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A Community Health Worker Model to Address Childhood Asthma: Perspectives of Program Participants

LSA family health service

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ABSTRACT

In 1997, Little Sisters of the Assumption Family Health Service (Little Sisters) established the Environmental Health Services program in response to high rates of asthma among East Harlem children. The program provides a continuum of services meant to mitigate the negative effects of poor living conditions on asthma-related health outcomes. Led by a team of community health workers (CHWs), program activities include assessments of the home environment, hands-on training and education on safe and effective ways to address unhealthy living conditions, and advocacy services for tenants to get necessary repairs from housing management. In 2011, with funding from the U.S. Department of Housing and Urban Development (HUD), Little Sisters began implementation of *Controlling Asthma through Home Remediation* (CAHR), a demonstration of their program model, specifically targeting families living in public housing. The demonstration included an evaluation of the program by The New York Academy of Medicine (the Academy)—findings included statistically significant reductions in nighttime awakenings, emergency department visits, and use of rescue medications. As part of the evaluation, a sample of 17 caregivers participated in interviews, with questions that focused on their perceptions of program quality, impact, and lessons learned. As described in this report, caregivers noted that CHWs helped them to develop knowledge and skills to reduce household asthma triggers; in addition, CHWs and Little Sisters proved to be influential advocates, facilitating the settlement of complaints with housing management. As New York State and local health care systems adopt and promote more community-based health programs, CAHR represents a promising example of an intervention that can produce improvements in asthma-related health outcomes, while supporting grassroots efforts to create changes in policies and practice.

"I was naive when I started the program and I actually didn't want it. I was more like, you know, 'that's a waste of my time, just people in my life.' But I'm glad it happened, you know. I grew up, I realized that this was something that was worth it, and it's such great people to have. It really is. They really work hard, they help you, and they get the job done."

– EAST HARLEM MOTHER OF FOUR

OVERVIEW

In 1997, Little Sisters of the Assumption Family Health Service (Little Sisters) established the Environmental Health Services program in response to the disparately high rates of asthma prevalence among East Harlem children. The program model—which is consistent with recommendations from the Community Preventive Services Task Force[1]—provides its clients with a continuum of services meant to mitigate the negative effects of poor living conditions and indoor air quality on asthma-related health outcomes. Led by a team of community health workers (CHWs), clients receive comprehensive assessments of the home environment, hands-on training and education on safe and effective ways to address unhealthy living conditions, and advocacy services for tenants to get necessary repairs from housing management for conditions that negatively affect their overall health and wellbeing. The program uses a three-phase model to describe the role of the CHW throughout the intervention: (1) to provide immediate assistance to families and develop trust; (2) to build relationships and individual capacity; and (3) to support local leadership and community development. The Environmental Health Services program thus embeds relatively short-term, family-specific goals (i.e., improve home management behaviors, living conditions, and asthma-related health outcomes) into its long-term mission: to build community capacity for sustainable change and to integrate healthy homes principles into New York City (NYC) housing policies and practices.

In 2012, with funding from HUD and in collaboration with the Academy, Little Sisters began implementation of *Controlling Asthma through Home Remediation* (CAHR), a demonstration of their program specifically targeting families living in East Harlem public housing. The demonstration included an evaluation, with baseline and follow-up surveys, direct observation of housing conditions, and interviews with a sample of caregivers; the evaluation focused on the program's effect on child health outcomes, health care utilization, and household conditions.

COMMUNITY HEALTH WORKERS

Community health workers (CHWs) are on the frontlines of public health. They are generally members of the community they serve, or have a close understanding of that community. As such, they promote cultural and linguistic competency, facilitate trust, and serve as liaisons between community members and the health and social service sector.[8] CHW activities vary greatly, and may include outreach, health education and advocacy, health care navigation, care management, and social support.[8] A growing body of research supports the effectiveness—and cost effectiveness—of models that include CHWs in health promotion and the management of illness, including cancer, diabetes, HIV/AIDS, and asthma.[9–11] Recognizing their unique capabilities, state and federal health reform efforts have supported expanded engagement of CHWs, as a means to improve health and health care quality, particularly in communities facing disparities.[12, 13]

As reported elsewhere,[2] baseline and one-year follow-up survey data showed a number of statistically significant improvements in health indicators over time, including decreases in:

- Nighttime awakening in the prior two weeks: 3.47 nights at baseline, compared to 1.50 nights at follow-up;
- Use of rescue medication in the prior two weeks: 4.93 times at baseline, compared to 2.57 times at follow-up;
- Prescribed oral steroids in the prior year: 2.22 times at baseline, compared to 0.92 times at follow-up; and
- Asthma-related emergency department or urgent care visits in the prior year: 2.98 visits at baseline, compared to 1.18 visits at follow-up ($p < .001$ for each).

This report uses data from qualitative interviews to highlight and explicate key attributes of the program—and their impact—from the perspective of participating families.

BACKGROUND

There are significant disparities in asthma prevalence and control across the United States.[3] For example, the asthma hospitalization rate for East Harlem children, at 75 per 10,000 (ages 5–14), is more than twice the citywide rate and close to 10 times the rate of the Upper East Side, a neighborhood bordering East Harlem.[4, 5] The avoidable adult hospitalization rate in East Harlem is 648/100,000, compared to 46/100,000 on the Upper East Side.[4, 5] Although many factors contribute to the high prevalence of asthma and its poor control in particular communities, substandard housing conditions are common triggers in low-income NYC neighborhoods. In East Harlem, 76% of housing units have maintenance defects, including leaks, inadequate heat, pest infestations, and peeling paint.[4] Research has shown that multi-trigger, multicomponent interventions that address these defects and support sustained environmental changes in the home environment have positive impacts on the health of children with asthma.[1, 6]

FINDINGS

> *[My daughter] is not showing any outward signs. She is happy. She's sleeping better. She's not as irritable from lack of sleep because of constant coughing. She is back in sports activities. She's participating in school, so she likes to play soccer, basketball. We have more peace of mind ourselves ... all the other safeguards that Little Sisters provided us, the HEPA filters, the pillow cases, hypoallergenics and the roach remediation that they did, and all those things factored into making the environment more supportive of her well-being.*
>
> – EAST HARLEM FATHER OF THREE

The CAHR program model includes multiple home visits by a CHW over the course of three months. During these visits, CHWs provide an assortment of family–focused home remediation services, including direct apartment repairs (e.g., patching holes); mold removal; addressing pest infestations; and the provision of supplies (e.g., mattress covers and containers for food storage). All of these services provide immediate assistance to families struggling to maintain healthy home environments. According to program participants, CHWs provided these services in a nonjudgmental manner with an understanding of the personal impact of unhealthy home environments. An empathetic CHW–client relationship was repeatedly named as an essential feature of the CAHR program model, which built trust between participants and CHWs, and facilitated collaborative efforts to better maintain personal spaces.

> *We had an issue with the vents actually spewing dust and debris into the bathrooms, so Little Sisters did also offer me screening that they placed over the air vent to capture those dust particulates, so that they wouldn't be able to just easily flow into the apartment.*
>
> – EAST HARLEM FATHER OF THREE

> *He's just like, "Don't worry, we gonna handle this. You're not the only person. I deal with many clients that have issues and it's not just you." And he just repeatedly told me, "It's not just you." And I just had to keep thinking, "It's not just me." It was like, I had a therapeutic intervention with him, at times.*
>
> – EAST HARLEM MOTHER OF THREE

In addition to providing immediate remediation services to participants, CHWs also provided hands-on training and education to further support families in maintaining healthy home environments. Although several of the participants who were interviewed—particularly those that had a number of years' experience with asthma—reported that they knew a substantial amount about asthma management, others reported gaining significant knowledge from the CHWs. Interviewees most commonly reported learning about specific household triggers, (e.g., cockroaches, mold, and stuffed animals); they also learned to differentiate safe cleaning products from those that might exacerbate asthma symptoms.

> *They brought containers and showed us how to clean, what to look for, wipe things down, keep things dry, make sure that the roach droppings, you have to clean that. They showed us that the baking powder–how to clean green … I used to like to have the spray for the smell, but that can cause asthma too. So I changed. And instead of insecticide in the apartment, I use the little boxes (roach killers, etc.). Also, I used to give my kids stuffed animals even if the kids didn't play with them, and now I try not to buy them.*
>
> – EAST HARLEM MOTHER OF ONE

I learned that the cleaning products, although we think that we're using them to disinfect and clean our houses, that also the smelling agents that are in it are triggers for the asthma.

– EAST HARLEM MOTHER OF THREE

Participants also commented on the hands-on demonstrations provided by CHWs, especially when compared to less participatory forms of education offered in other settings of the health care system. Consistent with the program's goal to increase health knowledge and self-sufficiency, participants reported feeling more confident in their abilities to establish healthier and more sustainable living conditions at home and to share this knowledge with family, friends, neighbors, or other members of the community.

There's a difference between briefing you and actually sitting you down and showing you what you're supposed to do. You know? Because you can brief somebody on something and they do it wrong, versus you actually being: "Here, this is how it is," and hands-on. And you're now doing it right, because now you're seeing and listening and doing it with the person. You know? And [the CHWs are] telling you if you're doing it wrong. But usually when you go to the doctor, they give pamphlets. You've got to read it, but you could always read something but not do the process right.

– EAST HARLEM MOTHER OF FOUR

When I see somebody in the emergency room, I catch myself telling them about the program.

– EAST HARLEM MOTHER OF ONE

In many cases, CHWs were unable to provide all of the repairs needed by CAHR families. However, structural repairs and repairs that involved multiple units required tenants to legally engage with their housing management. In such cases, CHWs provided a variety of advocacy services to program participants. These included assessing damages to the unit, documenting grievances, preparing reports, and writing letters of support. Participants reported that these services, backed by the community standing of Little Sisters, facilitated more rapid responses to their grievances.

> *[The CHW], using the water moisture meter, they were able to identify that definitely there was a leak behind the wall without having to tear the wall down. We can determine that with the moisture readers that they were using. They, you know, were able to give me a report. They wrote reports that I had, ready to show the judge if necessary...They identified clearly what the conditions were, they made me aware, Little Sisters did, and I was able to then present that to NYCHA (New York City Housing Authority) effectively and demand that this be corrected, because it was the eminent danger that I now became aware of, that it posed to my daughter's health.*
>
> – EAST HARLEM MOTHER OF ONE

> *I don't know if you could call it that they give programs more respect than the tenants, that's what I call it, because I was battling for like four to five months. With taking them to court and I'm like telling the judge like, "I'm paying my bill, I'm on top of my rent, why isn't my repairs getting done?" Like I was surprised that a letter [from Little Sisters] would get, you know, for them to move quicker on it than the time period that I was going to court.*
>
> – EAST HARLEM MOTHER OF FOUR

As acknowledged within the Little Sisters environmental health services three-phase model and their broader advocacy activities,[2] a unit-by-unit response in large, multi-family buildings, is insufficient to establish sustainable changes that promote good health for all residents. This sentiment was clearly articulated by one participant. While commending the family focused services, he described a need for approaches that facilitate systemic change:

> ***You have to have the remediation aspect, the education component, but there should also be a legal wing to be able to actually take the fight to the court to force the landlords to make the proper repairs. Little Sisters, in their services were awesome but in the bigger picture, it's just putting on Band-Aids until the true heart of the matter is that the leak, the structural damage, is causing the condition. And if no one's gonna advocate for that proper repair, and ask that the court intercede and make that correction then you really, whatever Little Sisters can do will always be reactive and temporary and not as life-altering as it could be... So again, Little Sisters, incredible, awesome, everything that they did, I love them for it. But I am more aware that it's something greater than their services that was required to fix this, at least when you're talking about New York City housing.***
>
> – EAST HARLEM FATHER OF THREE

LESSONS AND IMPLICATIONS

The findings in this brief describe client perceptions of the CAHR program model, with a particular emphasis on the role of the community health worker. The perspectives captured by these 17 narratives make an important addition to the existing literature on the potentially positive role of CHWs in promoting knowledge gains, skill development, and improved health.[7–9] They illustrate the importance of CHWs, not only in providing trusted and effective family-focused home remediation services, but also in supporting ongoing self-advocacy on behalf of clients and their families.

Participants identified the trusting and collaborative relationships they developed with CHWs as key aspects of the program. They reported feeling that the CHWs were allies in creating a healthy home environment and appreciated CHW efforts to partner with them in learning and skills development with respect to environmental aspects of asthma prevention. They also appreciated CHW support for their efforts to advocate for themselves and their families and expressed their appreciation for the authority that Little Sisters, as a long-time East Harlem community-based organization, added to those advocacy efforts. In multiple cases, CHWs—and by extension Little Sisters—supported participants in communicating with their housing management and expediting repair processes. It should also be noted that in 2014, along with providing the services described here, members of the Little Sisters Environmental Health Services program, in collaboration with the organization Manhattan Together, participated in a successful class action lawsuit against NYCHA on behalf of their clients, for failing to provide adequate housing conditions for tenants with asthma.[2]

DISCUSSION

This brief contributes additional evidence for an asthma-focused home-based environmental intervention. Furthermore, this report shows the importance of prioritizing trusting CHW-client relationships and incorporating a structural component to home-based interventions, in order to address the root causes of asthma burden and health disparities. As New York State, and local health care systems, adopt and promote more community-based health programs, the Environmental Health Services program implemented by Little Sisters is a promising example of how a family and household-focused intervention can produce rapid improvements in asthma-related health outcomes, while simultaneously supporting grassroots efforts to create sustainable, system-wide change in policies and practice.

This analysis considered the perspectives of only a small fraction of Little Sister's Environmental Health Services clientele, and reported client experiences were somewhat varied. Still, analysis of the 17 narratives reviewed for this report revealed several consistent themes. The narratives showed that CHWs provide the foundation for the Environmental Health Services program: trusting CHW-client relationships were key to building the necessary knowledge and skills for sustained reduction of asthma triggers and for encouraging families to pursue more effective interactions with housing management. While many family-focused interventions may be limited in their ability to create sustainable and systemic change, the Environmental Health Services program has been able to amplify individual voices and systematically strengthen the collective pressure to adopt more equitable and health-promoting housing policies.

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METHODOLOGY

The findings in this report are based on interviews conducted with a sample of 17 caregivers who participated in the CAHR program. Interviewees were selected to represent different levels of engagement in the program. Interviews were conducted by members of the Academy evaluation team between September 2013 and March 2014 in either the individual's home or another private space convenient for the participant. The interviewers used a guide with open-ended questions focused on knowledge, skills, and behaviors related to asthma prevention, household maintenance, and management of asthma triggers and indoor air quality. Questions also addressed caregiver confidence regarding asthma control, barriers and facilitators to reductions in asthma triggers, overall perceptions of the CAHR program, and suggestions for program improvement. Participants received $20 in appreciation of their time and effort. The protocol was approved by the Academy's Institutional Review Board and all participants completed consent forms prior to involvement in the evaluation.

The 17 de-identified interviews were audio recorded and transcribed. Transcripts were managed and coded using NVivo, a software package for qualitative data. Codes reflected attributes and outcomes of the Environmental Health Services program model and allowed for systematic identification and review of notable themes.

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