

Asthma Mitigation Strategies

Professional, Charitable, and Community Coalitions

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Background: Asthma symptoms, severity, and mortality are known to be affected by personal, family, and neighborhood social factors. Many groups have become involved in asthma research, education, and activism in the past 20 years. This study explores the approaches to asthma taken by community-based organizations compared with those taken by other organizations that have a focus on asthma.

Methods: Priorities in asthma research and intervention were assessed through interviews with representatives of urban community-based participatory research (CBPR) coalitions; interviews with staff from charities focused on asthma, allergy, or lung diseases; interviews with physicians and scientists studying and treating asthma; participation in community forums; and participant observation of urban asthma coalitions. Interviews and data analysis were conducted in 2008.

Results: There are marked differences in priorities and approaches to asthma among experts in the field, organizations and coalitions at the national and local levels, and other stakeholders in asthma research and activism. CBPR coalitions are more likely than asthma-focused organizations to explore environmental and community-level structural factors that exacerbate asthma or complicate its management, while disease-focused organizations, especially physician specialty groups, place more emphasis on individual-level factors. CBPR coalitions have been particularly strong in producing the data needed to demonstrate that individual communities are affected by pollution hot spots or that local neighborhoods lack geographic access to affordable medical care, and in providing this data to improve local policy-making.

Conclusions: Because of its focus on structural rather than individual factors, CBPR has helped to broaden the debate on asthma beyond clinical care and education into social and environmental justice.

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Introduction

Asthma emerged as a major health crisis in the 1990s. From 1982 to 2004, asthma prevalence in the U.S. more than tripled, growing from 3.1% of the population to 10.7% (National Health Interview Survey).^{1,2} Hospitalizations for asthma increased sixfold among children from 1970 to the mid-1990s, and asthma mortality doubled from 1978 to 1999.³ Experience in the U.S. mirrors that in many industrialized countries including the UK, Germany, France, Australia, and New Zealand.^{4,5}

Asthma illustrates health disparities because of its socioeconomic gradient; asthma hospitalizations and mortality are most severe in inner city communities where racial minorities live in poverty.^{6–9} In some areas of Chicago,¹⁰

New York,^{11,12} and Philadelphia, up to 30% of children are reported to be asthmatic (unpublished data from the Philadelphia Asthma Task Force). Even with similar prevalence of wheezing, inner city children are more likely than suburban children to carry a diagnosis of asthma because of their greater severity of illness¹³ and the context in which they receive care (emergency department versus primary care).¹⁴ Poor-quality housing has been linked to asthma exacerbations since the 1930s.¹⁵ Exacerbations related to allergens,¹⁶ especially dust mites¹⁷ and cockroaches,¹⁸ environmental tobacco smoke,¹⁹ and diffusion of outdoor air pollutants contribute to illness.²⁰ Other explanations for increased asthma prevalence and severity in inner-city neighborhoods include lack of health insurance,²¹ poor access to high-quality providers in the inner city,^{13,22} and exposure to stress²³ and violence.²⁴

Individual, Neighborhood, Regional, and National Levels of Analysis

Until recently, most studies of asthma focused on exploring either secular trends at the aggregate level or risk factors at the individual level. Studies of secular

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trends have compared countries around the world²⁵; cities within a single country²⁶; or time trends within localities, regions, and countries²⁷ in order to generate hypotheses about the impact of clinical, environmental, and social factors. Researchers have taken advantage of natural experiments such as episodes of unusually high air pollution²⁸; the reunification of East and West Germany in the 1990s, which had had differing lifestyles and differing pollutant exposures for 50 years²⁹; and the change in commuting patterns during the 1996 Olympics to evaluate risk factors for asthma—air pollution in particular.³⁰ Other studies, particularly of healthcare access,³¹ adherence to medication,³² and allergic sensitization,⁶ have focused on individual-level variation.

There has been tremendous interest in exploring neighborhood health effects in recent years; incorporating concepts and methods from sociology, public health, social epidemiology, medical geography, and community activism to reconsider and reanalyze explanatory models and modes of intervention.³³ An early study³⁴ showed geographic disparities in asthma morbidity and mortality, with disproportionate burdens in New York City, Chicago, and Phoenix. Other studies showed that within affected cities, neighborhoods and individuals were at increased risk with increasing poverty, with the greatest burden among members of racial minority groups.³⁵ Neighborhood context may influence health through many pathways, including environmental exposures; public safety and exposure to violence; access to fresh fruits and vegetables (which may be relevant to asthma through increased antioxidant intake or reduced obesity); and access to open spaces for exercise. A study of the Chicago heat wave of 1995 that killed over 700 people found that physical isolation, social vulnerability, and lack of neighborhood vitality were predictive of who would die.³⁶ Multilevel modeling approaches have been essential to beginning to untangle some of these individual- and neighborhood-level effects.^{37–40}

Many different groups have become involved in asthma research, education, and activism in the past 20 years. Established groups such as the American Lung Association and the Asthma and Allergy Foundation of America, both of which have national networks of affiliates, have been joined by local and national coalitions dedicated to addressing asthma as a growing problem and an issue with substantial local impact. This study explored the approaches to asthma taken by community-based organizations compared to those of other organizations with a focus on asthma.

Methods

Priorities in asthma research and intervention were assessed through interviews with representatives of urban community–university community-based participatory research (CBPR) coalitions; interviews with physicians and scientists studying

and treating asthma; interviews with staff from charities focused on asthma, allergy, or lung diseases; participation in community forums; and participant observation of urban asthma coalitions. Interviews and data analysis were conducted in 2008.

A list of 31 local and regional asthma coalitions and charities with a focus on asthma, allergy, or lung disease were identified by a combination of literature review, Internet searches, consultation with experts, and snowball sampling. Local chapters of the American Lung Association and the Asthma and Allergy Foundation of America were excluded in order to avoid having a large fraction of the interviews reflect similar institutional priorities, but national offices were included. These organizations were contacted by letter in February 2008, and follow-up telephone interviews were conducted with staff and community steering committee members in March 2008. Organizations were contacted by telephone a maximum of three times, and interviews were conducted until theoretic saturation was reached and a range of organization types was represented (lay-led charities, medical professional-led organizations, community-based coalitions). Semi-structured interviews covered domains including the organization's interests in and activities around asthma, how they decided to work on asthma, what they thought were the main problems, whether and how they saw the problem in their community as well as at the national level, and what activities they felt were important but more properly undertaken by others. Interview notes and documents were reviewed for emergent themes using a case-based and ethnographic approach. Human subjects approval for study design and instruments was obtained from the University of Michigan Medical Center Institutional Review Board.

Results

Leaders of both national charities and organizations that focus on asthma, as well as local and regional coalitions, were interviewed. All were asked whether asthma was a problem for their constituents, and what aspect or aspects of the problem they felt were most important. They were then asked to describe their organization's activities and how they had decided on areas of focus and specific activities. Although all agreed that asthma is complex and multifactorial, organizations doing clinical work, education, advocacy, and research chose different points of intervention at which to focus their effort. Leaders described their priorities for work to address asthma as based on (1) likely impact on the problem overall; (2) the specific needs of their constituents or communities; (3) their own organizational strengths and skills; and/or (4) larger goals such as health promotion, environmental justice, and community empowerment. See Table 1 for a classification of asthma organizations by their main priority, and Table 2 to see the range of activities in the portfolios of selected organizations.

These coalitions took a variety of approaches based on local needs, including improving referrals to health

Table 1. Approaches to asthma at different levels

Self-management and medical adherence
Medical providers
Health insurers
Pharmaceutical companies
AAFA (and network of AAFA chapters)
Education and consumer empowerment
Allergy & Asthma Network/Mothers of Asthmatics
American Lung Association (and network of local Lung Associations)
Public health and coalition building (including healthcare access)
CDC
Robert Wood Johnson Foundation's Allies Against Asthma
ALIANZA
CINCH, Hampton Roads VA
FAM Allies
KCAF
LBACA
NCAC
PAAA
Coalitions in NY, Chicago, Boston, Seattle, Philadelphia, and other cities
Environmental justice and grassroots organizing around environmental issues
Alternatives for Community & Environment (Roxbury, MA)
WE-ACT (Harlem, NY)
Community Action Against Asthma (Detroit, MI)
LBACA

AAFA, Asthma and Allergy Foundation of America; ALIANZA, Alianza Contra el Asthma Pediátrica en Puerto Rico; CINCH, Consortium for Infant and Child Health; FAM, Fight Asthma Milwaukee; KCAF, The King County Asthma Forum; LBACA, Long Beach Alliance for Children with Asthma; NCAC, National Capital Asthma Coalition; PAAA, Philadelphia Allies Against Asthma; WE-ACT, West Harlem Environmental Action

insurance and affordable healthcare providers, educating health providers on asthma guidelines, public education, advocating for improved asthma awareness in schools, and research.⁴¹ The American Lung Association, with the resources of a national organization, was able to create education programs for multiple audiences, including schools, communities, and the general

public; to disseminate this work through its local chapters; and to provide it to other organizations seeking to improve awareness and understanding of asthma. One foundation officer, when asked the most important challenge in dealing with asthma, immediately replied "patient compliance." A leader at another organization said "knowledge" and "patient education" were most important. These organizations consequently chose to focus their efforts on patient and provider education, dissemination of protocols, and media campaigns to increase awareness of asthma and its treatment. In contrast, coalitions in Chicago, Boston, Washington, and Philadelphia were particularly active in healthcare access issues, with the Chicago coalition creating the first GIS map of affordable health clinics in that city, which they went on to share with the local health department and other providers and agencies, expanding their impact on the local safety net beyond asthma. The New York, Boston, and Chicago coalitions, which had evidence of underuse of preventive medications in their communities, even among children with asthma who had access to primary care, were also very active in disseminating evidence-based treatment guidelines to frontline and safety-net clinicians in their communities.

Asthma coalitions were formed in the mid-1990s in New York,⁴² Chicago,⁴³ and Philadelphia,⁴⁴ linking medical providers, researchers, schools, insurers, and community organizations to share information and educational materials, and plan joint projects. These coalitions were led by medical or public health professionals and had varying levels of community involvement over time through board membership, educational programs, and community interventions. Some reported difficulty recruiting and retaining community members in their initial efforts in the early 1990s. Informants from Chicago and Philadelphia explained that economic pressures and community violence seem like more pressing problems to many community members: "More than asthma, the people we are working

Table 2. Activities of asthma coalitions

Organization	Clinical and individual models ← → public health and social determinants									
	Patient education	Provider education	Research	Lobby	School	Housing	Pollution	Protest	Empowerment	
ALA	X	X	X	X	X		X			
AAFA	X	X	X	X						
AAN/MA	X			X	X					
NYC Asthma Partnership	X	X	X	X	X	X				
Boston Urban Asthma Coalition	X	X	X	X	X					
Chicago Asthma Consortium	X	X	X	X						
CAAA			X	X		X	X	X	X	X
ACE			X	X	X	X	X	X	X	X
WE-ACT			X	X	X	X	X	X	X	X

ALA, American Lung Association; AAFA, Asthma and Allergy Foundation of America; AAN/MA, Asthma & Allergy Network/Mothers of Asthmatics; CAAA, Community Action Against Asthma (Detroit); ACE, Alternatives for Community & Environment (Boston); WE-ACT, West Harlem Environmental Action

with are worried about getting food on the table, or not getting shot on the way home.”

By the late 1990s, CBPR collaborations^{45,46} across the country had joined university and medical researchers, and community groups and residents in research, policy work, and advocacy around inner city asthma,^{47–51} in which community members were full participants in the research, from framing research questions and study design, to analysis and dissemination of results. Coalitions in New York, Seattle, and Detroit were funded by the CDC as part of a larger effort to encourage urban community–university collaborations.^{52,53} Additional asthma coalitions were formed with funding from the Robert Wood Johnson Foundation in Puerto Rico; Hampton Roads VA; Milwaukee WI; Seattle/King County WA; Long Beach CA; Washington DC; and Philadelphia PA.⁵⁴

These later coalitions were more likely to focus on environmental issues, although access to health care and education remained priorities for many. Coalitions in Roxbury MA, Harlem, and Detroit identified pollutant sources within their neighborhoods as their major concern, especially garbage incinerators and bus depots, and advocated for local source remediation and blocking the location of new polluting facilities in their neighborhoods. At Boston's Alternatives for Community & Environment (ACE), students who were being trained in environmental science and community activism identified asthma as a priority for themselves and their peers. One third of their first group of students had asthma themselves, and the rest had family members with asthma.⁵⁵ Mothers in the community had noticed that bus exhaust pipes are at the same height as the breathing zone of elementary school children, and raised questions about whether their children's pollutant exposures were greater than generally recognized. Community members teamed up with researchers from the Harvard School of Public Health (HSPH) and used mobile air sampling devices to collect data on fine particulate matter and particle-bound polycyclic aromatic hydrocarbons. They created a GIS map of neighborhood pollutant levels, which found increased levels near bus depots, along bus routes, and in the 3-to-4 foot–high level at which many children breathe.^{56,57} This kind of neighborhood-level mapping has become feasible only recently, and the ACE–HSPH was one of the first groups to use it. The Long Beach Alliance for Children with Asthma (LBACA), partnered with the University of Southern California, also focused on neighborhood pollutant levels, placing air-quality monitors at eight schools in the community.⁵⁴

West Harlem Environmental Action (WE-ACT), in cooperation with Columbia University,⁵⁸ and Detroit's Community Action Against Asthma (CAAA), in partnership with the University of Michigan,⁵⁹ conducted comprehensive assessments of indoor and outdoor environmental exposures and their impact on asthma, using monitors in schools and homes. Each of these

projects involved a network of community organizations together with hundreds of families, and results were provided to community members and policymakers so they could inform policy decisions.^{49,60} Advocates from WE-ACT described the sensory experience and impact of living downwind:

Millicent Redick raised a son and daughter here in Harlem, across the street from the city's Mother Clara Hale Bus Depot. She recalls how they both suffered from eczema and asthma. “I was always led to believe that I had to keep the dust out of my apartment, so I cleaned all the time,” says Redick, 61, a retired accountant. “But I was never informed that the air we were breathing played a role . . . I thought it was all me.”⁶³

“We think (the depots are) very, very responsible for the high asthma rates in the community,” says Kizzy Charles-Guzman, policy coordinator of the group WE ACT for Environmental Justice.

“It goes beyond air quality . . . It's also quality of life impact. You have constant noise and vibrations from the buses, and we also have sanitation truck depots and sewage treatment facilities . . . We're not necessarily saying let's shut down the depots and move them all over the city, but if all the clean buses the (bus agency) claims to have in the fleet were assigned to these particular depots, that would help.”⁶¹

In Roxbury, Harlem, and Detroit, the emphasis on data generation was important because the citywide air pollution data from central monitoring sites failed to account for the impact of local industrial facilities and traffic patterns which could lead to local particulate levels 20- to 200-fold greater than city averages. One community informant from Detroit explained: “Working with the university brought a new level of sophistication. The idea that smoke has characteristics to it—components . . . But we were able to go a lot further with lobbying and testifying because we had better data.”

Discussion

Attempts to improve asthma have been split between those that focus on health care and individual behavior and those that focus on the social and physical environments that predispose residents to illness.⁶² The National Asthma Education and Prevention Program has issued three clinical guidelines and numerous reports on asthma since 1991.⁶³ Physicians, medical researchers, and public health experts on asthma have focused on developing and delivering state-of-the-art asthma prevention, treatment, and self-management. Healthcare provid-

ers, public health departments, and many others have worked to improve asthma care.

Medical providers, health insurers, and organizations that understand asthma as a problem of healthcare focus on individual behavior, particularly the use of medications. Use of preventive medicines such as inhaled corticosteroids have been a particular focus of research and intervention because they can prevent symptoms, reduce the frequency of exacerbations, and result in lower rates of hospitalization.⁶⁴ Traditional health charities with physician leadership or close ties to medical specialty societies have also tended to mirror this emphasis on individual behavior and medication adherence. The American Lung Association; American Thoracic Society; American Academy of Allergy, Asthma, & Immunology; American College of Allergy, Asthma & Immunology; and Asthma and Allergy Foundation of America have a substantial focus on asthma, and emphasize patient education, clinical care, and use of preventive medications. Although these organizations also advocate on issues of air pollution, poor housing, and other risk factors for asthma exacerbation, their major activities reflect predominant clinical orientations, as opposed to public health or environmental perspectives.

The persistence of high rates of asthma, despite intensive clinical efforts, has led many to conclude that coalitions are needed to address other aspects of the problem.^{54,65,66} Public health agencies and charities such as the Kaiser Family Foundation and the Robert Wood Johnson Foundation have emphasized access to primary care and have linked their work on asthma to this issue with broader healthcare-access and disparity-elimination campaigns.^{67,68}

More recently, two types of what sociologist Phil Brown has called “embodied health movements” have formed around asthma, in which sufferers, their families, and their communities participate in advocacy, policy work, and research while challenging some of the assumptions of the field.^{69,70} Movements around asthma have followed the example of breast cancer activism, combining approaches from public health research, community organizing, and environmental justice.^{71–73} Following other social movements, these asthma advocacy organizations use tools including consumer action, government regulation, and public pressure to increase access to treatment, improve housing conditions, and decrease pollution.^{74,75} Many of these organizations also created partnerships with researchers at local universities to demonstrate their neighborhood pollutant exposures and the consequent health effects.^{76–79} These approaches to citizen advocacy around asthma often employ strategies based on different experiences of the disease in diverse communities.

An informant from Detroit explained:

I didn't really think about it this way before, how different groups see asthma differently, but if you're

living in pristine suburban America, you're starting from a different place than urban folks. Where you start is where you live It's easier for local groups to look at the environmental issues because they can see it In the community we know it's black smoke and it's bad.

In general, the approaches taken by members of poor communities locate the cause of asthma in public nuisances that contribute to making their children sick, rather than focusing on an individualized ethic of health and disease located within the homes, families, and bodies of sick children.

Different Perspectives, Complementary Interventions

Medical and public health professionals, health insurers, pharmaceutical companies, charities, and CBPR coalitions all bring different emphases to their work on asthma. Asthma is a disease in which biologic susceptibility, environmental triggers, healthcare access, and social vulnerability all contribute to symptoms, hospitalization rates, and mortality. Although interventions directed at the individual, family, neighborhood, and broader societal levels all have the potential to reduce the burden of asthma, the recent emphasis on neighborhood-level predictors and the use of GIS, multilevel modeling, and CBPR have tremendous potential to improve asthma-related disparities.

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