



Identification of Gaps in the Diagnosis and Treatment of Childhood Asthma Using a Community-based Participatory Research Approach

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ABSTRACT *The goal of this investigation was to use a community-based participatory research approach to develop, pilot test, and administer an asthma screening questionnaire to identify children with asthma and asthma symptoms in a community setting. This study was conducted as the recruitment effort for Community Action Against Asthma, a randomized trial of a household intervention to reduce exposure to environmental triggers of asthma and was not designed as a classic prevalence study. An asthma screening questionnaire was mailed and/or hand delivered to parents of 9,627 children, aged 5 to 11 years, in two geographic areas of Detroit, Michigan, with predominantly African American and Hispanic populations. Additional questionnaires were distributed via community networking. Measurements included parent report of their child's frequency of respiratory symptoms, presence of physician diagnosis of asthma, and frequency of doctor-prescribed asthma medication usage. Among the 3,067 completed questionnaires, 1,570 (51.2% of returned surveys, 16.3% of eligible population) were consistent with asthma of any severity and 398 (12.9% of returned surveys, 4.1% of eligible population) met criteria for moderate-to-severe asthma. Among those meeting criteria for moderate-to-severe asthma, over 30% had not been diagnosed by a physician, over one half were not taking daily asthma medication, and one quarter had not taken any physician-prescribed asthma medication in the past year. Screening surveys conducted within the context of a community-based participatory research partnership can identify large numbers of children with undiagnosed and/or undertreated moderate-to-severe asthma. These children are likely to benefit from interventions to reduce morbidity and improve quality of life.*

KEYWORDS *Asthma, Child, Community-based participatory research, Screening, Urban.*

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INTRODUCTION

Asthma prevalence is on the rise, particularly among urban youth.¹ The ability to identify children with asthma in a given population is important to conduct surveillance of trends in asthma prevalence, to find children who may benefit from asthma-specific education or therapies, and to locate children eligible for asthma research protocols. Despite increased awareness of the problem of childhood asthma, many children with asthma symptoms and asthma-related morbidity have never been diagnosed with asthma by a medical professional.² Thus, identifying children with asthma based on encounters with the medical system may not include children with undiagnosed asthma and only selects children with access to health care. Community-based methods that allow for identification of children with undiagnosed asthma have the potential advantage over medical system-based methods because they provide a more complete ascertainment of asthma cases.

The asthma epidemic has disproportionately affected children from communities of color living in economically disadvantaged urban settings. Given the history of research conducted in these settings, in which community members have rarely perceived benefits and sometimes have actually been harmed, there is understandable mistrust and reluctance to participate in research studies.³ Community-based participatory research (CBPR) is an approach to research that involves community members and organizational representatives as equal partners with professional researchers in all aspects of the research process.³ A key component of CBPR is the active participation of community members in defining the research question, designing and implementing the research protocol, and interpreting and disseminating research findings.^{3,4} The CBPR approach is particularly well suited for application in marginalized communities and to the complex interplay of environmental and social influences on asthma morbidity in such urban environments because it emphasizes participation of members of these communities in identifying suitable research and intervention approaches.

We sought to identify children with symptoms of persistent asthma who would be eligible for enrollment in a large, community-based participatory intervention and environmental exposure assessment study known as Community Action Against Asthma (CAAA). Here, we report the successful administration of an asthma screening questionnaire conducted using a CBPR approach in an urban community setting to identify and describe children with known asthma or with probable undiagnosed asthma. We also sought to describe those demographic factors associated with a physician diagnosis, symptom severity, and undertreatment in this cohort. An analysis of the strengths and challenges of engaging in a CBPR approach is provided.

METHODS

Community-Based Participatory Research

This study was conducted using a CBPR approach, which emphasizes active participation of community members in the process of creating knowledge and taking action aimed at benefiting the community involved.³ CAAA grew out of and is affiliated with the Detroit Community–Academic Urban Research Center (URC), funded by the Centers for Disease Control and Prevention. The URC partnership involves representatives from community-based organizations (CBOs), the local health department, an integrated health care system, and academic researchers,

working together to address the health issues of concern to the eastside and southwest communities of Detroit, Michigan.^{4,5}

During the early phases of its development, the URC board identified the influence of the physical environment on children's health as one of its priority areas. A new CBPR Steering Committee was then established for the CAAA research and intervention project, with the committee consisting of representatives from each of the organizations involved with the URC along with several additional CBOs. (See Acknowledgement section for a list of the partner organizations involved.) This steering committee was instrumental in the design and conduct of the CAAA project aimed at addressing rising asthma morbidity and mortality among Detroit children.^{6,7} In accordance with the CBPR principles adopted by the CAAA Steering Committee,³ emphasis has been placed on utilizing the local expertise of community partners to tailor the study to local circumstances and needs.

Questionnaire Design

The asthma screening questionnaire was derived from a validated instrument used in prior assessments of asthma prevalence in Detroit.^{2,4} This instrument was modified from the American Thoracic Society respiratory questionnaire for adults⁸ and validated in third to fifth grade urban African American schoolchildren by comparing responses to physician diagnosis and postexercise bronchial hyperresponsiveness.^{2,4,9} The self-administered questionnaire, which is completed by parents, is designed to identify children with a physician-diagnosis of asthma as well as those children who experience symptoms consistent with asthma, but who have not yet been diagnosed by a medical provider. It further allows for the classification of children into asthma severity categories as defined by the National Asthma Education and Prevention Program (NAEPP) 1997 report.¹⁰

For this study, an additional question on sleep disturbance was added to the original seven-question instrument to facilitate classification of asthma severity according to the NAEPP classification scheme. The CAAA questionnaire included eight symptom questions (Table 1) six non-exercise-related symptoms (five daytime and one nighttime symptom) and two exercise-related symptoms. Parents were also asked demographic information and if their child had ever been diagnosed by a medical care provider with any of the following conditions: asthma, bronchitis, bronchiolitis, reactive airways disease, pneumonia, or asthmatic bronchitis. In addition, parents were asked whether their child had taken prescription medication for any of these conditions in the last 12 months and, if so, whether they were taking these medications on a daily basis.

A passive consent procedure was used in the distribution of this questionnaire. The study protocol was approved by the CAAA Steering Committee and by the University of Michigan institutional review board.

Population

The population of interest was children between the ages of 5 and 11 years living in the east and the southwest sections of Detroit. Demographically, the eastside community is approximately 90% African American, and the southwest is the area of Detroit where the highest concentration of Hispanic residents reside (35% Hispanic, 40% African American, 15% non-Hispanic white).¹¹

Pilot Testing

An earlier version of the questionnaire with a different visual layout was pilot tested for readability and understandability by other investigators in both Detroit elementary

TABLE 1. Asthma-related health questions on the Community Action Against Asthma asthma screening questionnaire: Parents were asked, "In the past 12 months, how often has your child ..."

Nonexercise		
Daytime	Nighttime	Exercise
Had wheezing (whistling sound from the chest) with a cold	Sleep been disturbed because of wheezing, coughing, chest tightness, or shortness of breath	Wheezed with exercise or running or playing hard
Had wheezing (whistling sound from the chest) without a cold		Coughed with exercise or running or playing hard
Had an attack of wheezing that made it hard to breathe or catch his or her breath		
Had a cough that would not go away		
Complained that his or her chest felt tight or heavy		

schools and a pediatrician's office in 1996 (L. Anderson, personal communication, October 8, 2002). Minor modifications to question wording were made as a result.

Based on the recommendation of the CAAA Steering Committee, the survey distribution technique was pilot tested in two elementary schools (one in each area of the city) in February 1999 to determine which of four incentive plans would offer the highest rate of return. A total of 646 questionnaires were mailed to the homes of age-eligible children using address labels provided by the Detroit Public Schools. The four different incentive plans utilized were (1) \$2 in cash included with the mailing, (2) a \$2 gift certificate to a discount shoestore chain included with the mailing, (3) an offer of a \$4 gift certificate to the shoestore chain if the questionnaire was mailed back to the study office, and (4) an offer of a \$4 gift certificate to the shoestore chain if the questionnaire was returned to a partner CBO. Stamped return envelopes were included with the mailing. Two weeks after the mailing, 42 surveys had been returned, with equal return rates associated with options 1–3 (lower return rates were seen with option 4). We chose to proceed with the main study using option 3 because it was equally effective and potentially more economical than options 1 or 2 if return rates fell below 50%.

Questionnaire Distribution

The CAAA Steering Committee played an important role in designing a combination of methods that were used to reach the population of interest. These can roughly be divided into school-focused and community-focused methods. A field coordinator was hired by the steering committee to carry out these recruitment efforts. The coordinator is a long-time resident of southwest Detroit, with extensive community ties and knowledge of the communities involved.

School-Focused Methods School enrollment lists with home addresses were obtained from the public school district office for children in grades 1–4 in the 1998–1999 academic year for all of the public elementary schools (N=42) in the geographically

defined communities involved. Three private elementary schools at which community partners had relationships with the principals were also approached, 2 of which agreed to participate in the study. A total of 44 schools participated: 29 in the eastside and 15 in the southwest. This distribution reflects the relative geographic and population size of the two areas involved.

Per request of public school district administrators, for children attending public school, introductory letters and questionnaires ($n=9,437$) were distributed through US mail to children's homes in the spring of 1999. Principals of the 2 private schools preferred that questionnaires be handed out in school to the children ($n=190$) and were to be hand-carried home. Parents with more than one child in the specified age range were asked to fill out the questionnaire in reference to the child who they felt had the most significant breathing problems. For 9 schools at which there was a high enrollment of Spanish-speaking children, English and Spanish versions of the letter and questionnaire were distributed together to allow parents to choose the language they preferred. Families were asked to mail the survey to the study office or to return it to their child's school. Teachers were given a supply of small gifts (e.g., rulers, erasers) to provide an immediate reward for children returning the questionnaire.

All schools received a visit from the project's field coordinator to request the principal's assistance in achieving a high response rate. Principals took various approaches to offering assistance. Sixteen principals allowed additional distribution of questionnaires directly to students, and most allowed the field coordinator to make a presentation at a parent meeting, at which she distributed flyers describing the purpose of the project and additional copies of the questionnaire as needed. To encourage them to have their parent(s) complete the questionnaire, a few principals followed up with specific children in their schools whom they knew to have asthma or recurrent breathing problems.

Immediately following the initial mailing, principals distributed flyers to families (in both English and Spanish) to remind them to complete the questionnaire. All families also received by mail two reminder postcards encouraging them to return the questionnaire whether or not their child had breathing problems. The postcard included a toll-free number parents could call to request an additional copy of the questionnaire if one was needed. Near the end of the school year, a third reminder and another copy of the questionnaire were mailed to families who had not yet responded.

Most completed questionnaires were mailed to the study office, and some additional ones were collected from the schools. A \$4 gift certificate to a shoestore was mailed to all parents who returned the questionnaire. Fifty dollars were given as a gesture of appreciation to each of the two schools with the best return rate.

Community-Focused Methods The field coordinator conducted a community campaign to raise awareness of the CAAA project and to encourage families to return the survey instrument. This approach was designed as an overlapping strategy to reach the sample population focused on in the school-based methods to enhance response rates. Introductory flyers and questionnaires were distributed at 13 churches (7 eastside, 6 southwest); 12 branch public libraries (10 eastside, 2 southwest); 7 markets; 5 Women, Infant, and Children offices; and 4 YMCAs (Young Men's Christian Associations). In addition, presentations were made and materials were distributed at 17 parent and neighborhood meetings, 3 police precinct community relations meetings, and 5 board meetings of local CBOs. The steering committee was instrumental in identifying many of these organizations.

Follow-up

All families returning a questionnaire were sent a letter reporting the results of their child's asthma screening questionnaire. Children identified with any severity level of asthma were advised to follow up with their health care provider. To help families who might not have health insurance or a source of primary health care, contact information was provided to two social services agencies (one on the eastside and one in southwest Detroit) for assistance in accessing the health care system. All children meeting criteria for persistent asthma were also invited to enroll in the CAAA program, combining a home-based intervention to reduce exposure to indoor asthma triggers and an epidemiological study to characterize exposure to environmental asthma triggers. As part of this program, access to primary health care services was reassessed quarterly. Outreach workers connected those families without health insurance or a regular health care provider with local community agencies with expertise in addressing these issues.

Asthma Definitions

Asthma definitions were derived from the NAEPP guidelines and from the recommended case definition of asthma developed by the Epidemiology Section of the American Public Health Association.^{10,12} A child was considered to have known or probable current asthma if he or she met any of the following three criteria: (1) had received a doctor diagnosis of asthma, reactive airways disease, or asthmatic bronchitis and reported any asthma symptom or doctor-prescribed asthma medication use within the last year; or (2) reported three or more of the non-exercise-related symptoms within the last year (at any frequency); or (3) reported an exercise-related symptom occurring three or more times in the past year. Sensitivity and specificity of very similar definitions have been evaluated previously.⁹

The classification scheme used for asthma severity was based on the frequency of symptoms reported in light of asthma medication use. Extra weight was given to reports of nighttime awakening and to symptoms occurring despite daily medication use. The National Heart, Lung, and Blood Institute guidelines define severity based on clinical features before treatment; therefore, frequent breakthrough symptoms occurring in the presence of daily controller therapy were considered to represent more severe asthma. A child's asthma was considered moderate-to-severe persistent if the following were reported: (1) any daytime symptom present every day, or (2) sleep disturbance more than once a week or every day, or (3) daily use of doctor-prescribed medication with any daytime symptom reported as present more than two times per week. A child's asthma was considered mild persistent if he or she did not meet the above criteria for moderate-to-severe persistent asthma and any of the following were true: (1) report of three or more daytime symptoms present more than two times per week, (2) report of any use of doctor-prescribed asthma medicines and two or more daytime symptoms present more than two times per week, or (3) report of daily use of doctor-prescribed medicine and nighttime symptoms present more than two times per month. Children who met criteria for known or probable asthma but did not meet any of the above criteria for persistent asthma were categorized as having mild intermittent asthma.

Data Analysis

Analysis of the screening questionnaire data focused on identifying those demographic factors associated with having a physician diagnosis of asthma, with asthma severity, and with potential undertreatment of persistent asthma symptoms.

The SAS system (SAS Institute, Cary, NC), version 8.0, was used. Chi-square analysis was used for baseline comparisons of categorical variables. We used *t* tests for comparing continuous variables between groups. Logistic regression was used to adjust for the effect of potential confounding variables when the outcome was binary. When an outcome was an ordered categorical variable, such as asthma severity categories, a logistic proportional odds model was used. This model assumes that the odds ratios associated with a one-level increase in outcome were constant across the spectrum of outcome levels.

RESULTS

Reaching the Population of Interest

Questionnaires were mailed to the parents of 9,437 children through public school distribution, and an additional 190 surveys were distributed through private school distribution, for a total of 9,627 potentially eligible children. Of the mailed questionnaires, 2,144 were returned by the post office as undeliverable, for a total of 7,483 children who were potentially reached through the initial school-focused distribution. There were 2,182 children who hand-carried an additional letter and questionnaire home in a second wave of school-focused distribution because of the supplementary efforts of the field coordinator and the school principals. Some of these hand-carried surveys may have reached families who did not receive a mailed survey because of an undeliverable address. It is not clear how many additional families were reached through community-focused methods, but 75 phone calls were received on the project's toll-free line requesting a survey. Some of these callers were responding to the reminder postcards and some to information they had received at a community meeting or location.

Families returned 3,342 questionnaires; 117 were excluded because they were blank. Multiple questionnaires were received for 55 children (2 surveys from 54 children and 3 surveys from 1 child). In these cases, the second and third questionnaires received were excluded. We excluded 65 because the child lived outside the study area, and 37 were excluded because the child was either younger than 5 years old or older than 11 years. Questionnaires for 3,067 children were analyzed.

Cohort Characteristics

The demographic characteristics of the children who returned surveys ($n=3,067$) are displayed in Table 2. The average age was 8.7 years, 51.5% were male, and 61.2% lived on eastside Detroit. There were 65.8% African Americans and 20.5% Hispanics; the remainder self-reported as either Caucasian/white, multiracial, or another ethnic background. English was spoken by 82% as their usual language at home; 5.7% were bilingual in English and Spanish at home, and 12% spoke primarily Spanish. Ethnicity and primary home language were not evenly represented in the different regions of Detroit, reflecting the underlying demographics of the city. The eastside was predominantly African American (96.1%) and English speaking (99.4%), and the southwest was more diverse ethnically (52.1% Hispanic, 29.3% white/multiracial/other, 18.7% African American) and linguistically (55.0% English, 30.4% Spanish, 14.2% English/Spanish). There were 1,489 children (49.9%) who lived in households in which at least one person smoked tobacco.

TABLE 2. Distribution of demographic characteristics among survey respondents (n = 3,067)

Characteristic	N	%*
Age, years		
5–6	313	10.7
7	608	20.7
8	808	27.5
9	648	22.1
10–11	571	19.4
Male	1,568	51.5
Location of residence		
East	1,827	61.2
Southwest	1,157	38.8
Ethnicity		
African American	1,986	65.8
Hispanic/Latino	620	20.5
Caucasian/multiracial/other	413	13.7
Primary language at home		
English	2,493	82.0
Spanish	364	12.0
English/Spanish	173	5.7
Other	10	0.3
At least one smoker living in household	1,489	49.9

* Totals may not add to 100% because of rounding. Percentages are calculated for non-missing responses. Responses were missing for 22 children on sex, 129 children on age, 48 children on ethnicity, 83 children on location of residence, and 27 children on primary language spoken at home and 84 children on smoker living in household.

Asthma Identification

The frequency of asthma-related symptoms among survey respondents is shown in Table 3. There were 1,570 children (51.2% of survey respondents, 16.3% of the eligible population) who met the definition of current known or probable asthma (current asthma). The eligible population consisted of those 9,627 children enrolled in the 44 participating elementary schools. Of those meeting the criteria for current asthma, 755 (48.1% of survey respondents with asthma, 7.8% of eligible population) met criteria for current physician-diagnosed asthma (current known asthma) and an additional 815 (51.9% of survey respondents with asthma, 8.5% of eligible population) reported current symptoms consistent with asthma, but had never been diagnosed with asthma by a health care provider (current probable asthma).

Asthma Severity

Among children who met the criteria for current asthma (n=1,570), 398 (25.3% of survey respondents with asthma, 4.1% of eligible population) met the definition of moderate-to-severe asthma, 310 (19.8% of survey respondents with asthma, 3.2% of eligible population) met the definition of mild persistent asthma, and 862 (54.9% of survey respondents with asthma, 9.0% of eligible population) were categorized as having mild intermittent asthma. A large proportion of children with

TABLE 3. Frequency of asthma-related symptoms among survey respondents (n = 3,067)

Symptom (Number missing data)	Symptom frequency, N (%)					
	Never	1–2 times/year	3–12 times/year	More than 1 time/month	More than 2 times/week	Everyday
Cough that won't go away (66)	1,000 (33.3)	957 (31.9)	524 (17.5)	251 (8.4)	196 (6.5)	73 (2.4)
Wheeze without a cold (33)	2,029 (66.9)	400 (13.2)	259 (8.5)	177 (5.8)	112 (3.7)	58 (1.9)
Wheezing with shortness of breath (25)	2,128 (69.9)	385 (12.7)	241 (7.9)	155 (5.1)	99 (3.3)	35 (1.1)
Chest tight or heavy (41)	1,875 (62.0)	535 (17.7)	267 (8.8)	202 (6.7)	118 (3.9)	29 (1.0)
Wheezing with exercise (44)	1,937 (64.1)	384 (12.7)	244 (8.1)	166 (5.5)	154 (5.1)	139 (4.6)
Coughing with exercise (35)	1,529 (50.4)	611 (20.2)	314 (10.4)	209 (6.9)	198 (6.5)	171 (5.6)
Wheezing with a cold (37)	1,491 (49.2)	795 (26.2)	462 (15.2)	283 (9.3)		
	Never	1–2 times/year	3–12 times/year	More than 1 time/month	More than 1 time/week	Most nights
Sleep disturbed by wheeze, cough, shortness of breath, chest tightness (32)	1646 (54.2)	583 (19.2)	348 (11.5)	250 (8.2)	77 (2.5)	131 (4.3)

Percentages are based on non-missing data and may not add to 100 because of rounding.

TABLE 4. Of children with current asthma (n = 1,570), proportion of children with a diagnosis of asthma by symptom severity category

	Moderate-severe persistent	Mild persistent	Mild intermittent	Total
Diagnosed asthma	276 (69.4%)	178 (57.4%)	301 (34.9%)	755 (48.1%)
Symptoms without diagnosis	122 (30.7%)	132 (42.6%)	561 (65.1%)	815 (51.9%)
Total	398	310	862	1,570

symptoms of persistent asthma had never been diagnosed with asthma: 30.7% of those with moderate-to-severe persistent symptoms and 42.6% with mild persistent symptoms (Table 4).

Frequency of Asthma Medication Use

Among the 1,570 children identified with current asthma, 47.7% reported use of medications prescribed for breathing problems; 52.3% did not, suggesting that these children may have been undertreated (Table 5). As might be expected, having a physician diagnosis of asthma was strongly associated with whether a child was

TABLE 5. Variation in medication use pattern of children with known or probable current asthma (n = 1,570) by asthma characteristics

	Medication use			Total
	None	Intermittent	Daily	
Asthma diagnosis				
Yes	155 (21.2)	300 (41.2)	274 (37.6)	729
No	651 (83.3)	107 (13.6)	25 (3.2)	789
Active symptoms (daytime ≥ twice/week, nighttime ≥ twice/month)				
Yes	216 (35.9)	173 (28.8)	212 (35.2)	601
No	596 (65.0)	234 (25.5)	87 (9.5)	917
Asthma severity				
Moderate-severe persistent	98 (25.4)	88 (22.8)	200 (51.8)	386
Mild persistent	118 (39.1)	85 (28.2)	99 (32.8)	302
Mild intermittent	596 (71.8)	234 (28.2)	0 (0)	830

A child is defined as having persistent asthma if he or she has active symptoms or if he or she is using daily medications for breathing problems; the distinction between mild and moderate-to-severe asthma is then made on the basis of frequency of symptoms. Data on medication use were missing for 52 participants.

using prescribed asthma medications ($P < .01$). Of those with a physician diagnosis of asthma and symptoms within the last year, 78.7% of the children were using medication at any frequency. Of those children with symptoms of asthma without a diagnosis, only 16.7% were using prescribed medications for breathing problems.

The NAEPP expert panel has recommended that children with persistent symptoms of asthma be treated with a controller medication on a daily basis.¹⁰ Among our respondents, 48.2% of children with moderate-to-persistent asthma and 67.2% of those with mild persistent asthma were not using a medication for breathing problems on a daily basis.

Looking more closely at the issue of potential undertreatment of symptomatic children, 39.6% of our population with current asthma reported having at least one daytime asthma symptom at a frequency of twice a week or more or waking up with breathing problems more than two times per month. Among these poorly controlled asthmatics, 216 (35.9%) were not using any medication, 173 (28.8%) were using medication on an intermittent basis, and 212 (35%) were using medicine prescribed daily (Table 5). We do not have information about the specific kinds of medications children used.

Characteristics Associated with Physician Diagnosis

Compared to those with a known diagnosis of asthma, those who were symptomatic without a diagnosis (current probable asthma) were more likely to be female, to live in southwest Detroit, to speak Spanish as the primary language at home, and less likely to be African American (all P values $\leq .01$). There was no difference in age between those with a diagnosis of asthma and those who were symptomatic but did not have a diagnosis. In a multivariate logistic regression model that included age, gender, location of residence, ethnicity, and asthma severity (see next section), asthma severity had the strongest association with having a physician diagnosis. Once asthma severity was taken into account, only gender remained significantly

associated with physician diagnosis, with boys more likely than girls to have a physician diagnosis (odds ratio [OR]=1.4, 95% confidence interval [CI] 1.13–1.74).

Characteristics Associated With Asthma Severity

Among those responding to our questionnaire, African American residents were more likely to report symptoms consistent with moderate-to-severe persistent asthma than those who were not African Americans (28.0% African American, 19.3% Hispanic, 18.5% white/multiracial/other; $P < .001$). Similarly, compared to respondents who reside in southwest Detroit, eastside residents were more likely to report moderate-to-severe persistent asthma symptoms (27.6% vs. 20.7%, respectively, $P = .01$). Respondents were more likely to report more severe symptoms for older children. There was no difference in asthma severity by gender in our sample. In a proportional odds logistic regression model adjusting for age, gender, location, and ethnicity, location was no longer associated with severity, but ethnicity was. The odds ratio of being a moderate-to-severe persistent asthmatic as opposed to a mild persistent asthmatic was 1.42 for African Americans compared to Hispanics ($P = .004$).

Characteristics Associated With Medication Use

To gain a better understanding of the problem of potential undertreatment, we performed an exploratory analysis to identify demographic factors that were associated with lack of daily medication use among persistent asthmatics. In bivariate analysis, location of residence and primary language spoken at home were associated with taking daily medications, but ethnicity was not (Table 6). Among children with

TABLE 6. Bivariate association of demographic factors with medication use pattern among children with known or probable current asthma who also meet criteria for persistent asthma (n = 708)

	Medication use			Total
	None	Intermittent	Daily	
Gender*				
Male	99 (26.6)	102 (27.4)	171 (46.0)	372
Female	117 (37.6)	71 (22.8)	123 (39.6)	311
Location of residence*				
East	146 (30.5)	113 (23.6)	220 (45.9)	479
Southwest	67 (34.0)	59 (30.0)	71 (36.0)	197
Ethnicity				
African American	162 (31.2)	122 (23.5)	236 (45.4)	520
Hispanic	29 (30.9)	33 (35.1)	32 (34.0)	94
Caucasian/other	23 (34.3)	17 (25.4)	27 (40.3)	67
Language*				
English only	187 (31.0)	144 (23.8)	273 (45.2)	604
English/Spanish	14 (41.2)	7 (20.6)	13 (38.2)	34
Spanish only	14 (32.6)	21 (48.8)	8 (18.6)	43
Age, mean (SD)	8.7 (1.3)	8.8 (1.3)	8.8 (1.4)	688

A child is defined as having persistent asthma if he or she has active symptoms or if he or she is using daily medications for breathing problems. Data were missing for 25 children on gender, 32 children on location, 27 children on ethnicity, 20 children on language, and 9 children on age.

*Statistically significant difference in medication use pattern at least at the $P = .05$ level.

persistent asthma (either mild or moderate to severe), eastside residents were more likely to be on daily asthma medicines compared to southwest residents (45.9% vs. 36%, respectively). Respondents who spoke Spanish only were significantly less likely to use medications on a daily basis, compared to those who spoke both Spanish and English or English only (18.6% vs. 38.2% and 45.4%, respectively), although the number of non-English speakers with persistent asthma was small. These differences in use of daily medication appear to be attributable to differences in asthma severity among these groups, as adjustment for age, gender, and asthma severity eliminated the associations of demographic factors to use of daily medications seen in bivariate analysis (results not shown).

DISCUSSION

The recruitment efforts for the CAAA project described here display how the use of a CBPR approach can successfully identify and characterize children with known or probable asthma with persistent symptoms in a community setting. Of the children identified, many reported frequently occurring asthma symptoms, and many of these children had never been diagnosed with asthma. Even among those who have been diagnosed, many are on levels of medication that appear inadequate for their degree of symptoms. Over one third (254/708) of children reporting symptoms frequent enough to be classified as having persistent asthma according to the NAEPP guidelines did not report a physician diagnosis of asthma. Approximately half of those reporting a moderate-to-severe persistent level of asthma symptoms and two thirds of those reporting mild persistent symptoms did not report using daily asthma medications as recommended by the NAEPP. Our results suggest there is considerable underdiagnosis and undertreatment of asthma among children living in these Detroit communities.

It is important to recognize that the information presented here does not describe the underlying prevalence of asthma or asthma severity in the general Detroit population. The intent of this study was to identify children with persistent asthma symptoms, regardless of their contact with the health care system, who would be most likely to benefit from the CAAA intervention. Therefore, we asked parents with more than one child between 6 and 11 years of age with asthma to complete the questionnaire regarding only the child in the family with the most severe breathing problems. It is also probable that families who had a child with breathing problems were more likely to return the survey than families who did not. Although our methodology does not allow us to estimate accurately the underlying asthma prevalence in the overall population, the strength of these data is to describe characteristics of symptomatic children independent of a child's interaction with the health care system. From these data, we are able to identify and derive a picture of those children who may not be receiving adequate care from the medical system.

Our findings in Detroit are consistent with studies in other regions, which showed that a large number of probable asthmatics with asthma symptoms have never been diagnosed with asthma.^{2,9,13,14} It is this large subgroup of children who reported asthma symptoms but who had not been diagnosed with asthma (or at least whose parents were unaware of an asthma diagnosis) we were particularly concerned may be at high risk for having adverse health consequences of asthma. Similarly, despite large-scale attempts at disseminating and educating physicians on the NAEPP treatment guidelines and educating physicians on their use, several investigators have identified a discrepancy between guideline recommendations and actual practice patterns.^{15,16}

Studies conducted in the Bronx, New York, and Baltimore, Maryland, have each estimated that approximately 55% of children with moderate-to-severe persistent symptoms are not using daily anti-inflammatory medications.^{15,17} A study of asthmatic children receiving Medicaid insurance in Connecticut identified a similar percentage.¹⁸ Although these studies did not distinguish between issues related to physician practice pattern and family medication adherence, other authors have documented several barriers to physician adherence to the practice guidelines.¹⁹⁻²⁶ These issues include financial, systems, or geographic barriers to accessing health care, barriers in communication between families and physicians, physician knowledge of diagnostic and treatment guidelines and belief that they are relevant to their patients, family health beliefs about the use of medications, and social stresses that interfere with families' ability to adhere to treatment recommendations.

Exploration of the causes of underdiagnosis and undertreatment was beyond the scope of the current study. However, for the subgroup of 298 children who were eventually enrolled in the CAAA program, we do have some potentially relevant information. Clearly, this is an economically stressed population, with 60% reporting a family income of \$15,000 or less. Yet, among the children enrolled in CAAA, 94% had both a source of regular health care (excluding the emergency room) and health care coverage. Of CAAA participants, 9% reported that during the last 12 months they had delayed seeking medical care for their child because of worries about cost or inability to afford care. Although financial barriers likely are critically important factors influencing care utilization for some children, we were struck by the relatively low proportion of families reporting lack of insurance or cost having influenced care-seeking behavior. This suggests that we need to look beyond the lack of insurance coverage alone to identify the causes of underdiagnosis and treatment in the Detroit community.

A key strength of the methods described here is the ability to identify children whose asthma is underdiagnosed and/or undertreated because these children are likely to benefit from intervention efforts. Input from the community partners on the steering committee was critical in guiding the efforts to identify children with asthma. For example, community partners were instrumental in hiring a community member to coordinate the recruitment, in suggesting incentive options to be tested, in facilitating contacts with the Detroit elementary schools, and in guiding implementation of the community-focused recruitment methods. Once these recruitment efforts were designed, the field coordinator's long-standing history in the community was extremely helpful in implementing them. She brought both knowledge of how to spread information within the community and an intrinsic sensitivity to the interests and concerns of community residents.

These factors were key in setting up initial appointments and in generating interest in the project among school principals and parents. The fact that messages about the study as conveyed in letters, flyers, and oral presentations had all been coauthored and edited by community partners and were delivered by the field coordinator helped bridge a mistrust of researchers in the community. Without the combined knowledge, expertise, and guidance of the steering committee community partners and the field coordinator, it is likely that the response rate to the questionnaire would have been much lower. Community partners have similarly guided the design and implementation of the CAAA household intervention, enhancing participant recruitment and retention, improving the accuracy of measurements and

strengthening the links between research and community needs.⁷ In these ways, we feel that the use of a CBPR approach directly enhanced the quality, validity, and relevance of the current study.

CBPR incorporates both the idea that the research occurs in the community setting and that community members are equal partners in designing and conducting the research.³ Participation of community members in all aspects of research is increasingly recognized as an important factor in (1) improving the quality and validity of research; (2) increasing the relevance of research to and usefulness of results by the people it is designed to benefit; (3) bringing together partners with diverse knowledge and expertise to address complex problems; and (4) overcoming the understandable distrust of research on the part of communities that have historically been the “subjects” of such research.^{3,27–38} Indeed, funding agencies are beginning to emphasize the value that CBPR approaches contribute to medical research, particularly when conditions with a large community impact are involved.³⁹

CBPR is not without challenges.³ Developing the trusting relationship between academicians and community members that is necessary for a successful partnership takes time and ongoing effort. Many decisions need to be made by committee, which can be a slow process for researchers used to decision-making autonomy. Furthermore, conducting research in the community setting requires flexibility and, if appropriate, accommodation of research protocols to the realities of community life. For example, during the design phase of our study, the governor of Michigan replaced the elected Detroit school board with appointed officials. This created a politically charged atmosphere in the school system, which required protocol adjustments in the timing and methods used for contacting student families. The knowledge and expertise of the community partners on the steering committee were instrumental in negotiating these hurdles.

Some limitations of our study include relatively low response rate, limited information on the type of medications used, and lack of information on factors, such as insurance status, that may affect access to care or ability to adhere to physician recommendations for care. The design of our recruitment procedure does not allow us to assess differences in response rates by subgroup. The reported association between ethnicity and asthma severity should therefore be interpreted cautiously. This association may reflect a true relationship between African American ethnicity and more severe asthma or may represent differences in response rate by both ethnicity and severity. Although we rely on parental report to ascertain asthma status, there is considerable precedent for using symptom questionnaires to define asthma, and the literature supports use of surveys as sufficient to identify persons with asthma.^{9,40}

Identifying a group of symptomatic children with asthma is the first step toward further study of the factors influencing their health and toward designing direct interventions and changes in health care systems to improve asthma health outcomes and quality of life. Other studies have pointed out that underdiagnosis and undertreatment of asthma in children tend to be multifactorial problems involving physician knowledge and attitudes toward practice guidelines, physician communication skills, health care systems issues, family knowledge and beliefs about the chronic nature of asthma as well as risk/benefits of asthma medications, and competing stresses and financial strains on families.^{15,16,20,21,41–45} The extent of underdiagnosis and undertreatment of childhood asthma in east and southwest Detroit highlights an opportunity for improving health outcomes through further community–academic collaborative research and intervention.

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