

ORIGINAL ARTICLE

Urban adults' perceptions of factors influencing asthma controlMaureen George, PhD, RN, AE-C, FAAN¹, Shimrit Keddem, MSc², Frances K. Barg, PhD, MED², Sarah Green, MPH³, and Karen Glanz, PhD, MPH^{1,3}¹Department of Family and Community Health, University of Pennsylvania School of Nursing, Philadelphia, PA, USA, ²Department of Family Medicine and Community Health, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA, USA, and ³Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA, USA**Abstract**

Objective: To identify urban adults' perceptions of facilitators and barriers to asthma control, including the role of self-care, medications, environmental trigger remediation, and primary care. **Methods:** Semi-structured open-ended qualitative interviews were conducted. Audio recordings were transcribed verbatim and entered into NVivo 10.0 (QSR International Pty Ltd, Doncaster, Victoria, Australia) for coding, analysis, and integration with demographic and asthma control data. Results were analyzed by the level of asthma control. A modified grounded theory approach was used in the analysis. **Results:** Thirty-five adults with persistent asthma (94% Black; 71% female; 71% with uncontrolled asthma) from the five West Philadelphia zip codes with the highest asthma burden participated. Generally, all participants understood the roles of inhaled corticosteroid (ICS) and short-acting β -2 agonist (SABA) therapies in asthma self-care although they attributed systemic side effects to topical ICS administration. Compared with participants with controlled asthma, uncontrolled participants reported overusing SABAs, underusing ICS, rejecting medical and trigger remediation advice, having more negative experiences with primary care providers, and preferring more unconventional strategies to prevent or manage asthma symptoms. **Conclusions:** Personal health beliefs about control can undermine adherence to medical and environmental remediation advice and likely contributes to high rates of uncontrolled asthma in this population. Clinicians need to know whether, and to what degree, these health beliefs can be modified. It is likely that new models of care, such as patient-centered shared decision-making approaches, and new partners, such as community health workers, may be required to modify these beliefs. This would be an important first step to enhance asthma control in vulnerable populations.

Keywords

Minority, community, environmental, triggers, qualitative

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Introduction

According to national guidelines [1], the goal of asthma management is to achieve and sustain well-controlled asthma. A person with well-controlled asthma should experience infrequent symptoms, be free of activity limitations, and demonstrate normal lung function. However, of the 24 million Americans who have asthma, as many as 71% of those 12 years of age or older have uncontrolled disease [2]. In 2008, half of all individuals experienced an asthma attack [3] and urban populations were disproportionately represented within that population [4]. Although there are many explanations for the high rates of uncontrolled asthma, four are more common in urban adults: low rates of asthma self-care training to assist in the early identification of, and response to, signs of worsening asthma, personal health beliefs that may impede

adoption of medical recommendations, less use of primary care services, and more barriers to enacting environmental control measures.

Many asthma attacks could be prevented if individuals received asthma self-management training [3]. Healthy People 2010 sought to increase the proportion of individuals receiving asthma training from 8% to 30%, but only 12% of adults report having received such training and only 30% have an asthma action plan [3]. A significantly lower proportion of minorities and adults with Medicaid or no insurance, compared with Whites and adults with private insurance, report having received asthma self-management training or an asthma action plan [5]. As a result, only slightly more than half of all adults with asthma can recognize the early signs of an attack or know how to control environmental triggers [3].

Health beliefs about asthma and its management are one of the most significant factors affecting inhaled corticosteroid (ICS) adherence, the primary approach to achieving and maintaining control of persistent asthma [1]. Although ICS adherence is disappointingly low in all groups, averaging only

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50% [6], ICS adherence has been reported as low as 29% in Blacks [7]. The low rates of ICS adherence in Black adults with asthma have been attributed to higher rates of negative ICS beliefs compared with Whites [8,9]. These include a fear of being overmedicated, developing tolerance or addiction to ICS, concerns about medical experimentation [8–14], as well as a preference for more unconventional care [11,12,15]. Suboptimal ICS adherence has been directly linked to life-threatening attacks, acute health care utilization, and deaths from asthma [7] and may explain, in part, the widening disparity seen in asthma outcomes by race/ethnicity [4]. Primary care visits are a likely venue for delivering asthma self-care training; however, primary care remains underutilized even for those who have access to services [16].

Environmental factors that aggravate asthma are common in urban settings and evidence suggests that if avoidance is not possible, remediation is the most effective management strategy [1]. However, environmental remediation can be costly and may be difficult to implement in urban settings where many homes are rental properties. For example, landlords may not want to remove wall-to-wall carpeting because it is seen as adding value to the property. In addition, there may be competing priorities. For example, removing a cat from the home as part of a comprehensive strategy to manage cat-allergic asthma may be in keeping with evidenced-based recommendations but may be unacceptable to the patient who values prevention of rodent infestation over reduced allergen exposure [17]. Barriers like these likely reflect the challenges to implementation that many face, contributing to low rates (50%) of adherence to environmental remediation advice [3].

Taken together, urban adults face many obstacles to effective asthma self-management: inadequate self-care training, health beliefs that compete with medical advice, insufficient rates of routine primary care, and restricted ability or motivation to manage one's own environmental triggers. In this context, there is likely much to be gained from an enhanced understanding of patients' perspectives of the factors that impede or facilitate asthma control in their home and their community, and which disease management strategies are more salient in the setting of competing demands. Unlike deductive quantitative methods that answer hypotheses about *whether* and *how much*, the goal of inductive qualitative approaches is to produce credible data that captures patients' beliefs, attitudes, and perceptions gleaned from their lived experience to answer *how*, *why*, and *what* questions. Qualitative research has unique metrics to determine data collection adequacy (data provides depth and breadth) and data-analysis adequacy (iterative data reduction produces a rich narrative of the commonly occurring themes). The relevance of this type of information is becoming increasingly important as patients and families manage chronic illness largely outside of the health care system using approaches they value but that do not necessarily align with the best evidence. Knowing that discrepant views of disease management exist offers the clinician an opportunity to avert conflict over treatment choices before they occur, fostering greater alignment of patient and provider goals. To gain a greater understanding of these views, we therefore undertook qualitative interviews with urban adults with persistent asthma, most with uncontrolled asthma.

Methods

A purposive sample of individuals who participated in a prior research study was recruited from the five zip codes in West Philadelphia with the highest asthma burden. Purposeful sampling, rather than random sampling, is used in qualitative research to achieve a variety of responses to a shared experience. In this study, the sample shared the same neighborhood and medical condition. Specifically, the sample was stratified to achieve representation from each zip code and to include both males and females. Inclusion criteria required that participants be >21 years of age, have provider diagnosed persistent asthma and currently have a prescription ICS asthma treatment. Those who were non-English speaking and those with serious mental health conditions that would affect study participation or ability of the individual to provide full informed consent were excluded. The Institutional Review Board of the University of Pennsylvania reviewed and approved this study.

Data collection

As detailed in Table 1, in-person, semi-structured, open-ended interviews lasting 20–40 min were conducted in respondents' homes to identify their perceptions of factors in the home and neighborhood that affected asthma control. The role of ICS and short-acting β -2 agonist (SABA) medications, environmental avoidance or remediation strategies, and routine primary care were also elicited. Participants received \$25 cash for study participation.

Participants provided demographic data and completed a detailed asthma history and medication review. In addition, participants' level of asthma control was calculated at the time of the interview using metrics recommended by national asthma guidelines [1]. This calculation included two patient-reported outcomes: the number of SABA doses in the prior 7 d and the number of nocturnal awakening due to asthma in the prior 30 d. Using these two outcomes, we were able to classify participants as 'Well-controlled' (SABAs ≤ 2 d per week and/or awakenings $\leq 2 \times$ per month), 'Not Well-Controlled' (SABAs > 2 d per week and/or awakenings $1\text{--}3 \times$ per week) or 'Very Poorly Controlled' (SABAs several times a day and/or awakenings $\geq 4 \times$ per week). For the purpose of analysis and interpretation, we then collapsed the two categories of uncontrolled asthma ('Not Well-Controlled' and 'Very Poorly Controlled') into one category ('Uncontrolled') which allowed us to characterize participants as either 'Controlled' or 'Uncontrolled'.

Data analysis

Interviews were transcribed, de-identified, and entered in NVivo 10.0 for coding, analysis, and integration with demographic and asthma control data. A modified grounded theory [18] approach was used for analysis. Our analysis was typical for qualitative studies in that it employed an iterative process of reading transcripts to identify common themes, retaining themes that were relevant and discarding information that was extraneous until a rich narrative about a shared experience was produced. To accomplish this, line-by-line coding was performed by one researcher (SK) and a subset of transcripts was independently coded by a second researcher

Table 1. Interview guide.

1. What are things in your neighborhood that can affect how you feel?
 - (a) What do you think can be done about these things?
2. How do you think your neighborhood compares with other neighborhoods in terms of things that are bad for your health?
3. What kinds of community activities happen in your neighborhood?
4. How do you interact with people in your neighborhood? (Probe: What are your relationships like with your neighbors?)
 - (a) How do you feel about these relationships with your neighbors?
 - (b) How do you think these relationships affect your health?
5. How do you think that your home affects your asthma control?
6. The last time you ran into trouble with your asthma when you were at home, what happened? Please tell me everything you can remember about that event. (Prompt for what happened before, during, and after the episode)
 - (a) How typical was this for you? (If atypical, probe for why)
 - (b) Please give us a step-by-step description of what you did to regain control of your breathing
7. What role do your prescription asthma controller medicines have in the day-to-day management of your asthma?
8. Please tell me what it is like to try to eat a healthy diet.
9. Where do you go to get healthy food in your neighborhood?
10. Please comment on what it is like for you to exercise. (Probe: What makes it hard to exercise? What makes it easier to exercise?)
11. What do you do to try to manage stress in your life?
12. Are there other things that you think we should know about how it is to keep healthy or to manage your asthma?

(MG) and assessed for inter-rater reliability. Discrepancies were resolved by discussing with the group until consensus was achieved.

Results

A total of 108 potential participants living in the five targeted zip codes were identified from the prior multi-center research study. We were unable to reach 57 individuals after multiple attempts, 11 scheduled appointments that they did not keep, 4 declined participation, and 36 were enrolled. Of the 36, one participant was dropped from the analysis because they were found to be ineligible (lived outside targeted zip codes). Most of the 35 who enrolled were Black (94%) females (71%) with uncontrolled asthma (71%) (Table 2).

Analysis of transcripts identified thematic categories reflecting participants' views of asthma self-care specifically as it related to monitoring and responding to signs of deteriorating asthma control, beliefs about ICS and SABA, perceptions of environmental triggers, and need for routine primary care. Results are presented by level of control.

Monitoring and responding to deteriorating control

Participants with controlled asthma

Although the majority of participants with controlled asthma understood the different roles of ICS and SABAs, several used ICS treatments only when symptomatic and were overly reliant on SABAs. In addition, participants reported many alternative treatments for preventing or managing asthma symptoms, such as relaxation, deep breathing, rest, prayer, water, coffee, tea, and fresh air. Table 3 provides a complete list of alternative symptom management strategies that respondents said they used.

Controlled participants also recognized errors in past self-care behaviors, such as delays in seeking medical treatment during protracted severe attacks, saying they had learned from past mistakes. For example, one subject said "What I was doing that was wrong. I took my albuterol, and I kept using the albuterol hoping that it was gonna' get better. And really I was doing more damage to myself by keep using the albuterol."

Table 2. Subject characteristics.

Characteristics	N = 35	Controlled n = 10	Uncontrolled n = 25
Age mean (SD)	55 (11)	61 (15)	53 (8)
Gender			
Male	10	2	8
Female	25	8	17
Race			
Black/African American	33	9	23
White ^a	2	1	2
Highest educational level			
<High school	7	1	6
Completed high school	11	3	8
Some college	11	4	7
College/post graduate	6	2	4
Insurance			
Medicaid	14	2	12
Medicare/SSI	7	4	3
Medicaid & Medicare	8	3	5
Commercial	6	1	5
BMI			
Normal weight	6	1	5
Overweight	7	5	2
Obese	22	4	18

^aOne subject reported her race as White/Native American.

Participants with uncontrolled asthma

Like controlled participants, most uncontrolled participants knew the correct roles of ICS and SABA in asthma self-care. However, they were more likely to describe overusing SABA and underusing ICS because they believed they had been prescribed more ICS than necessary for their level of asthma severity and because they attributed systemic side effects (e.g. weight gain) to the topical ICS treatment. Uncontrolled participants also identified alternative treatments for asthma symptoms (Table 3).

Similarly, those who were uncontrolled admitted to making self-care errors and learning from past mistakes. For example, one subject with uncontrolled asthma said "I go to the doctors on a regular basis to have myself checked out. So maybe I didn't do all those things before. I wasn't so proactive before about it, because – like after the last hospitalization it was like okay, I think you got a wake-up call. Like this is real, it ain't

Table 3. Alternative symptom management.

CAM-A items	Controlled	Uncontrolled
Relaxation/stress reduction exercises	✓	✓
Deep breathing	✓	✓
Adequate rest	✓	✓
Limit activity/avoid exercise	✓	✓
Prayer/church attendance	✓	✓
Fresh air/air movement from fan or air conditioner	✓	✓
Water	✓	✓
Coffee	✓	✓
Use air cleaners	✓	
Move above tree canopy	✓	
Use HEPA filters		✓
Hyperventilate		✓
Healthy diet		✓
Use large “party” tent to keep leaves and pollens from settling in backyard		✓
Use ceiling fan or in-window fan to reduce pollen levels in the home		✓
Distraction		✓
Use facemask		✓
Shower		✓
Hall’s lozenges		✓
Avoid spicy foods		✓
Cold compresses/cold from freezer		✓
Steam		✓
Houseplants to enrich oxygen		✓
Use “green” household products		✓

HEPA, high efficiency particulate air.

playing.” However, others denied a need for behavior change saying “Sometimes I wasn’t taking the inhaler (ICS), because like I’m fine now, you see what I’m saying? So yeah, I’ll be honest; I don’t take it when I’m fine. I don’t take it every day like I’m supposed to. So I’m admitting it. And of course they get on me about it. But I be truthful. Like now, I don’t have a cold. I’m fine. So I didn’t take it.”

Beliefs about ICS and SABAs

Participants with controlled asthma

There was more endorsement for the use of ICS among controlled participants compared with those with uncontrolled asthma. Comments included “It’s the one thing I try to do, I take my (brand name ICS), because that’s maintenance, and it keeps me really open.” However, one subject did describe her ICS as a “bandaid” that caused weight gain and “didn’t solve the problem.”

Participants with uncontrolled asthma

Many participants were skeptical that asthma could be controlled and offered alternatives to ICS such as drinking water and getting adequate rest. Others commented that ICS could be helpful in achieving asthma control but that forgetting doses was common.

Triggers avoidance/remediation

Participants with controlled asthma

Controlled participants identified conventional allergen and irritant triggers such as cats, dust (mites), odors, cockroaches, exercise, pollution, weather, stress, food, and pollens.

However, one subject with known cat allergy felt that she could not follow advice to get rid of her cat because the cat was important for rodent control and because she had developed an emotional connection to the pet. She said:

I could get rid of this cat that’s here for the mice, because I’m allergic to cat and dog dander, but I need a cat because we have mice. They’re in the corner house, and you know there’s all these little holes somewhere and they do get in here, I ain’t even gonna’ lie. And this cat has to be here and we just got this cat. I came home from the hospital there was a cat here. So if we didn’t have to have a cat that would be a lot better as well. He’s starting to grow on me.

One participant with seasonal allergies indicated that she planned to limit pollen exposure by moving to an upstairs apartment so she could be above the tree canopy. Another participant indicated that exercise should not be performed because of exposure to environmental triggers.

Participants with uncontrolled asthma

Those with uncontrolled asthma identified the same triggers as the controlled group with the addition of dogs, cigarettes, upper respiratory infections, fatigue, co-morbidities (obesity and gastroesophageal reflux disease), and feathers. Interestingly, two uncontrolled participants complained that there were too many trees in the neighborhood causing excessive pollen exposure. Five participants reported cat and/or dog allergies but were unwilling to part with their pets. One subject did not want to deny her child the right to a pet; another rejected cat avoidance advice saying “What’s the point of having cats if you don’t have them on the bed?” A third subject with uncontrolled asthma believed that the presence of the pet improved asthma by desensitizing affected family members. She commented:

My dog went away for the summer; she went to my daughter’s house, because I went to Florida. Then I missed her...but then when she came back it affected it (allergies) then, because I guess I wasn’t used to her hair anymore and then I was constantly sneezing, constantly sneezing and coughing and gagging for air. So I had to take and bathe her, because see I’ll wash her every three days with baby wipes. But I love my dog, she’s my baby. I have a cat too...the reason why I have the cat is because my youngest granddaughter has asthma – the one that lives in the house with me has asthma – and they have to be – I don’t know what it is with them, when there’s not an animal in the house their asthma is worse. It triggers. I guess because the dog, they’re always – the dog is always licking them in the face. I don’t know. But long as the dog is there she’s okay... when he came back she was having like sneezing, sneezing, sneezing for a little while, but then it went away.

Several participants offered unconventional trigger avoidance measures, such as using a large party tent in the backyard to serve as a physical barrier to pollen and leaves, using ceiling fans and window fans to blow pollen back outside, and using houseplants to enrich oxygen levels in their home. Others identified triggers as a reason not to exercise.

Role of primary care

Participants with controlled asthma

The majority of participants in the controlled group believed that primary care played an important role in controlling asthma. Controlled participants also saw themselves as being engaged consumers of health care services saying "One of the things is to be upfront with your doctor. And if you feel that your doctor is not giving you the right treatment or he's not listening to you, change doctors."

Participants with uncontrolled asthma

Most uncontrolled participants also identified routine primary care as important. One subject said "See the doctor...when-ever they want to see you" and another said "Do what you got to do, do what you supposed to do. If you diagnosed with asthma, they (providers) know what they talking about. Don't think they don't know." However, only uncontrolled participants complained that their providers did not listen to them, and as a result, participants rejected medical recommendations. Exemplars include the following:

The first person who's gonna' prescribe you something is your regular (primary care provider). He's the first person you're gonna' have to see before you can get to the pulmonologist. Okay? So he needs to be better trained on how to prescribe the proper medicine. In other words, don't go first to steroids, okay, because sometimes that's not what we need.

And I did go see a nurse practitioner and she was like 'Yeah, you're just crackling everywhere. Here's some prednisone.' I was like, no, that's okay. Let's start with antibiotics, and then we'll see. And I did take antibiotics and it did clear itself up within two days.

If you don't feel any better then I guess you have to go see a doctor. But usually my treatments work and I don't have to go see my doctor, because all they gonna' do is give you some more prednisone, which in turn is not really good for you.

Discussion

This qualitative study of adults with asthma provides a new understanding of urban adults' perspectives of the facilitators and barriers to asthma control, including the role of self-care, medications, environmental triggers, and primary care. Participants in both groups had an adequate understanding of the roles of ICS and SABA in asthma self-care. However, compared with participants with controlled asthma, more adults with uncontrolled asthma reported being non-adherent to ICS, expressed doubts about the ability to control asthma, rejected medical advice, and described more negative experiences with primary care providers. Further, most did not attempt to remediate environmental triggers that were within their control, preferring unconventional strategies to evidence-based recommendations. Lastly, several participants believed that exercise should be avoided in asthma.

Several of our findings have been reported in previous studies of urban minority adults. For example, beliefs that ICS

treatments are over prescribed are unnecessary for asthma control and cause systemic side effects have been identified as contributing to low ICS adherence in these groups [8–14,19] and likely contributed to the high rates of uncontrolled asthma we saw in this population. These beliefs create significant challenges to achieving asthma control in overweight adults who may require higher-longer doses of steroids but who may not treat their asthma sufficiently due to fears of weight gain from inhaled steroids.

In addition, rejection of environmental remediation advice is common [3]. However, important new perspectives on triggers and trigger remediation were obtained from this study. These included the belief that purposeful pet exposure can help to control asthma by desensitizing the individual to the offending allergen. This is different from the belief in Latino communities that a magico-religious transfer of asthma can occur between humans and Chihuahuas [20]. In addition, participants in both the controlled and uncontrolled groups complained that trees in their neighborhood were the source of their pollen allergen despite the paucity of trees, parks, and green spaces in these zip codes. Because participants identified a specific offending tree as the source of their pollen exposure, and not pollen drift, they had very localized plans for reducing exposure, such as moving above the tree canopy or using a large tent to keep pollens from drifting down to their ground level apartments.

While participants with both controlled and uncontrolled asthma believed exercise was important for overall health, they avoided physical activity. Considering that most participants in this study had uncontrolled asthma, this might be a reasonable approach to maintaining asthma control. However, 83% of participants in this study were either overweight or obese (Table 2); regular physical activity should be an integral component of their broader asthma self-management plan.

Uncontrolled participants described distrusting medical advice and highlighted several negative encounters with providers. Distrust of providers and dissatisfaction with care are associated with poor control in other chronic conditions, such as hypertension [21] and diabetes [22]. Creating a more satisfactory experience within the time constraints of primary care remains a challenge. However, improved satisfaction with care may not require more time with a patient, but rather may require a different type of patient-provider partnership, one that is characterized by a more patient-centered model of care delivery [23,24]. In the shared decision-making model derived from the Chronic Care Model [25,26], providers enter into deliberate patient-centered discussions to resolve differences in what evidence-based guidelines identify as preferred treatments and what patients want and value. A discussion of the risks and merits associated with all treatment options can help to reconcile differences leading patients to select treatments that more closely align with evidence-based recommendations [23,24].

Qualitative studies by their nature are small in size and not meant to be generalizable but rather to produce credible and relevant data from individuals having a shared experience. These small non-random samples do not allow for frequency response comparisons typical of quantitative approaches although they allow for the development of hypotheses that

can be explored in the future. There are several additional limitations that should be noted. This study enrolled a convenience sample of 35 adults. Therefore, the potential for self-selection bias exists in that only those who could be reached by phone and who agreed to an in-home interview were enrolled; they are likely different from those we were unable to reach or who declined to participate. Because men, non-Blacks, and those with who were normal weight or underweight were underrepresented in this sample, we are not able to determine if the perceptions we describe are unique to Black overweight women. There is also a risk of social desirability in that participants may have answered in a manner to please the investigators; inability to confirm the accuracy of self-report is a limit of qualitative approaches.

Conclusions/key findings

In summary, this study of urban adults' perceptions of facilitators and barriers to asthma control highlights that negative medication beliefs remain a significant obstacle to ICS adherence, and likely contributes to the high rates of uncontrolled asthma in this population. In combination with an overreliance on SABAs, inadequate ICS use increases the risk for poor clinical outcomes in a population already experiencing marked health disparities. Importantly, participants appeared to understand the different roles of ICS and SABAs suggesting that their current self-care behavior was not due to a lack of knowledge but rather to negative (and erroneous) beliefs about ICS. This would indicate that the clinician should provide evidence-based re-education and engage patients in treatment negotiations during clinical encounters. Reconciling differences in treatment preferences is central to the shared decision-making patient-centered model of care.

Similarly, many participants understood recommendations for environmental remediation but chose not to implement interventions due to competing demands, such as feelings of affection for the pet or needing a cat to augment rodent control. Others offered unconventional approaches to trigger remediation or proposed non-biomedical explanations for why they believed trigger exposure was safe. This suggests that patients may benefit from both an evidenced-based remediation education and a shared decision-making approach. In addition, all patients with asthma, not just those who are overweight or obese, would benefit from an exercise program that promotes optimal lung health and well-being. Although no participant identified unsafe neighborhoods as the reason for not exercising, anticipatory planning to that effect may be helpful in identifying safe options once asthma control is achieved and concern about exercise triggering an asthma episode is no longer a concern.

Together, these data provide guidance for planning future clinical encounters, particularly important in primary care settings where the judicious use of limited time is needed if better asthma control is to be achieved and sustained. Future research that examines the degree to which health beliefs about the need for controller medication and environmental remediation can be modified is critically important. It is likely that new models of care, such as patient-centered shared decision-making models, may be required to attain these

outcomes. Achieving and sustaining asthma control may also require new partnerships that extend beyond the patient, the provider, and the payer. For example, community health workers, trusted members of the community, may be more capable of modifying beliefs undermining the medical plan than any member of the health care team. Therefore, future investigations should focus on the contributions of community health workers and patient-centered models of care in achieving disease control. New approaches to disease management such as these are desperately needed if the health disparity gap is to be narrowed in vulnerable populations.

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Declaration of interest

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

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