

#### Journal of Asthma



ISSN: 0277-0903 (Print) 1532-4303 (Online) Journal homepage: http://www.tandfonline.com/loi/ijas20

# Improving the asthma disparity gap with legal advocacy? A qualitative study of patient-identified challenges to improve social and environmental factors that contribute to poorly controlled asthma

Drew A. Harris, Anne Mainardi, Osatohamwen Iyamu, Marjorie S. Rosenthal, R. Douglas Bruce, Margaret A. Pisani & Carrie A. Redlich

To cite this article: Drew A. Harris, Anne Mainardi, Osatohamwen Iyamu, Marjorie S. Rosenthal, R. Douglas Bruce, Margaret A. Pisani & Carrie A. Redlich (2017): Improving the asthma disparity gap with legal advocacy? A qualitative study of patient-identified challenges to improve social and environmental factors that contribute to poorly controlled asthma, Journal of Asthma, DOI: 10.1080/02770903.2017.1373393

To link to this article: <a href="https://doi.org/10.1080/02770903.2017.1373393">https://doi.org/10.1080/02770903.2017.1373393</a>

Accepted author version posted online: 05 Sep 2017. Published online: 20 Oct 2017.	Submit your article to this journal 🗹
Article views: 154	View related articles 🗹
View Crossmark data 🗹	Citing articles: 1 View citing articles 🗷





## Improving the asthma disparity gap with legal advocacy? A qualitative study of patient-identified challenges to improve social and environmental factors that contribute to poorly controlled asthma

Drew A. Harris, MD<sup>a</sup>, Anne Mainardi, MD<sup>a</sup>, Osatohamwen Iyamu, MD, MPH<sup>b</sup>, Marjorie S. Rosenthal, MD, MPH<sup>c,d</sup>, R. Douglas Bruce, MD, MPH<sup>e,f</sup>, Margaret A. Pisani, MD, MPH<sup>a</sup>, and Carrie A. Redlich, MD, MPH<sup>a,g</sup>

<sup>a</sup>Division of Pulmonary and Critical Care Medicine, Yale University, New Haven, CT, USA; <sup>b</sup>Department of Medicine, Yale University, New Haven, CT, USA; <sup>c</sup>Department of Pediatrics, Yale University, New Haven, CT, USA; <sup>d</sup>Yale Robert Wood Johnson Foundation Clinician Scholars Program, New Haven, CT, USA; <sup>e</sup>Division of Infectious Disease, Yale University, New Haven, CT, USA; <sup>f</sup>Cornell Scott Hill Health Center, New Haven, CT, USA; <sup>g</sup>Yale Occupational and Environmental Medicine Program, Yale University, New Haven, CT, USA

#### **ABSTRACT**

Objective: To identify challenges that disadvantaged adults with asthma face in mitigating social and environmental factors associated with poor symptom control. Methods: Using a community-engaged approach, we partnered with a community health center in New Haven, CT to conduct in-person interviews and a written survey of asthmatic adults with poor symptom control. Using the constant comparative method, we analyzed participant interviews to establish emerging themes and identify common barriers to improved outcomes. Through a written survey utilizing clinically validated questions, we assessed information on access to medical care, asthma control, and selected social and environmental risk factors. Results: Twenty-one patients (mean age 47, 62% female, 71% Black, 95% insured by Medicaid) participated. The average Asthma Control Test (ACT) score was 11.6. Seventy-six percent of participants were currently employed and of those, 75% reported work-related symptoms. Among participants currently in housing, 59% reported exposure to domiciliary mice and 47% to mold. We identified three themes that summarize the challenges the study participants face: 1) Lack of knowledge about home and workplace asthma triggers; 2) Lack of awareness of legal rights or resources available to mitigate adverse conditions in the home or work environment; and 3) Fear of retaliation from landlords or employers, including threats of eviction, sexual assault, and job loss. Conclusion: Patients with poorly controlled asthma in a disadvantaged urban northeast community identified common barriers in both the domestic and work environments that impeded attainment of symptom control. These challenges may be best addressed through legal advocacy for those most at risk.

#### **ARTICLE HISTORY**

Received 19 July 2017 Revised 19 August 2017 Accepted 26 August 2017

#### **KEYWORDS**

Asthma disparities; community-based participatory research; community-engaged research; legal advocacy; medical-legal partnerships; social determinants of health

#### Introduction

Asthma disproportionally impacts the socioeconomically disadvantaged and communities of color (1). Patient, community, provider, and health system-based factors have all been identified as contributing to asthma disparities. For example, disadvantaged populations have reduced access to care, and are less likely to be prescribed or adherent to controller medications (2). Importantly, a number of overlapping and intersecting social and environmental factors, including stress, substandard housing, violence, nutrition, air pollution, and work exposures substantially contribute to poor asthma outcomes in these communities (3–8).

Despite an extensive literature demonstrating that modifiable social and environmental factors contribute to the burden and severity of asthma in disadvantaged patients, efforts to identify and address these factors have been limited to date. Interventions to improve asthma outcomes in disadvantaged adult populations have centered on improving access to medical care, medication adherence, and patient education (9–14), with variable success (15). With asthma disparities increasing in the last decade (16), the American Thoracic Society has recently stated the need for innovative approaches to identify and address modifiable targets, including social and environmental factors, in order to improve asthma outcomes in disadvantaged populations (17).

A community engaged approach to research (18) partners academic researchers with community members throughout the research process. Through community engagement, researchers are better positioned to design interventions that reflect patients' insight and perspective

that might lead to uncovering barriers to improve health outcomes (18). For example, survey questionnaires of asthmatics, in a predominantly Latino neighborhood in New York City, revealed many in the community desired the inclusion of Latino folk medicinal practices into traditional asthma management plans. Utilizing these survey findings, The North Brooklyn Asthma and Environment Consortium (a partnership between New York University, El Puente: a community based organization focusing on Latino Health, Multiple Community Health Centers as well as a community advisory committee including multiple community leaders and churches) reduced annual asthma related hospitalizations in this community by over 50% through a culturally rooted asthma education program (19).

Given rising asthma disparities in the US, community engaged research may provide a vehicle for clinicians, researchers, and policy makers to better understand and address asthma disparities that persist despite decades of disparities-focused research and interventions (14). Accordingly, using a community-engagement approach, we sought to characterize the challenges disadvantaged adult asthmatics face when trying to address social and environmental factors at home or at work that impact asthma. Using a qualitative approach, we hoped to describe the lived experience of disadvantaged adults with asthma; specifically, we sought to learn from the personal and unique perspectives describing how asthma morbidity is shaped by adverse social and physical environments. Through this understanding, we hoped to identify challenges that disadvantaged patients with asthma face in improving social and environmental factors that could then be addressed in future interventions to reduce the asthma disparity gap.

#### Methods

#### Study design and sample

Through a community-engagement approach, integrating direct interface with patients residing in a community at risk, we partnered with a large Federally Qualified Health Center in New Haven, Connecticut. This health center serves a low-income, predominantly African American community and provided care for 34,563 patients, including 2,295 patients with asthma in the past year (20). We chose a qualitative approach as we were exploring a complex, potentially sensitive, and stigmatizing topic (21) that is difficult to measure using only quantitative methods.

We recruited a purposeful sample of patients with uncontrolled asthma (22). Purposeful sampling is a technique widely used in qualitative research for the

identification and selection of patients. Purposeful sampling involves identifying individuals that are especially experienced with a disease or condition of interest, that are available and willing to participate, and comfortable communicating their experiences and opinions. In contrast, probabilistic or random sampling is used to ensure the generalizability of findings by minimizing the potential for selection bias (22). In this study, we sought to identify disadvantaged patients with asthma and poor symptom control. In addition, in an attempt to identify patients who were likely to have relevant social and environmental determinants of health contributing to their asthma, we partnered with the Cornell Scott Hill Health Center, which serves a predominantly low-income community of color.

We first identified all adult Cornell Scott Hill Health patients with persistent asthma as defined by both 1) a provider-coded diagnosis of asthma in the electronic health record and 2) a pharmacy record that included prescribed inhaled corticosteroid medication (288 individuals). We then identified patients with poor symptom control based on an emergency room or inpatient admission at Yale-New Haven Hospital within the prior 12 months (51 individuals). We excluded patients with active smoking or chronic obstructive pulmonary disease (COPD) to help ensure a correct diagnosis of asthma. We also excluded patients with severe psychiatric illness or a history of aggressive or violent behavior to ensure safety of the study team during the one on one interview. Lastly, we excluded patients with lack of proficiency in conversational English that was needed by the study team for an in-person interview. This left us with 30 patients, who we randomly called and interviewed until we reached thematic saturation, which occurred after 21 interviews.

Following principles of grounded qualitative research, we did not test pre-specified hypotheses (23) but aimed to identify themes from the data. We interviewed patients using semi-structured in-person interviews (24) until the study team agreed that no new themes emerged from successive interviews, that is, we reached thematic saturation (25) at 21 interviews.

Immediately after the qualitative interview, each participant completed a written survey with assistance from a study team member as needed for those with limited literacy. All questions from our 22 question survey were obtained from the Health Leads Questionnaire (26), which combines clinically validated guidelines from the Institute of Medicine, Centers for Disease Control and Centers for Medicare and Medicaid Services. Through this survey we assessed specific social and environmental factors in the home and work environment. In addition, we obtained participants' Asthma Control Test (ACT) score. The ACT score is a self-administered tool for identifying those with poorly controlled asthma based on a four-week recall regarding symptoms and functioning. ACT scores range from 0 to 25, with scores greater than 19 indicating adequate control (27). Following the written survey, we reviewed medical records from each patient's most recent asthma-related inpatient or emergency room to determine how often medical teams inquired about relevant social and environmental factors.

The Institutional Review Board of the Yale University School of Medicine and the Cornell Scott Hill Health Center, both in New Haven, Connecticut, approved the research protocol. Verbal informed consent was obtained from participants to participate in the interview, written survey, and subsequent medical record review. Participants received \$40 cash upon completion of the interview and survey.

#### **Data collection**

Two members of the research team (DH or OI) conducted in-person, semi-structured interviews using a standardized interview guide (Table 1). The interview guide was created with input from both academic and community research partners, using lived experience (28) and the existing asthma literature that describes the impact of selected social and environmental factors in the home and workplace. We began each interview with an open-ended, non-threatening question ("Tell me about where you live." Or, "Tell me about where you work"). This initial question helped ensure the respondent felt no cues about the expected content of responses and allowed the participant to direct the conversation to what he or she felt was most important (29). Subsequent questions were posed to participants to determine if they had self-identified social or environmental factors that contributed to their asthma. If the participant identified social or environmental factors, standardized probes (30) were posed to assess barriers or challenges in addressing these factors ("What are you doing / what have you done to try to improve the [identified factors]?"). We piloted the interview guide on three patients in order to establish that our questions were clear, able to be answered by participants, as well as determine if any changes to the interview guide were required. The three pilot interviews were full

Table 1. Interview guide questions.

- 1) Tell me about where you live/work?
- 2) Does anything about where you live/work make your asthma worse?
  a. What are you doing/have you done to try to improve the environmental triggers named in Question 2?
- 3) What do you find stressful about your living situation (prompts: finances, work, family, home)
  - a. What are you doing/have you done to try to improve the social determinants of health named in Question 3?
- 4) What would you do if you had a problem with leaky pipes and mold in your house and your landlord wouldn't help you?

of rich data, so we included them in our analysis and did not make further adjustments to the interview guide.

Interviews consisted of the interviewer and an individual participant. All interviews were audio-recorded in a private room within ¼ mile of the Cornell Scott Hill Health Center. Professional transcriptionists transcribed interviews, and the interviewer reviewed the transcriptions to ensure accuracy. The average length of the recorded interview was 29 min.

#### Statistical analysis

Three members of the research team (DH, AM, CR) reviewed and analyzed the interview transcripts using the constant comparative method (31). Initially, we independently analyzed the first five transcripts creating codes to represent emergent themes within the data. Subsequent transcripts were continuously analyzed and coded in the larger summative context to extract recurrent themes throughout the analytic process. This process involved discussing and negotiating consensus on differing interpretations of interview data, as well as refining the coding structure until no new themes emerged (23). We then applied a final coding structure to all interviews and selected representative quotations to illustrate the emergent themes. We used qualitative analysis software (ATLAS.ti 5.0; Scientific Software Development, Berlin, Germany) to facilitate data organization and retrieval for the purposes of data analysis.

#### Results

Twenty-one adult asthma patients met the study inclusion and exclusion criteria and completed the interview and survey. Study participant characteristics are shown in Table 2. The mean age of the study participants was 47, 62% were female, 71% were black, 53% were obese (BMI > 30) and 95% had Medicaid insurance. Asthma control amongst study participants was suboptimal: the mean ACT score was 11.6 and median emergency or urgent care visits for asthma in the preceding 6 months was 2 (range 1–6).

Fourteen participants reported living with mold, mice, roaches, or water leaks; yet, only 2 patients' health record revealed documentation confirming the inpatient medical team had inquired about the home environment. In addition, asthma triggers at work were common: 12 out of the 16 employed study participants reported work-related asthma exacerbations, including 8 who had previously been fired from a job because of their asthma. However, only one patient's inpatient medical team inquired about work-related asthma. Other social factors identified included food insecurity, utility insecurity, and intimate partner/community violence.

Table 2. Written survey and medical record review.

Patient self-identified characteristics	N = 21
Demographics/anthropometric/socioeconomic	
Mean age, years (range)	47 (24–69)
Female, <i>n</i> (%)	13 (62)
Race/ethnicity, n (%)	
Black	15 (71)
Hispanic	4 (19)
White	2 (10)
Body mass index (BMI), mean (range)	31.8(16.8–51.6)
Obesity (BMI $>$ 30), $n$ (%)	11 (52%)
Self-reported household annual income, mean (range)	\$9,597(\$0-\$35,000)
Currently employed, n (%)	16 (76)
Inability to afford asthma medications, n (%)	8 (38)
Medicaid insurance, n (%)	20 (95)
Asthma history	
Asthma control test (ACT) score, mean (range)	11.6 (5–25)
Emergency room or urgent care asthma visits in prior 6 months, median (range)	2 (1–6)
Housing	
Subsidized housing, n (%)	12 (57)
Homeless, n (%)	4 (19)
Current home with mold, mice, roaches or water leaks, n (%)	14 (82 <sup>*</sup> )
Mold	8 (47*)
Mice	10 (59 <sup>*</sup> )
Roaches	5 (29*)
Water leaks	7 (41*)
History of eviction or fearing eviction, n (%)	13 (62)
Employment	13 (02)
Currently employed, n (%)	16 (76)
Currently experiencing increased asthma symptoms at work, n (%)	12 (75**)
Number of work days missed in past 6 months, mean (range)	3.25 (0–4)
History of being fired due to asthma, n (%)	8 (38)
Other social factors	- ( /
History of intimate partner violence, n (%)	4 (19)
History of community violence, n (%)	7 (33%)
History of food insecurity, n (%)	11 (52)
Inpatient/emergency room medical record documentation	(/
Inquiry made about any housing-related exposures, n (%)	2 (10%)
Inquiry made about any work-related symptoms or triggers, n (%)	1 (5%)
Inquiry made about any other social or environmental trigger, n (%)	1 (5%)

<sup>\*</sup>Out of 17 participants who were not homeless.

#### **Qualitative themes**

Through our qualitative analysis, we identified three central themes that describe challenges disadvantaged patients with uncontrolled asthma face in improving social and environmental factors. These themes include patients': 1) Lack of knowledge about home and workplace asthma triggers; 2) Lack of awareness of legal rights or resources available to mitigate adverse conditions in the home or work environment; and 3) Fear of retaliation from landlords or employers, including threats of eviction, sexual assault, and job loss. A summary of the representative quotations for each identified theme is shown in Table 3.

#### Theme 1: Lack of knowledge about home and workplace asthma triggers

Patients described a lack of knowledge of living with mold in their home environment and working with an asthmainducing trigger at work. For example, some patients lived with mold in their apartments but were not aware of it:

"I seen the black stuff on the wall but I didn't know what it was." (see Figure 1) – 52-year old female

"Three months after I moved into the apartment, black started growing in the back part of my daughter's closet. I never knew what mold was. We would get the bleach and wash it off the wall but it would come back." - 42-year old female

Other patients were able to recognize mold but were unaware that mold can be an asthma trigger:

"I started coughing, coughing, coughing a lot and my son started coughing too. I saw the mold but I didn't [know] how dangerous it is for me. I found out when I got so sick [that] I went into the hospital." - 61-year old female

In addition to mold, occupational exposures were also unsuspected asthma triggers. This was perhaps best illustrated in an auto body painter who spent 40 years

<sup>\*\*</sup>Out of 16 employed participants.



**Table 3.** Representative quotations from the three central themes.

Central theme	Representative quotation
Lack of knowledge about home and workplace asthma triggers	"I seen the black stuff on the wall but I didn't know what it was." – 52-year old female "Three months after I moved into the apartment, black started growing in the back part of my daughter's closet. I never knew what mold was. We would get the bleach and wash it off the wall but it would come back." – 42-year old female "I started coughing, coughing, coughing a lot and my son started coughing too. I saw the mold but I didn't [know] how dangerous it is for me. I found out when I got so sick [that] I went into the hospital." – 61-year old female "I figure my asthmad nothing to do with work until I read about isocyanate in the paper, but I was retired by then."
Lack of awareness of legal rights or resources available to mitigate adverse conditions in the home or work environment	-71-year old male "When I told [the landlord], 'Oh I got mold over there in the window.' He come and spray with paint. He covered the mold. They cover the mold. For all the years that I live there, 17 years." – 59-year old female "The basement got mouses. I got the cat in the house, but he full of mouse. [The landlord] tell me it's okay. Mouse is an animal they not going to bother nobody. Who want mouses in your refrigerator, on your bed, and on your table? The housing authority] say you got to move, find somewhere to move because [the landlord] is not going to fix this."  - 56-year old female "[The Housing Authority] came and they said it was mold but they didn't make the landlord do nothing we needed to get out of the apartment but housing and nobody wouldn't help us and I ain't have that much money to just go and run and find another apartment so I had to wait and wait." – 44-year old female "You were supposed to wear a mask at all times, but one of the things was the mask wasn't sufficient. I got used to not being able to breath and the smell of the chemicals stayed in my lungs, my nostrils. I end up having to quit. I asked [for a new assignment at work], but because I was new [they denied my request] All they had to do was bring me upstairs and I would have been able to breathe." – 53-year old female "After the sexual [assault] with the landlord I had went everywhere. I called a police report, downtown to victim's advocate. I cried out for help. There was no relevance to it. I understand the quiet voice. I take it and tuck it, tolerate it. What does it do to tell?" – 53-year old female "I can't sit down at a desk and access information with so many other things going on. I have to be in [to the shelter] at 4PM. It's snowing. I haven't showered in 2 days. I'm not used to smelling. I know how to do it [the section 8 application] now. It's different when you're right in the middle of it." – 55-year old male "I was struggling to feed my family I tried to apply for them [food stamps], but the way I
Fear of retaliation from landlords or employers	think I filled out something wrong. I waited for about three weeks and they denied me." – 55-year old female "I got extremely depressed, anxious, afraid, going through all the threats from the different tenants in the house because I complained I was a target because [the environment] wasn't acceptable for me. They wanted to shut me up, so I became a target for everyone. [The landlord] said he was going to get me gang raped." – 50-year old female "You have to consider the retaliatory potential, they'll threaten [to evict you], they'll stop returning phone calls or say they didn't get my [rent] check." – 58-year old male "I couldn't breathe. I was having an asthma attack. I told him [the work supervisor] I couldn't come in [to work]. He's like, "If you don't come in, then we gonna fire you." – 34-year old male

mixing paints with isocyanate. During this time period he had multiple exacerbations at work.

"I figure my asthma had nothing to do with work until I read about isocyanate in the paper, but I was retired by then." – 71-year old male

### Theme 2: Lack of awareness of legal rights or resources available to mitigate adverse conditions in the home or work environment

Patients described lack of self-efficacy if they advocated for themselves with a landlord or the housing authority and yet environmental hazards remained in their home environment:

"When I told [the landlord], 'Oh I got mold over there in the window.' He come and spray with paint. He covered the mold. They cover the mold. For all the years that I live there, 17 years." – 59-year old female

"The basement got mouses. I got the cat in the house, but he full of mouse. [The landlord] tell me it's okay. Mouse is an animal they not going to bother nobody. Who want mouses in your refrigerator, on your bed, and on your table? The housing authority] say you got to move, find somewhere to move because [the landlord] is not going to fix this." – 56-year old female

"[The Housing Authority] came and they said it was mold but they didn't make the landlord do nothing... we needed to get out of the apartment but housing and nobody wouldn't help us and I ain't have that much money to just go and run and find another apartment so I had to wait and wait." – 44-year old female

Patients described uncertainty in obtaining workplace accommodations to avoid occupational exposures.

"You were supposed to wear a mask at all times, but one of the things was the mask wasn't sufficient. I got used to not being able to breath and the smell of the chemicals stayed in my lungs, my nostrils. I end up having to quit. I asked [for a new assignment at work], but because I was new [they denied my request] ... All they had to do was bring me upstairs and I would have been able to breathe." – 53-year old female

Patients who had faced sexual assault were unaware of legal rights or resources to cope with sexual trauma and felt powerless to achieve a safe home environment:

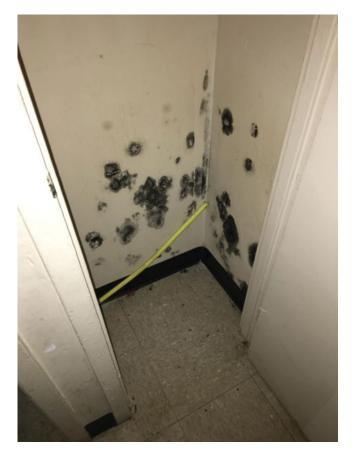


Figure 1. Mold in the apartment building of a study participant.

"After the sexual [assault] with the landlord I had went everywhere. I called a police report, downtown to victim's advocate. I cried out for help. There was no relevance to it. I understand the quiet voice. I take it and tuck it, tolerate it. What does it do to tell?" - 53-year old female

When living in adverse social circumstances such as homelessness, some patients prioritized immediate shelter and safety needs over addressing other social determinants of health:

"I can't sit down at a desk and access information with so many other things going on. I have to be in [to the shelter] at 4PM. It's snowing. I haven't showered in 2 days. I'm not used to smelling. I know how to do it [the section 8 application] now. It's different when you're right in the middle of it." - 55-year old male

Patients were aware of existing subsidies for food and housing but had difficulty accessing them:

"I was struggling to feed my family.... I tried to apply for them [food stamps], but the way I went about them was like I think I filled out something wrong. I waited for about three weeks and they denied me." - 55-year old female

#### Theme 3: When advocating for improving their environment, patients described fear of retaliation from landlords or employers, including threats of sexual assault, eviction, and job loss

Patients who alerted their landlord about home environmental hazards described retaliation in multiple forms including the threat of sexual assault or eviction:

"I got extremely depressed, anxious, afraid, going through all the threats from the different tenants in the house because I complained.... I was a target because [the environment] wasn't acceptable for me. They wanted to shut me up, so I became a target for everyone. [The landlord] said he was going to get me gang raped." -50-year old female

"You have to consider the retaliatory potential, they'll threaten [to evict you], they'll stop returning phone calls or say they didn't get my [rent] check." - 58-year old male

Patients described a threat of termination from employment if they alerted their supervisor of exposures or asthma symptoms.

"I couldn't breathe. I was having an asthma attack. I told him [the work supervisor] I couldn't come in [to work]. He's like, 'If you don't come in, then we gonna fire you.' " - 34-year old male

#### Discussion

Our qualitative study identified challenges that disadvantaged patients with uncontrolled asthma face when addressing social and environmental triggers. These themes include patients': 1) Lack of knowledge about home and workplace asthma triggers; 2) Lack of awareness of legal rights or resources available to mitigate adverse conditions in the home or work environment; and 3) Fear of retaliation from landlords or employers, including threats of eviction, sexual assault, and job loss.

The first identified theme of our study is consistent with the existing literature that shows patient education remains a gap in ideal asthma care (15,32). Environmental and social factors that contribute to asthma are challenging for patients and providers to identify and address, especially in disadvantaged populations. In addition, our study extends the literature by identifying two themes which asthma education alone cannot address, including patients' lack of awareness of legal rights or resources available and the fear of retaliation.

Patients who approach their landlords or employers are often met with resistance when requesting home improvements or workplace accommodations. In our study, participants reported that landlord and/or employer responses ranged from complete inaction to unhelpful fixes such as painting over mold without

addressing the source of the problem (leaky roofs, pipes, or windows). These patients were often unaware of legal recourse or resources available to assist them in achieving environmental changes in their home or workplace.

The lack of awareness of community resources is also a barrier for patients when addressing other social factors. In our study, while many patients were aware of existing housing or food subsidies, they had difficulty accessing these programs. Patients were unsure of how to ask, or to whom to turn to, for assistance in benefit applications especially when an initial application was denied. Patients experiencing domestic violence did not connect with community organizations such as emergency shelters or legal aid that could assist them.

Fear of retaliation, including threats of eviction, sexual assault, or job loss, discouraged participants from seeking help, including approaching their landlords or employers to make environmental changes. The high rates of prior eviction, homelessness, employment termination, and sexual violence described by those in our study contributed to a paralyzing fear. This fear, which contributed to participants' ongoing exposures to social and environmental triggers, highlights the need for interventions to help patients understand their housing and workplace rights. This study confirms prior research that links sexual violence and asthma (33). These threats of sexual assault are an extreme example of a barrier to fixing social and environmental factors related to asthma, but speak about the serious barriers to healthcare that education is inadequate to address.

Although work-related asthma was not a primary focus of the study, it is notable that 12/16 employed participants reported work-exacerbation of their asthma, and 8 of these reported job termination due to their asthma. Work-exacerbated asthma is recognized as an occupational disease, similar to a work-related injury, which can entitle a worker to medical care, disability benefits, and work accommodations (34). However, only one of these participants was diagnosed as having work-exacerbated asthma, which, if identified, can frequently be managed by reducing workplace exposures and/or work accommodations. Nor were any participants aware of potential rights or benefits such as workers' compensation. These findings are consistent with recent studies showing that work-exacerbated asthma is common, under-recognized by patients, clinicians, and employers, and contributes to worse clinical and socioeconomic outcomes (35,36). Recognizing the challenges disadvantaged asthmatic workers face provides opportunities to help them remain gainfully employed, and if unable to work, access available benefits.

Our study not only illuminates barriers that patients face while trying to address social and home and workplace environmental factors relevant in asthma, but also highlights the inadequacy of the current healthcare system in addressing these factors. Although there is an increasing trend in understanding social determinants of health in medical education (37), most medical providers are not trained to identify and address the challenges identified in this study. Previous studies have suggested that many providers perceive that most social and environmental needs cannot be remedied (38). However, this likely reflects insufficient training and familiarity with social and community-based, collaborative resources.

Many providers will recognize that social workers are often at the forefront of helping to ameliorate the social and environmental conditions that impact asthma. Although social workers are vital in the care of many disadvantaged asthmatics, this study illuminates two key points: 1) many of those interviewed identified social and environmental issues that were not documented in their medical record and therefore were unlikely to come to the attention of social workers and 2) many of the issues identified are challenges that may be best addressed with legal advocacy. Collaboration with lawyers, who can advocate through legal recourse including tenant-landlord law, housing code enforcement, eviction and utility shutoff prevention programs, and workers' compensation, may be an effective approach to address the challenges identified in this study (39). Medical teams may consider partnerships or collaboration with non-profit legal aid programs as part of a multidisciplinary approach to improving asthma outcomes in disadvantaged patients. Often funded in part by Legal Services Corporation (an independent non-profit established by Congress in 1974 to provide support for civil legal aid to low-income Americans), there are over 133 independent non-profit legal aid programs, at least one in every state (40). Despite this funding, there remains a substantial gap between low-income Americans' civil legal needs and available resources to address them (41). Increasingly health systems are recognizing the importance of legal solutions to many social and environmental problems (42) and future research is needed to study the effectiveness of legal interventions and partnerships to improve health outcomes, such as in asthma.

#### Limitations

Several limitations of this study should be noted. First, we were unable to question the landlords or employers identified in interviews. Doing so may have validated or offered an additional perspective of the participants' experiences; however, we did not pursue this due to the possibility of retaliatory responses directed at participants. Additionally, although we conducted interviews until data saturation, given our small sample size and

purposeful sampling from a single community health center serving a predominantly urban, African-American community, the barriers identified in this study unlikely encompass all barriers patients with uncontrolled asthma from disadvantaged communities face. Given that stress related to immigration and acculturation factors are known to impact asthma outcomes (43), further study is needed to assess barriers to improve social and environmental factors in immigrant or refugee communities. Additionally, since we purposefully excluded smokers in this study to help ensure a correct diagnosis of asthma (versus COPD), additional study is warranted to better understand how smoking and environmental tobacco smoke impact barriers to addressing social determinants of health. Lastly, our focus was not on the clinicians' role in identifying and addressing social and environmental factors. Given the infrequency in which inpatient medical teams documented social or environmental factors, which were commonplace in our study patients, further investigation is warranted to assess providers' perspectives and challenges in this regard.

#### **Conclusion**

Our qualitative study identifies challenges that disadvantaged patients with uncontrolled asthma face when addressing social and environmental triggers. These novel findings should help providers, researchers, and policy makers design multidisciplinary interventions to improve asthma outcomes in disadvantaged patients. Patients' fear of retaliation when approaching landlords/employers, and lack of awareness of legal recourse or resources available to assist them in mitigating adverse factors in the home or workplace, are challenges that may be best addressed by incorporating medical legal partnerships into multidisciplinary approaches to improve asthma outcomes. Future research is needed to study the effectiveness of legal interventions and partnerships on reducing asthma disparities through improving social and environmental factors.

#### **Declaration of interest**

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

#### **Funding**

This study was funded, in part, by the Deupree Family Foundation. The funding source had no role in the design, analysis, or reporting of the study or in the plan to submit the manuscript for publication.

#### References

- 1. Forno E, Celedon JC. Health disparities in asthma. Am J Respir Crit Care Med. 2012;185(10):1033–5.
- 2. Canino G, McQuaid EL, Rand CS. Addressing asthma health disparities: a multilevel challenge. J Allergy Clin Immunol. 2009;123(6):1209–17; quiz 18–9.
- 3. Williams DR, Sternthal M, Wright RJ. Social determinants: taking the social context of asthma seriously. Pediatrics. 2009;123 (Suppl 3):S174–84.
- 4. Ribeiro-Silva Rde C, Oliveira-Assis AM, Junqueira SB, Fiaccone RL, Dos Santos SM, Barreto ML, et al. Food and nutrition insecurity: a marker of vulnerability to asthma symptoms. Public Health Nutr. 2014;17(1):14–9.
- 5. Suglia SF, Enlow MB, Kullowatz A, Wright RJ. Maternal intimate partner violence and increased asthma incidence in children: buffering effects of supportive caregiving. Arch Pediatr Adolesc Med. 2009;163(3):244–50.
- 6. Quinn K, Kaufman JS, Siddiqi A, Yeatts KB. Stress and the city: housing stressors are associated with respiratory health among low socioeconomic status Chicago children. J Urban Health. 2010;87(4):688–702.
- 7. Archea C, Yen IH, Chen H, Eisner MD, Katz PP, Masharani U, et al. Negative life events and quality of life in adults with asthma. Thorax. 2007;62(2):139–46.
- 8. Guarnieri M, Balmes JR. Outdoor air pollution and asthma. Lancet. 2014;383(9928):1581–92.
- Sobel RM, Paasche-Orlow MK, Waite KR, Rittner SS, Wilson EA, Wolf MS. Asthma 1-2-3: a low literacy multimedia tool to educate African American adults about asthma. J Community Health. 2009;34(4):321-7.
- Tatis V, Remache D, DiMango E. Results of a culturally directed asthma intervention program in an inner-city Latino community. Chest. 2005;128(3):1163-7.
- 11. Press VG, Arora VM, Shah LM, Lewis SL, Charbeneau J, Naureckas ET, et al. Teaching the use of respiratory inhalers to hospitalized patients with asthma or COPD: a randomized trial. J Gen Intern Med. 2012;27(10):1317–25.
- 12. Blixen CE, Hammel JP, Murphy D, Ault V. Feasibility of a nurse-run asthma education program for urban African-Americans: a pilot study. J Asthma. 2001;38(1): 23–32
- 13. Paasche-Orlow MK, Riekert KA, Bilderback A, Chanmugam A, Hill P, Rand CS, et al. Tailored education may reduce health literacy disparities in asthma self-management. Am J Respir Crit Care Med. 2005;172(8): 980–6.
- 14. Clarke AR, Goddu AP, Nocon RS, Stock NW, Chyr LC, Akuoko JA, et al. Thirty sources of disparities intervention research: what are we doing to close racial and ethnic gaps in health care? Med Care. 2013;51(11):1020–6.
- Press VG, Pappalardo AA, Conwell WD, Pincavage AT, Prochaska MH, Arora VM. Interventions to improve outcomes for minority adults with asthma: a systematic review. J Gen Intern Med. 2012;27(8):1001–15.
- Bhan N, Kawachi I, Glymour MM, Subramanian SV. Time Trends in racial and ethnic disparities in asthma prevalence in the United States From the behavioral risk factor surveillance system (BRFSS) study (1999–2011). Am J Public Health. 2015;105(6):1269–75.
- 17. Thakur N, McGarry ME, Oh SS, Galanter JM, Finn PW, Burchard EG, et al. The lung corps' approach to reducing

- health disparities in respiratory disease. Ann Am Thorac Soc. 2014;11(4):655–60.
- 18. Harris DA, Pensa MA, Redlich CA, Pisani MA, Rosenthal MS. Community-based participatory research is needed to address pulmonary health disparities. Ann Am Thorac Soc. 2016;13(8):1231–8.
- Corburn J. Combining community-based research and local knowledge to confront asthma and subsistencefishing hazards in Greenpoint/Williamsburg, Brooklyn, New York. Environ Health Perspect. 2002;110 (Suppl 2): 241–8
- 20. The Cornell Scott Hill Health Center Fact Sheet. http://www.cornellscott.org/documents/resources/Fact Sheet.pdf. [Accessed 1 April 2017].
- 21. Gottlieb L, Hessler D, Long D, Amaya A, Adler N. A randomized trial on screening for social determinants of health: the iScreen study. Pediatrics. 2014;134(6):e1611–8.
- Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Adm Policy Ment Health. 2015;42(5): 533-44
- 23. Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. Health Serv Res. 2007;42(4):1758–72.
- 24. Britten N. Qualitative interviews in medical research. BMJ. 1995;311(6999):251–3.
- 25. Varpio L, Ajjawi R, Monrouxe LV, O'Brien BC, Rees CE. Shedding the cobra effect: problematising thematic emergence, triangulation, saturation and member checking. Med Educ. 2017;51(1):40–50.
- 26. Health Leads: Social Needs Screening Tool Kit. https://healthleadsusa.org/tools-item/health-leads-screening-toolkit/. [Accessed 3 July 2017].
- 27. Nathan RA, Sorkness CA, Kosinski M, Schatz M, Li JT, Marcus P, et al. Development of the asthma control test: a survey for assessing asthma control. J Allergy Clin Immunol. 2004;113(1):59–65.
- 28. Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical dilemmas in community-based participatory research: recommendations for institutional review boards. J Urban Health. 2007;84(4):478–93.
- 29. Warnecke RB, Johnson TP, Chavez N, Sudman S, O'Rourke DP, Lacey L, et al. Improving question wording in surveys of culturally diverse populations. Ann Epidemiol. 1997;7(5):334–42.

- 30. Given LM. The Sage encyclopedia of qualitative research methods. Los Angeles, (Calif.): Sage Publications; 2008.
- 31. Malterud K. Qualitative research: standards, challenges, and guidelines. Lancet. 2001;358(9280):483–8.
- 32. Clark NM, Mitchell HE, Rand CS. Effectiveness of educational and behavioral asthma interventions. Pediatrics. 2009;123(Suppl 3):S185–92.
- 33. Santaularia J, Johnson M, Hart L, Haskett L, Welsh E, Faseru B. Relationships between sexual violence and chronic disease: a cross-sectional study. BMC Public Health. 2014;14:1286.
- 34. Baur X, Aasen TB, Burge PS, Heederik D, Henneberger PK, Maestrelli P, et al. The management of work-related asthma guidelines: a broader perspective. Eur Respir Rev. 2012;21(124):125–39.
- 35. Vandenplas O, Toren K, Blanc PD. Health and socioe-conomic impact of work-related asthma. Eur Respir J. 2003;22(4):689–97.
- 36. Henneberger PK, Redlich CA, Callahan DB, Harber P, Lemiere C, Martin J, et al. An official American thoracic society statement: work-exacerbated asthma. Am J Respir Crit Care Med. 2011;184(3):368–78.
- 37. Pettignano R, Bliss L, McLaren S, Caley S. Interprofessional medical-legal education of medical students: assessing the benefits for addressing social determinants of health. Acad Med. 2017;92(9):1254–1258.
- 38. Fleegler EW, Lieu TA, Wise PH, Muret-Wagstaff S. Families' health-related social problems and missed referral opportunities. Pediatrics. 2007;119 (6):e1332–41.
- 39. McCabe HA, Kinney ED. Medical legal partnerships: a key strategy for addressing social determinants of health. J Gen Intern Med. 2010;25 (Suppl 2):S200–1.
- 40. Legal Services Corporation. 2015 LSC By The Numbers; [accessed 2017 May 1]. http://www.lsc.gov/.
- 41. Legal Services Coporation. The Justice Gap: Measuring the Unmet Civil Legal Needs of Low-income Americans. http://www.lsc.gov/sites/default/files/images/TheJustice Gap-FullReport.pdf. [Accessed 3 July 2017].
- 42. Cohen E, Fullerton DF, Retkin R, Weintraub D, Tames P, Brandfield J, et al. Medical-legal partnership: collaborating with lawyers to identify and address health disparities. J Gen Intern Med. 2010;25(Suppl 2):S136–9.
- 43. Koinis-Mitchell D, Sato AF, Kopel SJ, McQuaid EL, Seifer R, Klein R, et al. Immigration and acculturation-related factors and asthma morbidity in Latino children. J Pediatr Psychol. 2011;36(10):1130–43.