Home visits are needed to address asthma health disparities in adults

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Research on asthma frequently recruits patients from clinics because the ready pool of patients leads to easy access to patients in office waiting areas, emergency departments, or hospital wards. Patients with other chronic conditions, and with mobility problems, face exposures at home that are not easily identified at the clinic. In this article, we describe the perspective of the community health workers and the challenges they encountered when making home visits while implementing a research intervention in a cohort of low-income, minority patients. From their observations, poor housing, often the result of poverty and lack of social resources, is the real elephant in the chronic asthma room. To achieve a goal of reduced asthma morbidity and mortality will require a first-hand understanding of the real-world social and economic barriers to optimal asthma management and the solutions to those barriers. (J Allergy Clin Immunol 2016;138:1526-30.)

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The highest rate of asthma-related deaths and hospitalizations is in low-income minority adults,[1] yet most research does not focus on such adults, particularly those with comorbidities or tobacco exposure.[2-4] Intervention studies are needed. The Patient-Centered Outcomes Research Institute supports comparative effectiveness research, particularly in vulnerable populations.

Abbreviation used
CHW: Community health worker

The Patient-Centered Outcomes Research Institute offered a Funding Opportunity: "Treatment Options for African American and Hispanic Latinos for Uncontrolled Asthma."[2] Our ongoing randomized controlled trial of an intervention, funded through this opportunity, "Using IT to Improve Access, Communication and Asthma in African American and Hispanic/Latino Adults (AS-1307-05218),"[5] involves using community health workers (CHWs) to recruit and follow adults with uncontrolled asthma to whom the patient portal is introduced. (Please see Apter et al[5] for a full description of the study.) The purpose of this article was to describe the observations and insights of the CHW who visited these patients to recruit them, observe their environment, and help them with access to the patient portal. These visits provide additional knowledge regarding socioeconomic stressors that are not routinely collected by the clinician or the researcher. As we recruit, enroll, and follow these adults, even experienced asthma investigators have been dismayed by the depth of illness and poverty encountered during home visits. We describe the visits and the implications for clinicians, researchers, and public health professionals.

CASE EXAMPLE

The CHW was able to schedule Ms J for a home visit after several telephone attempts and 2 attempts to make an initial home visit with no answer. Ms J is a 50-year-old black woman who has known she has had asthma since she was a child. Over the past 10 years her symptoms have worsened. She now has a nightly cough and has difficulty doing any activities. Her asthma is triggered by weather change and exercise. Her medical history is further complicated by hypercholesterolemia, diabetes, and hypertension. She has a 12.5 pack-year smoking history, and currently smokes. She has had 20 emergency visits and 15 asthma-related hospitalizations over her lifetime. Within the past year she has had 2 hospitalizations, all of which required courses of prednisone upon discharge. She did not complete high school and is permanently disabled. Currently she lives with 3 other adults in a rental home although she has little social support. She reports difficulty paying utility bills. She has observed violence in the neighborhood and has difficulty walking to the bus stop, making it hard for her to go to church or medical appointments. She is unable to complete the literacy survey part of the protocol.

This case illustrates the significant morbidity from asthma in low-income minority patients and the barriers to recruiting and completing research, which are also the same barriers to

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providing health care. Comorbidities such as hypertension, diabetes, and obesity as in this case require a multitude of prescribed medications, which can cause not only confusion and resistance to using controller medications but also significant expense, which taxes limited disposable income. For this reason, investigators may avoid recruiting patients with comorbidities to limit issues of confounding and heterogeneity of treatment effects. But with design for simplicity in analysis for internal validity comes a loss of generalizability of research findings of efficacy and safety to the real and heterogeneous world of complicated diseases and lives, multiple exposures, and varied environmental risks. Other stressors such as low literacy, utility bills, and violence may further impact this patient's ability to manage asthma. Although smoking is clearly not the best avenue for dealing with these stressors, smoking is perceived as a stress reliever.

As in this case, uncontrolled asthma results in increased utilization of health resources. This patient had numerous emergency visits and hospitalizations. Most often we focus on recognized patient-level predictors of frequent emergency department use, which potentially can be addressed in the health care setting, such as suboptimal self-management, limited or inadequate health insurance, and underlying severity of asthma.[6] However, there are often other unrecognized barriers that cannot be addressed in an emergency department visit or even an outpatient setting.[7] Without home visits, health care professionals do not observe and cannot appreciate the home environment, work, and family obligations that influence patients' ability to manage a chronic disease. Furthermore, in the typical outpatient setting, much of the clinical optimization of care may be addressed by prescribing the appropriate medications, but the medicine regimen is not routinely tailored to fit into the patient's daily environment. In one study, only 30% of the clinicians relate regularly helping patients make decisions about asthma management and only 33% of the clinicians reported consistently tailoring medication schedules to the patient's routines. Leaving these needs unaddressed creates barriers for optimal health management for the sickest people with asthma.[8] Home visits by researchers will allow consideration of these barriers in research protocols and also provide insight for practicing clinicians.

Increasing income and wealth inequity[9] is reflected in the inadequate housing we see in our participants. Our home visits confirm that housing has become even more critical than was seen earlier when years ago house calls were routine practice for physicians. In fact, there is an extreme shortage of affordable housing for very low income households.[10,11] Poor living conditions make attention to an intermittent health condition difficult. For example, in Philadelphia many houses are rowhomes built in the late 19th century and are difficult to maintain when inhabitants have limited resources. In this setting, residents are exposed to common indoor asthma triggers such as rodents, roaches, and mold.

WHAT RECRUITING IN THE HOME COMPARED WITH THE CLINIC TOLD US

In previous studies of adults, we recruited and met patients in the clinic where they received health care.[12,13] In this study, we initially planned to enroll 300 patients in the primary care or specialist office with subsequent home visits for those randomized to receive them. The eligibility criteria for this study were as follows:

- age 18 years or more
- living in a low-income Philadelphia neighborhood
- a provider's diagnosis of asthma
- prescribed an inhaled corticosteroid
- required oral steroids for an exacerbation, and/or had an emergency or inpatient visit within the last 6 months.

As our CHWs made calls, they discovered that the eligible participants had additional comorbidities, ambulation difficulties, home environmental risks, exposure to neighborhood violence, and limited public transportation. Some patients were primary care givers to children or older relatives and could not easily leave them. On the basis of these findings and investigator experience,[8,14,15] we then realized that initial contact in the home would be the best way of engaging this hard-to-reach population. We found this method to be very successful and we were able to meet our goals for enrollment.

DESCRIPTION OF CONTACT WITH PARTICIPANTS DURING STUDY PARTICIPATION

At enrollment CHWs administer several standardized surveys on demographic characteristics, asthma history, asthma control, health literacy, depression, social support, numeracy, and quality of life.[5] For those in the intervention arm, the CHWs make 4 home visits to each participant. At the first home visit, the CHW conducts a needs assessment, that is, determines whether the patient has an asthma action plan, contact information for their asthma provider for an exacerbation, daily medications available, and a follow-up appointment scheduled with their asthma provider. They also help participants identify goals for asthma care, such as being able to exercise or quit smoking. At the 3 subsequent home visits, CHWs review asthma medications to be taken at home, proper technique of asthma devices, and asthma action plan. They provide resources to assist participants in meeting their goals while also reviewing and encouraging use of the patient portal. For those in the control arm as well as those in the intervention arm, there are 5 data collection sessions approximately 3 months apart; the first and the last take place in person. Other sessions are in person or by phone, and participants are offered the option of conducting these sessions in their homes, at community sites, or in the asthma practice they attend.

The CHWs are trained to document participants' responses to questions and other comments made during the interview. They also are encouraged to record their own observations in a comment section that would help explain responses or nonresponses to the questionnaire. Their comments on the context of the homes of participants, and participants' description of the health goals follow.

UNDERSTANDING THE CONTEXT OF THE PARTICIPANTS

Table I describes the cohort of 301 adults:16% live alone and 71% on rent. Many rented 1 room and others lived with several family members in crowded quarters. Only 25% were currently employed part-time or full-time. The vignettes below further characterize the home settings:

A 44-year-old female who smokes constantly lives in a basement with no windows and no ventilation.

A middle-aged female with limited ambulation lives in one small room which housed her bed, sink, and toilet.

TABLE I. Baseline characteristics of 301 adults

Characteristic	N = 301
Age (y)	
Mean + SD	49 ± 13
Range	18-88
Sex: female, n (%)	270 (90)
Black, n (%)	229 (76)
Hispanic/Latino, n (%)	66 (22)
Annual household income <$20,000*, n (%)	214 (71)
Percent on Medicaid	63
Percent with Medicare only	10
Current smoker, n (%)	84 (28)
Hypertension, n (%)	175 (58)
Diabetes, n (%)	96 (32)

*Self-reported income; 88% responded to this query.

A middle-age male is paraplegic due to a gunshot wound, has no social support, and is unable to get to the doctor's office.

Although our CHWs observed many instances of poor housing conditions in our cohort, there were scarce resources for adequate housing or housing repairs (Fig 1). The most commonly used house repair resource for low-income owners had a waiting list of 3000 owners at the time of this study. As in most large cities, there is a long waiting list for subsidized housing in Philadelphia (up to 7 years) and many of these adults did not qualify because they were middle-aged and did not have young children. These stark living situations contributed to a sense of hopelessness and despair among some of the patients. CHWs report their general impressions of the encounters with the participants:

"There are a lot of sad stories. Patients seemed to have given up and checked out."

"It's not just the finances, it's the violence, lack of education and job opportunities."

"Patients seem grateful for information about medications but it's hard to change habits especially overuse of albuterol."

"Homes are in poor repair. Some are just unlivable." "The houses are full of smoke. Everybody smokes."

"Patients report that doctors are not responsive to them and sometimes just plain rude."

"Depression survey seems to trigger a lot of emotions. Often patients are crying as we try to complete it."

"I think only half of the African American patients have social support."

"Maybe 75% of the Latino families have social support."

These quotes capture a host of barriers including mental health problems, medication misuse, poor home repair, poor communication with providers, and lack of social support. Unsurprisingly many of the sicker patients with asthma are depressed and living in poor housing with very little hope for changing their current situation. They seemed to be happy to have someone to talk with them and try to help them identify resources. Although a supposition on their part, the CHWs were struck by the lack of social support the participants reported and became a source of support for the participants. Participants randomized to the home visit arm were encouraged to call the CHW if they needed assistance connecting with resources or their providers.

CHWs encounter some situations that are overwhelming even though they are equipped with available resources for participants. In one case, a middle-aged female lived with 4 other adults. She had had bilateral knee replacements within the past 6 months and was also responsible for taking care of her sister who recently suffered a debilitating stroke. Although raised in Philadelphia, she had never gone to school. Family members came in and out of the house, which was filled with tobacco smoke. The participant cried for 30 minutes as she related all the stressors she was facing to the CHW. In a second case at the CHW's first home visit to enroll a participant, the CHW noticed a puddle in the middle of the dining room floor. While she was enrolling the patient she heard a toilet flush above her then water came down from the ceiling into the dining room splashing into the puddle. In a third case, during the first visit the participant's daughter ran into the house because her son was being physically threatened. The altercation escalated in the front of the participant's house with the grandson being threatened by a man with a machete. The CHW could not leave until the altercation was over because she was afraid for her own safety. Although the CHW attempted to complete the enrollment at a subsequent visit, the participant refused, and this enrollment was never completed.

These situations exemplify highly significant social stressors in patients' lives that interfere with their ability to pay attention to their health. In the last case, recruitment of the patient to the study proved to be impossible, yet research on asthma in adults should include the experiences and outcomes of this type of patient to inform the frontline clinicians. Without addressing these social stressors, clinicians cannot treat the patient even if they can prescribe medications, and the health care system may be limited in its ability to improve the health of these sicker asthmatic people.

ASSISTING PARTICIPANTS IN CHOOSING GOALS, IDENTIFYING BARRIERS, AND PROVIDING SOLUTIONS

Identification of Care Coordination Goals by the patient and the CHW is part of the research protocol. In response to the encouragement of the CHW to think of the patients' goals, the most common patient responses are to become healthier (43%), eliminate triggers (32%), communicate better with their providers (16%), and reduce smoking (16%). Barriers to becoming healthier are time, motivation, poor general health, and limited access to healthy foods. Resources given to overcoming these barriers are community referrals to exercise programs at the Young Men's Christian Association, food trust programs, nonprofit hunger relief organizations, share food program, and farmer's markets. Barriers for eliminating self-identified triggers are lack of assistance in cleaning, living in an old house, and in crowded quarters. Very few housing resources exist but participants are referred to the Philadelphia Housing Authority if they need more suitable housing or to an emergency mortgage assistant plan if they are facing foreclosure, to affordable housing programs, and sheriff sales for those participants looking to purchase a home.

DISCUSSION

Asthma disparities continue to exist despite medical advancement because gaps persist in care for the sick, low-income patient.

FIG 1. Example of a neighborhood in Philadelphia. This illustrates the poor housing conditions and the inequality of housing our patients face. Image credit to www.flickr.com, photographer Tony Fischer, 2009, under Creative Commons attribution license CC BY 2.0.

Clinical research has given us evidence-based recommendations to improve asthma control, but disparities will continue to persist until there are solutions to the impact of socioeconomic factors on health. The national shortage of adequate housing for low-income families and individuals and widespread health disparities by income nationwide make it clear that this is not simply a Philadelphia experience and national attention is needed. The homes we saw may be infested with mites, cockroaches, and mice, but it is not clear that sensitivity to such allergens is the cause of asthma exacerbations and morbidity or whether their presence serves as a marker for a general insult on health related to inadequate housing, crowding, and exposure to tobacco. Our CHWs found all these environmental and social barriers to self-management of asthma as they made home visits to these participants. We found that some of the most extreme living conditions make it difficult or impossible for patients to attend medical visits and adhere to optimal asthma care. Without knowledge of these barriers, health providers do not have the information needed to create tailored, personal, and empathetic approaches to asthma management. In the home, the CHW is able to get a real-world view of the daily context and stressors patients face, which may interfere with their asthma management.

Home visits are no longer the current clinical practice, except in the context of research. Through visiting participants in their homes, our research team found a cohort of patients who have high morbidity, many hospitalizations and emergency department visits, comorbidities, and significant barriers including transportation difficulties to attending regular outpatient visits. These are the same patients who may be seen in clinic infrequently and are often labeled by clinic staff as "no shows."

The implication for research is testing whether visits by CHWs and their specified activities can improve and sustain patients' health and address their prevalent comorbidities. Cost-benefit must be examined. If successful, the implication for health care providers and especially payers is that home visits by CHWs should be part of the routine management for these vulnerable patients. For policymakers, the implications of our experiences are that interventions are needed to improve housing conditions and ensure healthy food is available in low-income communities. Clearly, our visits have found that a patient overwhelmed by basic needs cannot focus on taking a daily medication or engaging in

healthy behaviors such as exercise, tobacco cessation, or even attending a medical visit. Elimination of asthma disparities should be the goal instead of reducing disparities in asthma morbidity and mortality. This goal can be accomplished only by understanding the barriers to optimal asthma management and how to overcome those barriers. Poor housing is the elephant in the asthma room and must be addressed in a deliberate and intentional manner to truly eliminate disparities in outcomes among adult patients with asthma.

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