with asthma, and that it helped them to see each other as experts in the area.

From a CBPR perspective, the concept mapping approach

allowed for increased discussion, participation, and sharing among the community members, and in general allowed for more inclusion. For example, during the third session, participants gave feedback and tweaked the concept mapping results to yield a more accurate representation. If we only had a general findings presentation, participants may not have been as vocal, or would not have felt empowered to question certain findings. Because we presented it as, "This is what this algorithm found. Is it right?" rather than, "This is what we,

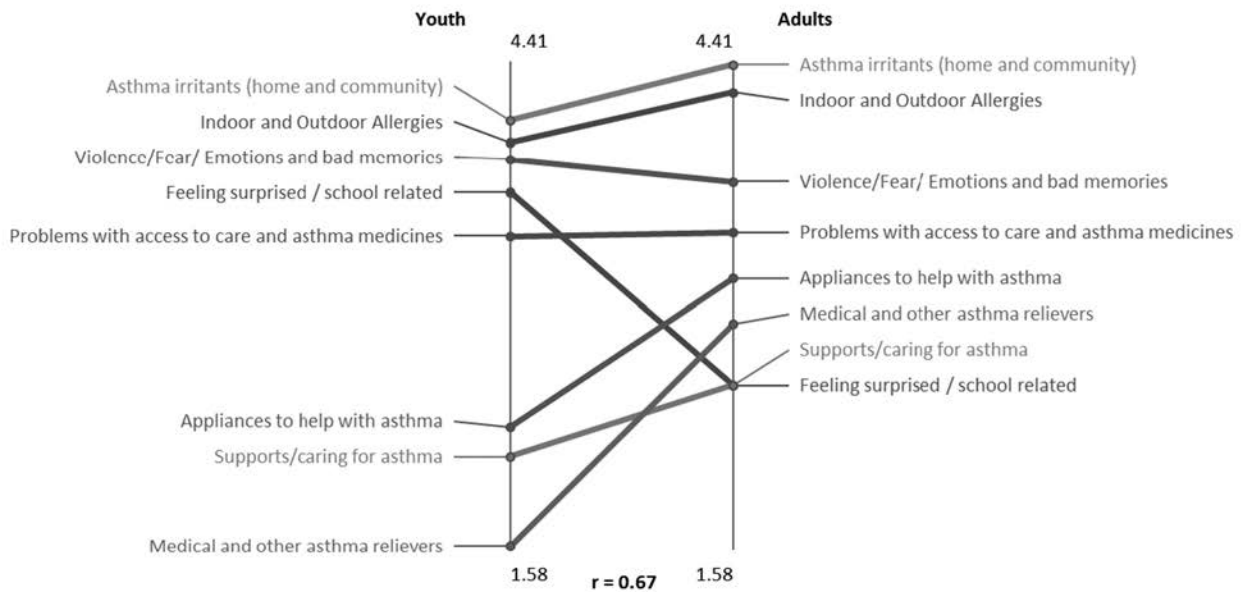


Figure 2. Pattern matching comparing adults and youth: asthma triggers.

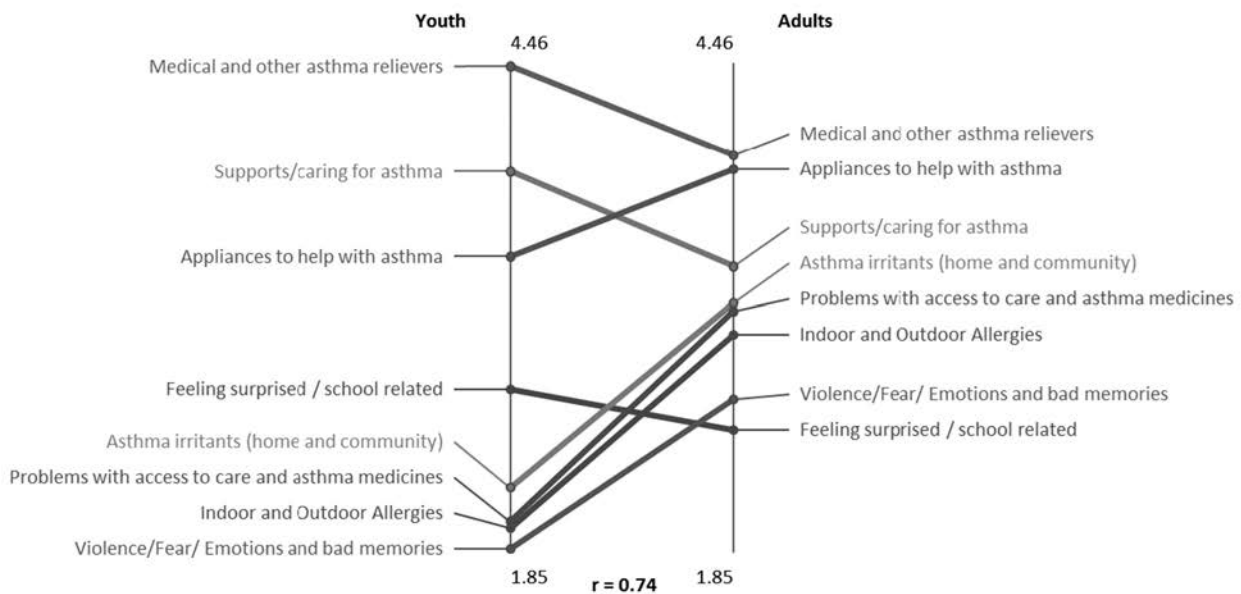


Figure 3. Pattern matching comparing adults and youth: care of asthma.

the expert, found. Is it right?”, participants may have been more likely to speak up. In this way, the participants were not forced to question the researcher’s expertise; rather, it set up a dynamic such that we were all—participants and researchers alike—questioning the software’s expertise.

Moreover, by combining qualitative and quantitative results in a visual form, we allowed for different types of discussion about the research. Participants could easily point at the map, and start a discussion from there. This method helped to solidify participants as co-researchers. Perhaps also notable was that the visual elements might have rendered the findings more comprehensible for those with low literacy levels, because we did have at least one participant who fell into that category.

In terms of lessons learned, one key issue was getting consistent participation. We took many steps to gain and maintain participation (e.g., recruiting through a community partner with an established presence in the community, check-ins/reminders with participants between sessions, and a monetary incentive for attending all three sessions), but it was still challenging. To gain and maintain higher levels of participation, it may help to connect with a group who is already established and who meets at a regular time. Because this group did not already exist for our focus on children’s asthma in this community, this was not an option for us.

Another lesson learned in this project was the importance of building rapport. Our community partner had interacted with several participants before starting the concept mapping activity, but for many, the members of the research team were new in addition to fellow participants. Having dinner provided for participants and their family members, and time set aside for the research team and participants to socialize before starting the concept mapping activity, allowed us to build rapport. Having three sessions of concept mapping also increased the rapport between the research team and participants. Not only did this enhance the third and final concept mapping session, but it also allowed us to follow-up with participants for future activities connected to the project.

## IMPLICATIONS FOR INTERVENTION

The data collected and the new relationships focused on asthma that we gained through the concept mapping process were used to identify community-specific priority areas of concern related to asthma for youth in Homewood. First, the

findings raised some new questions for us around issues of asthma, which led to and informed further data collection. To get a deeper understanding of the individual experience of asthma from the youth and caregiver perspectives, we followed up with a subsample of respondents and conducted in-depth qualitative interviews. We also used the results from the concept mapping, combined with the in-depth interviews, to inform a community-level assessment of caregivers of children with asthma. For example, knowledge gained in the concept mapping led to specific questions in the community-level assessment regarding a basic understanding of asthma care as well as specific questions about where people were receiving care.

The results from our concept mapping activity suggested the importance of using different strategies to address the experience of adult caregivers as compared with youth. An intervention aimed at adults might focus on knowledge around the impact of psychosocial stressors such as violence in the home and community on youth’s asthma. In contrast, interventions aimed at youth may be more successful if they focus on creating peer support groups or on stress management strategies to support youth in managing the psychosocial stressors affecting their asthma.

The concept mapping results also suggested we take a multipronged approach to addressing the different environments where youth spend time. For example, the findings led us to consider a home-based intervention that aimed to reduce smoking in the home by encouraging people to smoke outdoors. A school-based strategy to leverage nursing resources to care for asthma is another intervention possibility. The concept mapping findings also pointed toward the importance of out-of-school time and sports activities. We learned from the head of the local youth sports organization that several participating youth had inhalers, but the coaches did not have a deep understanding of asthma or care. Thus, the coach expressed a desire to train coaches in appropriate asthma care. This led to our team creating a training opportunity for the coaches on asthma led by a local expert.

The study findings also indicated a need for better educational outreach from the medical community that clarifies best practices around the care of children’s asthma. In response, an asthma specialist who was a member of our research team was able to secure office space in the local community-based health clinic, where he offered hours to see children with asthma.

Our research team also explored the potential for implementing an intervention focused on educating caregivers in the community about asthma. In this model, caregivers in the community are trained to be the teachers and help to educate other parents in the community around the issue of asthma.<sup>45</sup>

## STUDY STRENGTHS AND LIMITATIONS

A strength of our study is the CBPR approach. The study findings add to the more recent research that aims to incorporate community input on local stressors that may be contributing to asthma using a CBPR approach; specifically, using the tool of concept mapping as a way to engage community participants and study investigators as co-researchers.<sup>46,47</sup> In addition, the concept mapping methodology provided an ideal method to add to the smaller number of studies examining youth perceptions around the care of childhood asthma to inform culturally humble and sensitive intervention opportunities.<sup>48,49</sup>

The deep insights gained through this systematic, mixed methods study provide valuable insight to the local community context of factors impacting youth with asthma. The research team found the concept mapping to be extremely helpful in implementing and maintaining a participatory research focus and sharing of power and decision making throughout the research effort within the community and academic research team, as well as with the community participants. As compared with a traditional focus group or nominal group session, the concept mapping method allows for and facilitates a process where the participants individually generate and organize the data, prioritize through ratings the importance of items and groupings, and then collectively interpret the data. Similar to the Delphi method, concept mapping allows for the group or experts, which in this study were community youth and caregivers, but doing so face to face. A unique strength of the concept mapping approach is the ability to visually depict, discuss, critique, and interpret the findings that were generated, ranked, rated, and sorted by the expert community participants.

This method is limited, however, by the possibility that participants may identify items that are not supported or prioritized by the literature. For our study, we perceived this as a positive opportunity to increased awareness and learning, and to also complement the existing literature with community expert perceptions. Concept mapping uniquely allows for the broad and inclusive brainstorming of factors

perceived to impact children with asthma. It was our goal to incorporate this new knowledge and integrate it with all of the factors gained from the community expert perspective. We did not remove any unique items from the brainstorming list, and only worked to consolidate multiple factors that captured the same idea. For example, with our study, the community-generated data supported the importance of airborne pollutants as a trigger, but also illustrated the high perceived importance of social and environmental stressors impacting youth with asthma, which receives far less recognition in the traditional literature. For the youth and adults who live, learn, and play in Homewood, this is a critical exposure source and the information gathered through the concept mapping approach allowed for the inclusion of many social and environmental factors that the community and academic research team could never have imagined.

Another limitation of the study was the lack of specific participant feedback on the differences in the youth and adult responses. Although we posed this question to the participants during the third concept mapping session, there were very few responses. One reason may have been the late hour that the discussion was started. Much of the third session focused on the discussion of the item groupings and concept maps. A potential modification to the concept mapping, which should be tested in future work, would be to have a separate discussion explicitly focused on these adult and youth differences to try and understand the nuances of what we begin to unpack in this paper.

The small sample size and non-random participant sample selection also limits the generalizability of our findings. What may be important for this group of caregivers and youth with asthma in Homewood may not be true for residents in the neighborhood, or in other neighborhoods within and across different cities. Also, our sample may be more representative of the female perspective, because only a few sample members were male. Issues for female caregivers may differ; they may be more likely to be primary caregivers, whereas issues for male youth may differ if they are more likely to participate in sports. Future work can engage more male caregivers and youth, as well as test whether results could be considered transferable to other communities in similar setting.

Despite these limitations, the study findings contribute to our understanding of children's experience of asthma in an economically underserved community, helped to structure a

broader survey of caregivers of children with asthma in the community, and informed the development of a multilevel asthma intervention.

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