

'The blue one takes a battering' **DPEN** why do young adults with asthma overuse bronchodilator inhalers? A qualitative study

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ABSTRACT

Objective: Overuse of short-acting bronchodilators is internationally recognised as a marker of poor asthma control, high healthcare use and increased risk of asthma death. Young adults with asthma commonly overuse short-acting bronchodilators. We sought to determine the reasons for overuse of bronchodilator inhalers in a sample of young adults with asthma. **Design:** Qualitative study using a purposive extreme case sample.

Setting: A large urban UK general practice. Participants: Twenty-one adults with moderate asthma, aged 20-32 years. Twelve were high users of short-acting bronchodilators, nine were low users.

Results: Asthma had a major impact on respondents' lives, disrupting their childhood, family life and career opportunities. High users of short-acting bronchodilators had adapted poorly to having asthma and expressed anger at the restrictions they experienced. Overuse made sense to them: shortacting bronchodilators were a rapid, effective, cheap 'quick-fix' for asthma symptoms. High users had poorer control of asthma and held explanatory models of asthma which emphasised short-term relief via bronchodilation over prevention. Both high and low users held strong views about having to pay for asthma medication, with costs cited as a reason for not purchasing anti-inflammatory inhalers.

Conclusions: Young adults who were high users of short-acting bronchodilators had adapted poorly to having asthma and had poor asthma control. They gave coherent reasons for overuse. Strategies that might address high bronchodilator use in young adults include improving education to help young people accept and adapt to their illness, reducing stigmatisation and providing free asthma medication to encourage the use of anti-inflammatory inhalers.

INTRODUCTION

In total, 300 million people are estimated worldwide to suffer from asthma.¹ Despite the availability of effective treatments, poor asthma control is widespread in Europe, Asia

ARTICLE SUMMARY

Article focus

- Why do young adults with asthma overuse short-acting bronchodilators?
- Overuse of bronchodilators is internationally recognised as a marker of poor asthma control, excess healthcare use and asthma death-understanding the reasons for overuse is a key step towards developing interventions to address inappropriate inhaler use.

Key message

• Young adults gave coherent reasons for overuse: they were an effective, cheap, 'quick-fix' solution for asthma symptoms.

Strengths and limitations of this study

- First qualitative study to address this topic.
- Elegant, purposive sampling design provides contrast between high and low users of bronchodilators.
- Respondents recruited from a typical urban UK primary care practice.

and North America.² Frequent use of shortacting $\beta 2$ agonist inhalers is internationally recognised as a marker of poor asthma control, increased risk of hospital admission and death from asthma.^{3–10} The serum salbutamol levels in those dying from asthma are, on average, more than double those of controls of equivalent asthma severity.¹¹ The risks of oral corticosteroid course, emergency room attendance and hospitalisation rise progressively with increasing numbers of short-acting bronchodilator inhalers dispensed per year.⁶ Excess healthcare use, notably hospitalisation, increases the societal and healthcare costs of asthma markedly.¹² Reduced healthcare costs are associated with good control of asthma.

A cross-sectional analysis of prescribing data shows that an overuse of short-acting bronchodilators is common in young adults.

Thirty-nine per cent of Danish adults, aged 22–44 years, from a large regional prescribing database, used bronchodilators as monotherapy.⁸ Within a cohort of nearly 10 000 Canadians with asthma aged 15–34 years, 37% were using no inhaled corticosteroids, and 7% were using more than 12 canisters of bronchodilators per year.⁴

Asthma in adolescence, the period between the onset of puberty and attaining an independent responsible role in society,¹³ has received considerable attention, see, for example, Shah¹⁴ and Gabe,¹⁵ but little work has focused on young adulthood.

Despite the repeated documentation of bronchodilator overuse in observational studies across continents and over several decades,^{3–10} little is understood about why people, and young adults in particular, overuse their bronchodilator inhalers. We therefore sought, using qualitative methods, to examine the experiences of young adults who overused short-acting bronchodilator inhalers. We aimed to gain insight into reasons for their overuse.

METHODS

The study was set in a large urban general practice in the UK. We used purposive sampling to obtain an extreme case sample of patients using high and low amounts of short-acting bronchodilators. We searched computerised practice medical records to identify young adults with asthma aged 20-32 years, their prescriptions for short-acting bronchodilators and other asthma medication and their clinical and demographic characteristics. We identified patients at step 2 (ie, co-prescribed inhaled steroids) or above of the British Asthma Guidelines.¹⁰ We defined high users of bronchodilators as those who had received three or more short-acting bronchodilators in the last 3 months, and low users as those prescribed two or less in the last 3 months. We wrote to potential participants giving details of the study and inviting them to take part. We aimed to broadly match the high users and low users as far as possible with respect to a range of variables including: age, gender, BTS treatment step, duration of asthma diagnosis, smoking status and visits to accident and emergency departments and hospitalisations for asthma. We reviewed the sample as the study progressed to monitor and control the evolving composition of the groups. Patients who responded to our written invitation to the study were invited to meet with the researcher (SC) to obtain full details and to give written informed consent. The North and Mid Essex Local Research Ethics Committee approved the study (REC MH428). The study was funded by the East London and Essex Network for Research. The sponsor and funder had no influence on the design, analysis or writing.

Interviews

SC carried out semistructured depth interviews with 21 informants. Eighteen were carried out within the

surgery premises in a small private room and three within the subjects' own home for their own convenience, for reasons of childcare. Interviews lasted for about an hour and were recorded and then transcribed *verbatim* with the respondents' permission.

We developed a topic guide on the basis of the existing literature and our experience in qualitative research in asthma. This was refined during the first few interviews and covered areas including:

- ▶ Early memories of asthma diagnosis and treatment;
- ► Experiences and behaviour during asthma exacerbations;
- Impact of asthma on recreation and choices of careers;
- Explanatory models of asthma;
- Attitudes to medication and views on the role and use of medication, particularly inhaled therapy;
- Relationships with health professionals;
- ► Social and family networks;
- ► Trade-offs between the use of medication and other methods of control;
- ► Emotional responses to asthma.

Field notes were taken, and the researcher recorded general observations of each respondent's attitude and behaviour.

Analysis

We used the Framework approach to analyse data.¹⁶ This involves a series of five key stages: familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation. Software for qualitative data analysis (MAXQDA) was used to assist data handling. The thematic analysis was developed by two of the authors (SC and CG) who jointly coded all transcripts and resolved differences of interpretation as the analysis progressed. As a validity check, a third author (CS, a medical sociologist) independently read transcripts and identified no additional themes. The six themes that emerged from the data covering all 21 respondents comprised: impact of asthma, coping, stigma, explanatory models, rationalisation of inhaler use and costs. We created charts for each theme, cross-tabulating coded text for each against respondents.

RESULTS

Table 1 describes the sample interviewed. All were between 20 and 32 years of age. Most of the respondents were leading lives fairly typical of this age group; some were studying, others were in early careers, or they had young families or responsibilities for ill parents.

Impact of asthma on respondents' lives

Asthma had a major impact on the lives of most respondents. They described how asthma had restricted their childhood and disrupted the course of their lives (box 1). Examples included having to change schools,

Why do young adults with asthma overuse	e bronchodilator inhalers?
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	Low users of short-acting bronchodilators	High users of short-acting bronchodilators
Number interviewed	9	12
Mean age (range)	27.4 years (22–30)	26.3 years (20–32)
Mean age at diagnosis (range)	9.3 years (1–19)	8.3 years (1–26)
Female	4	1
Preventer inhalers (mean/year)	6	4
Number on BTS step 2 : step 3	4:5	3:9
Number on ICS/LABA inhalers	5	9
Oral steroids for asthma ever	3	6
Oral steroids in last year	1	2
A&E attendance for asthma ever	3	5
A&E attendance in last year	0	1
Admission for asthma ever	2	5
Admission in last year	0	0
Current smoker	4	6
Had a self-management plan	6	4
Pays for prescriptions	8	8

BTS, British Thoracic Society; ICS, inhaled corticosteroid; LABA, long acting beta agonist.

and altering employment opportunities, sometimes dashing hopes of a chosen career.

Asthma had implications for the social and personal lives of these young adults. Stigma was common; respondents described being 'excluded from team activities, football and things like that', and 'just wanting to be like the rest and not to have to stop and put this thing in my

Box 1 Impact of asthma on the courses of respondents' lives

It actually changed my life completely...Because I wanted to be a marine biologist and I actually wanted to study sharks, a PhD in sharks, had my name down at University and all the rest of it and I was diving and I spent many years just having to be a snorkeller because I couldn't use the tanks and stuff like that and any asthmatic who dives now, you cannot take your medication for so many hours before you dive and umm I couldn't be in that situation. If you can't dive, you can't do your job and actually, because it was all I'd ever aspired to.

Interviewer: So what did you do instead?

Patient: Nothing as far as I'm concerned (laughter). I just became...I did office work and umm that was basically it. I did computer work and very uneventful but then I've got my kids... 30f11-9 High user

I would have gone into the army if I had of not had it. I'd have loved to have joined the army. Really would have done and there's lots of things I'd like to have done. I'd like to have been a policeman...policewoman I should say. I'm not saying that I may not have been able to get in, but at the back of my mind I think it's not worth it. I've got asthma, I can't.

32f 1-12 High user

My mother stayed with me for a year when I was in Great Ormond Street and my brother and my father stayed in...I lived in a place called xxx which is quite a distance from London, so yeah it did cause a separation in the family. I remember going to them schools in the hospital.

29m19-9 Low user

mouth'. Asthma was 'so embarrassing' and inhalers were something 'to hide in a bag'.

These young adults gave candid descriptions of the restrictions they experienced, including the avoidance of wearing tight, fashionable clothes that could restrict the breathing, difficulties when dancing at clubs, the inability to stay over at friends' after a night out because bronchodilators had been forgotten, and the embarrassment of needing to use a bronchodilator during sexual intercourse (box 2).

Asthma attacks were frightening, life-threatening experiences (box 3).

An adverse impact of asthma was more often reported by high users of short-acting bronchodilators. Anger or resentment at having asthma was mentioned by 8 of 12 high users, but only 1 (who described 'irritation') of 9 low users. Other frustrations were the failure to find a cure, and the stigmatisation that they felt (boxes 4 and 5).

By contrast, despite similar experiences of asthma, low users did not express anger about their illness, describing it as something that was accepted and part of their lives (box 6). Sometimes, this normalisation reflected

Box 2 Impact of asthma on respondents' social and personal lives

Like wearing tight clothes and stuff. I've got some nice, pretty tops for going out clubbing and stuff and you can't...I couldn't wear tight clothing at all umm and some bras that you wear, you can't wear them either because it restrains your chest almost so you...it tightens up your breathing.

14-6 Low user

When I'm out having a dance, I get tight chested. Its a real pain. 17 High user

I might stop in the middle [of sex] to use the blue one. 27f 10-10 High user

Box 3 Respondents' experiences of asthma attacks

That's the biggest thing is not to panic but it's like...l've always described it as it's like drowning but you're drowning in air because you can't get it. It's like being six foot underneath the water and you know air is up there and you can't get it.

30f 11-12 High user

I was out playing once and I started to get really, really tight chested umm and it got really bad and I think I started to panic as well, which made it worse, and it got to the point where I was really, really struggling for breath umm and I probably...bad thing to do umm over used my inhaler just to clear it, which it did, I think it was about ten to fifteen minutes and it was very, very, very scary.

26m,17-2 High user

the influence of other family members with asthma. Parental attitudes may have been important, with low users reporting positive attitudes of parents to their illness, and high users reporting negative responses.

Asthma control, explanatory models and medication use

High users often reported poor control of their asthma symptoms (box 7). Of the 12 high users, 2 rated their

Box 4 Anger at having asthma

HIGH USERS:

Very angry because I get much iller than everybody else I know because of it and, you know, it's not fair and um...I suppose that when I was ten I did think...my Mum said 'oh don't worry, they'll find a cure for it before you [grow up]'. Here we go, is it twentytwo...yeah twenty-two years later, no not really much closer than what they were when I first [was diagnosed] I just wish they'd find a cure...I wish to God that they would.

32f 1-16 High user

Interviewer: Are you frightened by having asthma? Respondent: I'm angry with having asthma.

27f 9-9 High user

Do you feel angry about having asthma? Yes. I think, why me? I must admit, yes. I have a 6ft 2 brother who's in perfect health; there's nothing ever been wrong with him and you think, why me?

29f 5-8 High user

I did go on a sort of like a rebellious point and I didn't want my medicine. I moved abroad and said 'I've had enough' and that was it, I went away as far as I could.

30f 11-10 High user

LOW USERS

You didn't get angry about it? No, it's just one of those things in life isn't it?

30f 2-8 Low user

Did you resent it? I don't think so.

23f 7-9 Low user

It's not worth getting angry over. I'm not really that sort of constitution if you see what I mean—I'm a bit laid back. I don't really get angry to be honest.

29m 6-9 Low user

Box 5 Restrictions and stigma arising from asthma

You do get penalized for a lot of things I think if you've got asthma. I used to love running, used to love running in the 800 metres and cross-country and all that and, you know, I might have pursued that a bit further had I thought that I wouldn't keep getting jeopardised by having this every so often.

1-12 High user

I'm angry with the way people look at people with asthma because its still quite a...like I say it's either people are overly in your face about it or pretend it doesn't happen and a lot of people will say to me 'oh you can't do that, you've got asthma' and I think 'how dare you tell me I can't do something without letting me have a go at it first'. I suppose I feel a bit angry with being dealt with it when what I always wanted to do was farming and it has restricted me from doing it.

27f 9-9 High user

Well, as a child, it stops you doing quite a lot of things, it limits you umm maybe sets you apart from everyone else a little bit actually if you're quite honest about it (inaudible) as a child with asthma.

29m 19-2 Low user

asthma as mild, 8 as moderate and the remaining 2 as 'moderate-to-severe'; of the 9 low users, 6 reckoned their asthma to be mild and 3 to be moderate. Although respondents from both groups described always having a bronchodilator with them, high users reported 'having them everywhere' and being 'panicky' without one, with elaborate arrangements for having access to bronchodilators. These included having multiple bronchodilator inhalers at different sites (handbag, car, house, partner's

Box 6 Acceptance of asthma by low users

Yeah, yeah I mean asthma's nothing unusual to me. That's just part of life really (laughter) and that's the sort of thing...as I say my father's is worse than mine and my brother's also asthmatic but his isn't as bad as mine so.

29f 21-2 Low user

No, not really, because they (bronchodilators) work so fast and I think they're very effective and I've always had to take medicine since I've been quite young, fairly young, so I don't really see it like that. It's not worth getting angry over. I'm not really that sort of constitution if you see what I mean—I'm a bit laid back. I don't really get angry to be honest.

6-9 Low user

Not really no, I suppose because I've had it so long it's just kind of there.

23f 7-3 Low user

It doesn't now. I'm so used to it now, I don't even think about it really

25f 12-7 Low user

My mother's always....you know she started me off making sure I was using those at home but it was something that, as I say, I knew that I could get on and do things providing I took the medication and if I didn't take the medication, then I was going to be sat at home wheezing.

29f 21-7 Low user

Box 7 Asthma control

The blue one takes a battering, it really does and that's probably not the best way of doing things but it's the only way I think...I mean...if it's the only way you can be comfortable, then that's what you've got to do.

17-10 High user

It was when I sat my GCSEs I really...that's because I was incredibly ill, because I think my asthma's also brought on by stress as well. I start hyperventilating and things like that, and that was horrific.

30f11-9 High user

I don't use the blue inhaler at the moment, no. Well, at the moment, it feels like I've never had asthma—it feels like I haven't got it.

29m 19-4 Low user.

Once I got onto the Serevent and Flixotide, then that controlled it much better, and these days I'd use a Ventolin two, three times a year probably.

29f 21-2 Low user

Box 8 Explanatory models of asthma in high and low users

HIGH USERS:

It's something to do with the airways closing up and different things can trigger it like stress or anything—I just can't remember much of what the doc told me, I just got told basically the inhalers are there to help you and just use them when you need to and they basically gave me instruction on how to.

25f 4-1 High user

The inside of your lungs—when you breathe—they close up so the air can't...I think the oxygen goes in and then it goes into your lungs and into your blood and I just think they get...closed up or blocked up and the inhaler just opens them up. I'm probably completely wrong ...

26f 17-3 High user

Interviewer: What does the brown inhaler do? Respondent: I'm not too sure to be honest with you umm I've often thought that it actually coated your lungs with something.

26f 17-3 High user

Interviewer: OK, so what do you think the orange inhaler does? Respondent: Prevents it. Interviewer: How? Respondent: I've no idea.

20f 16-4 High user

I have a red one and a brown one at the moment. They're longlasting ones—I think.

29f 5-4 High user

LOW USERS:

When it's the first time, I take the Bricanyl inhaler as it sort of opens the airways. With the Flixotide, it's just generally used so it keeps the inflammation in the tubes down.

30f 2-7 Low user

The brown one? Well, it doesn't open up the—it doesn't dilate it in the same way, does it? It works through—a bit like adrenal hormones by reducing, not... inflammation, is it?

29m 6-3 Low user

home, holiday luggage), and needing to send an email around the workplace to gain access to bronchodilators in an emergency.

High users more often held explanatory models of asthma where the function of the inhalers was solely to provide quick relief of symptoms by bronchodilation (box 8). Only 2 of 12 high users spontaneously cited prevention as a function, compared with 8 of 9 low users.

This was reflected in the primacy of bronchodilator inhalers for this group-one described this as a process of 'becoming completely blue'. These inhalers figured prominently in their thinking about asthma (box 9); they were seen as a tool to enable young people to get on with their busy lives—'a quick fix...to have a couple of squirts and get back to what you are doing'. The convenience of a single inhaler was reflected in comments such as 'When I felt wheezy it [the inhaled steroid] didn't stop it, the blue one does. Umm...so why carry two around when you can make do with one?' The preference for short-acting bronchodilator inhalers was simple: 'Yep. Quick fix, cheaper'. The primacy of bronchodilator inhalers might reflect their prescription as sole therapy at diagnosis: 'Because you're prescribed the blue one first. I mean I was given the Ventolin and that was it, sent packing.'

Some high users had insight into their inhaler use: "and it isn't until you look back and think 'Christ, I'm

Box 9 Primacy of short-acting bronchodilator inhalers for high users

I think it's [the blue inhaler] probably for, you know, for young people, I think what it is is that the purple one is more of a build up isn't it really umm and the blue one's just a quick fix to fix your lungs or whatever quickly so you can just have a couple of squirts and get back to what you're doing as opposed to doing the purple one and having to wait X amount or do it and get built up and...even though it's still running in the background, you know umm the blue one's good because you can just have a couple of squirts and get back to whatever you're doing.

17-12 High user

I know that I've just got to have it [salbutamol] and silly little things like making sure I've got enough in the drawer because if it runs out then I've got to worry about getting another one because I would not go a day...The blue, yeah the reliever, I just have...it is quite a thing that I need to think about all the time.

27f 10-6 High user

The blue stops what's happening, happening straight away, where the preventative...you sometimes forget, it's at the back of your mind and you forget to use it...I think mainly that's why people...obviously you need to use the blue, when you get wheezy you have to use the blue where the brown is not going to help you when you're really short of breath. Umm and you could live by just doing that. You wouldn't have to have that preventative if you used your blue when you needed it.

27f 10-9 High user

The purple disk preventer I don't think about as much because I know I can survive without it.

27f 10-6 High user

doing it sixty or seventy times a day, God, what the hell am I up to?' Umm, that's when you sort of think...but like I say when I was at college and I couldn't afford both, that's why I always had the blue one. Umm, I never thought of buying a brown one in preference to the blue one...'

Cost of prescriptions for asthma medication

Most respondents expressed irritation at having to pay for asthma prescriptions. In the UK, medication is free only for children (aged less than 16 years), the elderly (over 60 years), the unemployed and certain risk groups (thyroid disorders and diabetes). Asthma was seen as a life-threatening condition, and as such should have medication provided free of cost. Cost was seen as a disincentive to obtaining preventive medication (box 10).

DISCUSSION

Principal findings

Asthma had a major impact on the lives of these young adults, most of whom were in their third decade. High users of short-acting bronchodilators described poor adaptation to their illness. They held explanatory models of asthma which focused on bronchodilation, with a minority mentioning prevention as a function of inhalers, or inflammation as a causal factor. Their preferential use of short-acting bronchodilators made sense to them: they were rapid, effective and cheap: a 'quickfix' that enabled them to get on with their busy lives. All respondents were concerned about the cost of asthma medication and some were clear that this was a major disincentive to obtaining prophylactic medication. In the UK, adults over the age of 16 only receive free

Box 10 Prescription charges a disincentive to use of preventer inhalers

Quick fix and cost, that was my reasons for becoming completely blue, and the brown one left aside, and even when I did...if mother got a prescription for me or something, I don't think I hardly used it because I became out of routine with it. Yes I must admit I just used to get the blue one which I think was perhaps why I got so dependent on the blue because I couldn't afford to get both.

27f 129-140 High user

For the preventatives, yes. Definitely, because I'm lazy and I'm naughty, I should do but there are times when I sort of 'I've got a bit in me preventative inhaler left at home, I won't go and get them any more.'

29f 8-6 Low user

I mean if you're paying for a prescription and you know that you need the blue obviously but not the brown, if you're short of cash then obviously you're going to get what you need umm and the preventative is going to be pushed to one side.

27f 118-120 High user

You have to come and pay for prescriptions, which I despise doing.

25f 14-10 Low user

medication if they are unemployed, or in certain risk groups (eg, diabetes and hypothyroidism).

Strengths and weaknesses

The strengths of our study included a qualitative approach appropriate to the research question addressed, with a purposive sampling strategy of subjects designed to generate two groups of respondents that were reasonably (but not perfectly) matched across a range of variables. Interviews generated rich data and considerable insight into personal and sometimes intimate aspects of respondents' lived experiences of asthma and the disruption it caused. A constant comparison approach allowed us to explore emerging themes as they arose. Reliability was aided by the full transcription of interviews, use of qualitative software that enabled tracking of the analysis, meetings to discuss and resolve coding differences, and the use of a structured approach (the Framework method) to analysis. Validity was supported by having data independently examined by a third author (a medical sociologist), who identified no additional themes. While our sample was relatively small, we achieved data saturation, the most important determinant of sample size in qualitative work. Our sample was drawn from a single general practice. While caution should be exercised in generalising findings from any qualitative work, the patients in this study are likely to be typical of any UK urban general practice.

Relevance to other work

To our knowledge, no other qualitative studies have examined this topic, or specifically this age group with asthma. While Gabe, studying schoolchildren, found that asthma sufferers generally adapted well to their illness,15 our data suggest that a minority of children with asthma strikingly fail to adapt to their illness as they reach young adulthood. Asthma caused significant disruption to their lives and aspirations,¹⁷ which was reflected in the feelings of anger, frustration and stigmatisation they expressed. These observations on the process of adaptation (or lack of it) echo those of Snadden who, in a sample of seven middle-aged Canadians with asthma, noted: 'the path to acceptance varied, and not everyone was able to complete the journey'.¹⁸ Similarly, Adams, also studying an older age group with asthma, identified 'deniers, accepters and pragmatists'.¹⁹ In a cross-sectional study, Diette found that emotional problems with asthma and the cancelling of social activities were both significantly more common in bronchodilator overusers.9

In a qualitative study of people with asthma in Australia, Goeman *et al*²⁰ also found that paying for asthma medication could compromise adherence. For children in the USA aged over 5 years with asthma, the more parents had to pay for medication, the less medication was used and the greater was the likelihood of hospitalisation.²¹ Interestingly, qualitative work in older people with asthma suggests that those in whom asthma

was diagnosed when treatment options were few can have a wider range of treatment strategies.²²

Clinical relevance

These data suggest that considerable benefit could accrue from improving the asthma control achieved by young adults who overuse bronchodilators. A number of strategies might achieve this.

First, more effective education, especially at the time of diagnosis, but also at routine review, could focus on helping young people accept and adapt to their illness as well as helping them to develop an explanatory model of asthma that focuses on prevention using antiinflammatory medication rather than quick relief via bronchodilators²³ Qualitative studies show that people with asthma value a preventive approach to care and, moreover, both seek and benefit from the formation of a partnership approach with their physician.^{24 25} There is currently limited evidence that specifically psychological interventions can improve symptoms and reduce hospital admissions for asthma.^{26 27}

Negative images of people with asthma are common. Reducing stigmatisation might help people with asthma feel more comfortable about using inhalers in public. This too could improve adaptation and acceptance.

Finally, strategies that might increase the use of preventive anti-inflammatory treatment in this age group include promoting the use of a single antiinflammatory/bronchodilator combination inhaler,²⁸ and providing free asthma medication. Further studies are needed to determine the impact of these strategies on asthma morbidity.

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Contributors SC and CG conceived the idea for the study and elaborated the study design. SC carried out interviews, which were coded by SC and CG. CG and SC were responsible for the data analysis, to which CS contributed critical input. CG prepared the first draft of the manuscript, including constructing boxes of illustrative quotes, with SC and CS providing critical comment. CG is the guarantor. All authors read and approved the final manuscript.

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