

Case Report

Community-Based Participatory Research in Boston's Neighborhoods: A Review of Asthma Case Examples

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ABSTRACT. Three case examples of asthma studies that differ in terms of community and involvement are considered. The Boston Chinatown studies faced limited funding that restricted the level of community involvement, but resulted in some of the first published evidence about asthma in Asian American children. These studies led to an asthma education program grant to a local Asian clinic and elementary school. The public housing study was a well-funded multi-year study of asthma and pest management with city, university and community partners. Residents were trained to collect data and participated throughout the study. Follow up pest management and pesticide buy-back programs headed by the city and community partners have been funded. The Dorchester case had more limited funding, but had the greatest level of involvement of parents of asthmatic children in all phases of the research. This survey led to an interesting novel finding of lower asthma prevalence in foreign born black residents.

KEYWORDS: African Americans, asthma, community-based participatory research, epidemiology, research methods

In the period 2001 to 2003, it was reported that 8.5% of children in the United States reported current asthma. The prevalence for children was higher than for adults. In addition, females were more likely to report asthma than males and Puerto Ricans and African Americans more likely to report asthma than were Mexican immigrants or whites.¹ In 1998, asthma accounted for an estimated \$12.7 billion in costs annually in the United States,² a cost that was estimated to have increased to \$16 billion by 2004.³ There are various measures of asthma morbidity by demographic variables, most of which point to higher morbidity for African Americans compared to white and Hispanic populations, but some of which suggest that Hispanics suffer morbidity between that of whites and African Americans.¹ Studies of asthma internationally suggest that asthma prevalence (or indicators of asthma prevalence, such as wheezing) are higher in more

developed countries such as the United States, UK, and Australia, than in developing nations.⁴ Although the causal pathways for development of asthma are not well elucidated, it is clear that a wide range of environmental factors exacerbate asthma in people who already have it.⁵

COMMUNITY-BASED PARTICIPATORY RESEARCH AND ASTHMA

Community-based participatory research (CBPR) may be particularly relevant for asthma research for several reasons. First, many communities have become concerned about rising asthma prevalence on their own and have begun to demand that something be done to address the issue. The Boston Urban Asthma Coalition (BUAC), a partner to one of

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our cases and contributing author to this article, is a good example of this. The BUAC grew out of concern about and interest in addressing asthma in Boston communities (<http://www.buac.org/>). Many community-based organizations, including BUAC, also *want* to be involved in any ensuing research in their community. Two of the case studies that we report below (the Dorchester/BUAC and public housing case examples) engaged grassroots community-based organizations that strongly demanded full involvement in the research process.

Second, at least some interventions aimed at reducing asthma morbidity are likely to be more successful if the families of asthmatics are actively engaged in responding to the problem. For example, pest management that aims to reduce cockroaches, mice, and other infestations that exacerbate asthma may work best when families prepare their home prior to professional pest management efforts.

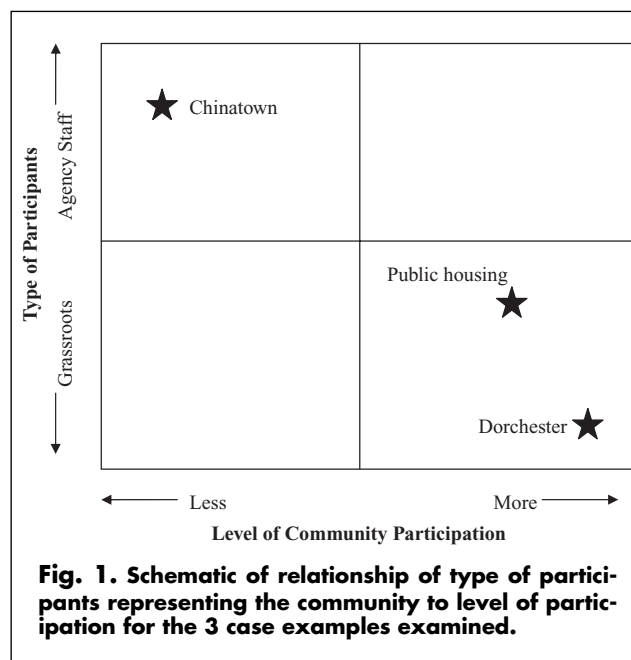
Third, CBPR may be better poised to incorporate the lessons of the research directly into program project interventions at the community level. These interventions, arising directly after completion of the research, may be tailored to the community needs and begin much sooner than interventions based on more traditional research approaches that have to filter their way through the publication process and then become known to agencies or entities that work with the affected communities. Finally, because asthma is a greater problem in low-income and minority communities and most researchers are high income and white, collaboration may bridge gaps across racial and class divisions.

For all of these reasons, there have been a number of CBPR studies addressing asthma that have been reported in the literature.⁶⁻⁹ One indication of a possible limitation, at least to date, of CBPR is that of the large number of rigorous randomized controlled trials addressing asthma, including both educational¹⁰ and environmental interventions,¹¹ we are aware of only one that was conducted in a CBPR paradigm.¹²

CBPR CONTINUA

Although at one time a more or less fringe methodology, community-based participatory research (CBPR) has been gaining acceptance in recent years in establishment circles, including the National Institutes of Health. In its fullest expression, CBPR is responsive to community needs and concerns and has community involvement in all phases of the research process.^{13,14} However, other models for community collaboration have also been described and critiqued.¹⁵ Self-declared CBPR efforts appear to vary along multiple axes or continua, two of which we will use in this paper to frame our case studies.

At the far pole of one continuum would be full participation of the community in every aspect of the research, including deciding on the topic(s) to be studied, the design of the study, data collection, entry and analysis, and interpretation, and dissemination of findings (*x*-axis on Figure 1). At the other end of this continuum would be partnerships in which the



community partner(s) participate in only limited ways in the research while professional researcher partners do the bulk of the science. This end of the continuum begs the question of when the project ceases to be a community collaboration and becomes traditional community placed research. For us, the research is still a collaboration so long as there remains a community partner with an interest in the results that plays at least a limited role of some sort, for example commissioning the study topic and/or receiving the findings.

The second continuum (*y*-axis on Figure 1) is from grassroots community partners, sometimes seen as the “affected” community to partners who work with the affected community, such as organizers, agency and clinical staff, and the like. For our case examples, the grassroots or affected community would be the people who have asthma, their immediate family members, and people who live in the same housing. It may be worth noting that working with the affected community will be decidedly different if that community is one with highly educated members who speak English than if it is a low-income and/or immigrant community. The latter will entail greater investment of resources, as we shall see in our case examples.

Here we examine community-based research on asthma in which we have participated that took place in 3 Boston neighborhoods: (1) public housing in South Boston and Dorchester, (2) the Dorchester population more generally, and (3) Boston Chinatown. These cases differed in terms of level of community involvement and the sectors of the community that were engaged (stars on Figure 1). We believe that the contrasting approaches and outcomes from these projects provide insight into some of the strengths and limitations of CBPR as we practiced it.

CASE 1: BOSTON CHINATOWN

The Chinatown case example involved partnership with staff at community-based clinics, schools, and organizations, with little attempt to involve the families of asthmatic children directly. Further, the involvement of the community in the research processes of this series of studies was relatively shallow, rather than deep (see Figure 1). That is, the community-based staff was involved in only aspects rather than most or all parts of the research process. Tufts University faculty and students led this series of relatively small-scale studies of asthma among recent Chinese immigrants living in or attending school or clinics in Boston Chinatown. The community partners included the Josiah Quincy Elementary School, the South Cove Community Health Center, the Asian Clinic at Tufts-New England Medical Center,⁴ and the Chinese Progressive Association.

There were good reasons for the relatively limited role that community representatives played in these studies. The community partners were professional staff (nurses, physicians, school administrators, health aides, and community organizers) who had very limited time available to commit to research, which constrained their involvement. Even more challenging was involving the affected population, the children with asthma, and the parents of those children. These families require substantial resources to engage because they do not speak English and work long hours in low-wage jobs while all of these studies had little or no funding. The partner organizations were also, in some cases, more interested in the research findings than in participating in all aspects of the studies. The community partners were, however, ethnically and linguistically Chinese and worked closely with the affected community on a daily basis.

The Chinatown asthma studies were all student projects and were conducted in 1 to 2 semesters. Accordingly, they mostly employed survey questionnaires, were cross-sectional and, with one exception, did not attempt to reach a representative population sample. Nevertheless, these studies were both highly efficient at producing interesting findings and contributed to the funding and development of an asthma educational program for the community.

The first study was a cross-sectional survey of all children in the local elementary school. This survey achieved a high response rate by sending the survey home with the school children and having them return it after their parents had completed it. We deemed the sample to be representative of the school population, which in turn draws from a largely Chinese catchment within Boston. The resulting paper was the first report of asthma prevalence in an Asian American population.¹⁶ A second study recruited a convenience sample of people on the street in Chinatown and, in that respect, resembled the Dorchester survey to be discussed in example 3.¹⁷

⁴Tufts-New England Medical Center is a separate corporate entity from Tufts University and the Asian Clinic counts as a community-based organization in our framework.

Three clinical population studies were also conducted. These studies recruited from 2 pediatric waiting rooms, which meant that they were appropriate for testing associations, but were enriched for sick and asthmatic children. Thus their findings could not address issues of population prevalence. The first of these studies included measurement of pulmonary function, but listed as its main findings problems with translation of key asthma concepts (wheezing) into Cantonese and large differences in asthma prevalence between native- and foreign-born children (in advance of the similar finding among African American respondents in Dorchester; see case 3).¹⁸ The second clinical asthma survey in Chinatown confirmed the native/foreign-born finding¹⁹ and demonstrated lower knowledge about asthma in Asian compared to non-Asian respondents.²⁰

Of significance, the Chinatown studies are among the first studies of asthma in Asian Americans (the first Boston Chinatown study¹⁶ was followed by 2 larger surveys, 1 in California²¹ and 1 in New York City²²) and they were the first to report on the role of language and nativity in asthma in this population.

The Chinatown asthma studies, by providing data for the first time on asthma prevalence and the unique issues facing the Chinese immigrant community with respect to asthma, helped lay the basis for a grant proposal that was funded by the Blue Cross/Blue Shield Foundation of Massachusetts. The funding was to the Asian Clinic at Tufts-New England Medical Center for a 3-year collaborative programmatic project to develop and deliver a linguistically and culturally appropriate asthma education program in Boston Chinatown. The main partner to the asthma education project was the Josiah Quincy Elementary School, which was also the community collaborator on the first asthma survey in the community. As this was primarily a service delivery project, it could not advance the participatory research paradigm beyond what had been done before in the community.

The education project developed a Chinese-English bilingual education program that has begun to be used in the school. The program includes translated materials, including an asthma action plan, a bilingual and culturally appropriate children's book developed specifically for the community, and a bilingual video. The educational intervention is presented by a bilingual nurse who was hired by the hospital and includes activities such as using a peak flow meter, naming asthma "triggers," a word hunt, "building a bronchiole," and reviewing medications. Evaluation of the effectiveness of the program is quasi-experimental, resting primarily on assessment of school absences before and after the intervention without a control group. To date, only the preintervention school absence data have been collected.

CASE 2: THE HEALTHY PUBLIC HOUSING INITIATIVE

The Healthy Public Housing Initiative (HPHI) is a university community-city collaboration that started with multiple

pilot studies that led to a complex, multiyear investigation of pest (cockroach) management and pediatric asthma.^b HPHI, throughout its multiple phases, engaged the affected community (public housing residents) in most aspects of the research process; however, agency staff were more deeply involved in the leadership and strategic direction of the work than were public housing residents (see Figure 1). Some of the lessons of the HPHI collaboration were recently published²³ however, here we will focus on those features that allow cross comparison to our other case studies.

Although HPHI had modest beginnings in a series of pilot CBPR studies that grew from cross-sectional surveys^{24,25} to more sophisticated exposure assessment,²⁶ the full expression of HPHI was large scale, complex, and ambitious. HPHI was primarily funded by US Department of Housing and Urban Development and the W. K. Kellogg Foundation, but included funding from local foundation and US Environmental Protection Agency. The partnership consisted of 10 organizations, including 3 community groups, 3 universities, and 2 city agencies plus consultants, all of whom were funded to participate. The research plan included focus groups, a scientific sample cross-sectional survey, and an intervention trial of integrated pest management.

HPHI was one of the first research efforts that sought to influence severity of asthma through integrated pest management (IPM).²⁷⁻²⁹ IPM is a method for controlling pest infestation, in this case cockroaches, that minimizes use of toxic pesticides. There were limitations to the HPHI intervention study, the most notable of which was the lack of a control group, a study design opposed by the community partners. This led to use of longitudinal analyses to assess efficacy.^{28,29} It must also be noted that the results of the analyses suggested that IPM was effective over 6 to 9 months, but that it was not fully sustained. Health outcomes showed some benefits for asthmatic children, but the causal association with the intervention was not firmly proven.

HPHI was particularly successful at generating benefits for the city/community. Following completion of the research phase, the W. K. Kellogg Foundation funded the city and the community partners to develop and implement integrated pest management (IPM) in Boston Public Housing. This program is building on the lessons learned from the research phase. The goal of the IPM program is to

1. Develop a citywide campaign to reduce the use of pesticides by educating families about their hazardous affects, particularly families with asthma.

2. Change the Boston Housing Authority (BHA) internal policy procedures on the minimum standards for how pest contractors should conduct in home pest management.

3. Conduct in-home one-on-one education with public housing residents on their role in pest management and allergen reduction.

To date, the Committee for Boston Public Housing (CBPH; a core community-based partner) has trained 11 Community Health Advocates recruited from the public housing developments, 9 of whom remain in the project. Six of these community health advocates speak Spanish, 1 speaks Chinese, 1 speaks Somali, and 1 speaks Haitian Creole, greatly facilitating access to the household of immigrant residents. Training consisted of a 3-week intensive program that included pest identification and behavior; exclusion, trapping, and clean-up; child injury prevention; data collection; evaluation and assessment; lead poisoning prevention; ethnic and racial data collection; asthma basics; mold; air quality and health care access.

CBPH staff, housing authority management, and pest contractors meet on a monthly basis to identify when and which families will receive intensive one-on-one education. A normal schedule involves the following: (1) BHA selects a pest contractor and a specific date on which the pest contractor will visit homes; (2) Community Health Advocates leaflet door to door to announce they will be coming a week prior to the pest contractor to educate families on what needs to get done before the contractor comes in; (3) CBPH Community Health Advocates conduct an in home assessment and discusses with families how to properly prepare for the contractor. The advocates play a critical role in easing concerns families might have about entering the program. Community Health Advocates also take the opportunity to sign up families who wish to volunteer for the one-on-one education.

The creation of jobs for residents as Community Health Advocates allowed them to ease family's concerns about strangers entering their homes and personal information being collected. Concerns of stigma and stereotypes were also put to ease because the advocates were their neighbors experiencing these same issues. Most important, the process was explained to them by neighbors who used layman terminology.

Subsequently, (4) the pest contractor visits homes, applying gel bait and assessing conditions in the apartment which encourage pest infestation; (5) using the contractor's reports, the annual living unit inspection that is conducted by the housing authority, and requests for pest management work orders, the housing authority site manager puts together a list of apartments which require intense one on one education; (6) CBPH staff along with management send an introduction letter to the head of household about their requirement to

^bThe research phase of the Healthy Public Housing Initiative was funded by the US Department of Housing and Urban Development's Office of Healthy Homes and Lead Hazard Control (grant no. MALHH0077-00), as well as grants from the W. K. Kellogg Foundation, the Boston Foundation, and the Jessie B. Cox Charitable Trust. In addition, HPHI received allergy-free mattresses from the Simmons Company and air filtration equipment from the Sharper Image Corporation. HPHI Partners are the Boston Housing Authority and the Boston Public Health Commission (BPHC); the Committee for Boston Public Housing (CBPH); the West Broadway Tenant Task Force and the Franklin Hill Tenant Task Force; Boston's 3 schools of public health at Boston University, Harvard University, and Tufts University; and Peregrine Energy and Urban Habitat Initiatives.

participate in the one-on-one education and set up a meeting time; (7) families receive their intensive education.

CASE 3: TO BREATHE OR NOT TO BREATHE (DORCHESTER)

This case example falls at one end of both of the continua we posited at the start of the paper. It had deep involvement of the affected community (parents of asthmatic children) in virtually all aspects of the research process (see Figure 1). The project was initiated by the Boston Urban Asthma Coalition (BUAC), which recruited faculty and students from Tufts University School of Medicine and students from the Harvard School of Medicine to help conduct their survey of asthma and environmental factors in Boston's largest neighborhood, Dorchester. The BUAC was funded by the Baker Foundation, with follow-up work funded by Tufts–New England Medical Center (NEMC) through its Dorchester Health Initiative. The university-based partners developed the survey questionnaire and methodology using an iterative process for input from the parents and BUAC staff. The primary goal of the study was to identify environmental factors contributing to asthma in Dorchester. Secondary goals included using the survey to expand outreach and education and to empower community members through their active participation in the project.

The use of a convenience sample (recruitment on the street in the community), albeit sizable (479 adults and 339 children), and the cross-sectional nature of the study are the main limitations to the science in this study. An effort was made to reduce sampling bias by advertising the survey as a health survey rather than an asthma survey. Use of validated scales for asthma also strengthened the methodology. Still, the survey could not be used to assess prevalence and instead was mostly of value in terms of associational analysis (as were the clinical surveys in Chinatown). In addition, the focus of the study, on environmental factors already known to be associated with asthma, somewhat restricted its originality. One novel finding coming out of this study was that foreign-born and native-born African American respondents had dramatically different prevalence of asthma. This is the first report of different asthma prevalence in immigrant and US-born African American.³⁰

The BUAC held 2 community meetings and 2 stakeholders meetings to develop a plan to respond to the findings of both the survey and a set of focus groups that they conducted on the same topic. The plan has many components, but the main pieces that resulted from the survey include promoting asthma education in Dorchester, developing and advocating for asthma legislation with the State Legislature, setting up parent support groups, raising public awareness, and connecting the Dorchester community to existing resources.

BUAC is in the process of meeting with each of the leaders in Dorchester Health Center to secure a commitment to increase asthma education. BUAC has succeeded in securing a commitment from 2 health centers and is in the process of meeting with 5 more. In addition, the asthma legislation

that BUAC codeveloped requires that health insurers cover asthma education, home visits, and in-home remediation. The State Legislature's Public Health Committee heard the bill in 2007, but it has not yet been enacted. BUAC is also working with local health centers to recruit parents for a support group. The Parent Asthma Leaders of BUAC held the first support meeting in 2007 in conjunction with a local health center.

Finally, the Parent Asthma Leaders developed a detailed resource guide of all health, housing, school, and day cares services in Dorchester that have specialized asthma services or asthma training. BUAC is disseminating this guide along with a public awareness billboard and public service announcement in spring through fall 2008 with a back-to-school focus. The guide will also be available from the 211 number, a statewide public health directory assistance funded by the United Way. The Parent Asthma Leaders implemented these activities to respond to the high rates of asthma they found in the Dorchester community through the survey and to provide individuals and children with asthma the supports they need to care for their asthma and address environmental issues in the home and community.

WHAT DO THESE CASE STUDIES TELL US?

The 3 case studies were chosen because they had overlapping subject matter (asthma), were conducted in the same city (Boston, albeit with quite different populations), all involved students in prominent roles and one of us (author DB) was a participant, although in a variety of roles, in all of them. The studies fell at different points along a bidimensional surface of CBPR that we envisioned (Figure 1). The full CBPR model employed in HPHI required greater resources than did the Chinatown studies. That is, involving public housing residents in all phases of the research process was resource intensive. The comparable effort in Chinatown, involving non-English-speaking, working class parents and their asthmatic children, was not undertaken precisely because of the lack of necessary resources. This line of reasoning is supported by the Dorchester survey example, which combined limited resources with full CBPR and was drawn out over several years to produce a single survey and one publication.³⁰ Also because of their limited funding, the Chinatown and Dorchester studies were unable to attempt more sophisticated research designs, such as the intervention used in HPHI.

In terms of leading to programmatic follow-up projects, HPHI was by far the most successful, leading to funding of the city and community partners for a large implementation project for integrated pest management in public housing. The Chinatown studies contributed to securing a smaller grant to develop an asthma education program in the community, which pro-rated for the scant resources used in the research is still impressive. The Dorchester survey was never seen as being primarily about publishing or developing service program. Rather the focus was on contributing to the

organizing and advocacy agenda of BUAC. In that sense, it was successful at engaging parents of asthmatic children in the target community and contributed to advocacy efforts of the organization.

HPHI was well positioned to leverage a major follow-on project for several reasons. First, it was funded by the W. K. Kellogg Foundation, creating a relationship with a party with the potential to fund programmatic implementation. Second, as a partnership of the key agencies (the housing authority, for example), organizations (the Committee for Boston Public Housing), and residents with an interest in pest management in public housing, HPHI brought the most important players together at the table. Third, because the project was structured as CBPR, it was never *only* a research project. From the beginning it had programmatic elements, including job training for residents and providing a pest service (the intervention) nested within the framework of a research study.

It is tempting to conclude from these examples that (1) that there is some trade-off between depth of community involvement and the level of resources needed, with less resources needed for traditional research or shallow community participation; (2) that an apparent advantage of CBPR is on the programmatic side, that is, its ability to facilitate translation of research directly into activities that address community problems (most evident in the HPHI and Chinatown examples) and possibly by contributing to organizing and advocacy efforts, as in the Dorchester example. It is not clear that this set of trade-offs is generalizable beyond our small case series given its limited scope. However, our observations and conclusions, tentative as they are, suggest a hypothesis that could be investigated in other community-based and CBPR projects to see whether or not what we observed is widespread. It is also possible that others reviewing the same evidence that we have would draw different conclusions from ours.

One possible advantage to CBPR that was not readily apparent from comparing our case examples is the possibility that CBPR is more likely to address community needs in the first place compared to traditional research. Even the Chinatown example, although not engaging the affected population directly, was still a community partnership with people who were in direct daily contact with the affected population, so this issue was not explored the way it might have been if we had included a truly noncollaborative example.

FINAL THOUGHTS

As CBPR becomes established as an acceptable and even desirable approach to research in communities, there is a need to assess its strengths and limitations and to address those weaknesses that might be found in order to improve the methodology. In this sense, CBPR is no different from any other methodological approach and should be amenable to refinement and enhancement. Although case studies like these that employ critical thinking are helpful and needed, there exists a need for larger-scale evaluation of CBPR. That

there is a core of value to CBPR should be evident to the reader, as the examples we explored produced a strong body of both scientific and program outcomes. But it should also be clear that we are, in many ways, still learning what we gain and what, if anything, we lose when we move from traditional research to community partnerships to CBPR. Our goal should be high-quality science coupled with robust benefits to the affected communities.

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