

Patient Perceptions of Living with Severe Asthma: Challenges to Effective Management



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What is already known about this topic? Symptom and treatment burden of severe asthma can impact daily life and psychological wellbeing, but the variety of individual challenges around disease-management decisions is unknown.

What does this article add to our knowledge? We report a wide range of challenges for patients to effectively manage severe asthma and a currently unmet need to address these, including psychological and social factors that influence treatment decisions and disease management behaviors.

How does this study impact current management guidelines? Novel individualized patient education approaches are needed to address perceptions and priorities that inform decisions relating to self-management. Identification of psychological and social support needs alongside improved public awareness of severe asthma is warranted.

BACKGROUND: The management of severe asthma poses many challenges related to treatment, adherence, and psychosocial morbidity. There is little direct data from the patient perspective to understand and negotiate the complexities of managing severe asthma.

OBJECTIVE: To explore the patient perceptions of living with severe asthma and the experience of managing severe asthma, in order to better understand the support that might promote more effective self-management for severe asthma.

METHODS: Participants were recruited from a specialist Difficult Asthma Service. Semistructured interviews were conducted by researchers independent of the patient's care. Interviews were transcribed verbatim and inductive thematic analysis was performed.

RESULTS: Twenty-nine participants (13 male; mean [standard deviation] age, 49.5 [13.6] years; mean Asthma Control Questionnaire 2.2 [1.2]) participated in an interview. Analysis resulted in 4 major themes describing the experience and challenges to managing severe asthma:

understanding of severe asthma, emotional impact of living with severe asthma (subtheme: fear of hospitalization), public perceptions of asthma, and concerns about medications.

CONCLUSIONS: Health care professionals need to consider and discuss with patients their perceptions of severe asthma and the relevant treatments; particular attention should focus around education of disease control and actively exploring thoughts around hospitalization. Our data highlight the potential for psychological and social support to enhance self-management by directly addressing the wide-ranging individual challenges patients face. There is also a need for greater public awareness and education about severe asthma to minimize patient distress particularly in the work environment. © 2019 American Academy of Allergy, Asthma & Immunology (J Allergy Clin Immunol Pract 2019;7:2613-21)

Key words: Severe asthma; Difficult asthma; Qualitative; Interview; Disease management

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This research was supported by a research grant from the National Institute for Health Research (NIHR): Research for Patient Benefit Programme (PB-PG-0712-28063). The funder had no role in the design of the study, data collection, analysis

and interpretation or writing of the report, and decision to submit for publication. R. A. Evans holds an NIHR clinical scientist fellowship CS-2016-16-020. The views expressed in this article are those of the author(s) and not necessarily those of the National Health Service, the NIHR, or the Department of Health and Social Care.

Conflicts of interest: The authors declare that they have no relevant conflicts of interest.

Received for publication October 2, 2018; revised April 14, 2019; accepted for publication April 17, 2019.

Available online June 6, 2019.

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2213-2198

© 2019 American Academy of Allergy, Asthma & Immunology
<https://doi.org/10.1016/j.jaip.2019.04.026>

Abbreviations used

ACQ- Asthma Control Questionnaire
 AQLQ- Asthma Quality of Life Questionnaire
 FEV₁- Forced expiratory volume in 1 second
 HADS- Hospital Anxiety & Depression Scale
 OCS- Oral corticosteroids

Management of severe asthma poses a significant challenge to the individual sufferer, health care professionals, and the health care system. Although representing only approximately 10% of the whole asthma population,^{1,2} 50% to 60% of the health care costs associated with asthma are attributed to those with severe asthma.³ The management of severe asthma is multifaceted, comprising pharmacological therapy, patient education, and self-management.⁴

Effective self-management for chronic illness has been described to encompass 3 sets of tasks: those relating to medical management for example taking medication, those relating to role management for example change in roles, and emotional management.⁵ For asthma, in general, the typical focus is the avoidance of known triggers, adherence to medication, and adjustment of treatment in the face of exacerbations or changing disease control. Although such strategies have been effective overall in asthma,^{6,7} adherence to self-management plans is nevertheless poor in the context of everyday life, seen by low levels of adherence to regular peak flow monitoring and preventor medication use.^{4,8} Current approaches to self-management when asthma is severe are a challenge for many patients, demonstrated by suboptimal adherence (<80% of prescriptions issued) to inhaled corticosteroids and oral corticosteroids (OCS) in 65% and 26% of patients, respectively.⁹ Gamble et al¹⁰ demonstrated that 35% of patients filled fewer than 50% of prescriptions for inhaled combination therapy. Nonadherence to inhaled (preventer) therapies has been linked to an increased likelihood of hospitalizations in previous 12 months¹⁰ as well as lower forced expiratory volume in 1 second and higher % sputum eosinophil counts.⁹ For clinicians, clinical outcomes are clearly defined, yet patient-related outcomes such as the psychological impact are poorly defined,^{11,12} with heterogeneity across patients' perceptions, needs, and participation in decision making.^{11,13,14} This poses a challenge for collaborative working between patients and health care professionals.

Psychosocial morbidity is often associated with severe asthma and alongside financial and employment problems have been associated with an increased risk of death.^{15,16} Those with poorer mental health have greater educational, support, and training needs specific to asthma management, further complicating the application of such strategies.¹⁷ Many of these factors could be considered potentially modifiable, yet attempts to address psychosocial complications have been limited. Psychoeducational programs targeting patients with severe asthma have shown short-term improvements in health-related quality of life and hospital admissions, but evidence is limited in those with multiple risk factors.¹⁸ A recent qualitative study has described the impact of severe asthma, impacting on all areas of daily life, including daily activities, independence, parenting, and employment, highlighting unmet emotional support needs.¹⁹

It is important to recognize that behaviors related to adherence and asthma management exist within a wider context of living

with chronic illness that go beyond disease-related tasks, and should therefore also take account of emotional adaptation, and illness and treatment perceptions.²⁰⁻²² Although a small number of qualitative studies have explored the perspective of those living with severe asthma,^{19,23-25} a greater understanding is needed of the self-management practices and desires of those living with severe asthma. Considering the higher symptom and treatment burden identified for those living with severe asthma,^{19,23} it is important to understand the experience of these individuals, which is likely to differ from those with milder asthma. To better understand the factors that support or prevent successful management of severe asthma, further attention needs to be given to the patient perspective.

We aimed to explore the attitudes of patients with severe asthma about their condition, their experiences of asthma management, and identify individual challenges and influences with respect to self-management. We aimed to highlight patients' experiences with a view to better understanding the support that might promote more effective self-management for severe asthma.

METHODS

We conducted a qualitative study investigating perceptions of living with severe asthma and its management using semistructured interviews. Qualitative research is a well-established approach for better understanding the experience of living with chronic illness and the barriers for self-care. Such an approach allows emphasis to be given to views and experiences that are recognized as a necessary component of robust applied health research.²⁶ The interviews were part of a larger feasibility study investigating Asthma Tailored Pulmonary Rehabilitation for severe asthma.²⁷

Participants

Patients were recruited from an adult Difficult Asthma Service, and they were eligible if they had been under the care of the service for at least 6 months, and after evaluation had severe asthma defined by step 4 or 5 of the British Thoracic Society/Scottish Intercollegiate Guidelines Network Asthma Management Guideline 2014²⁸ (ie, patients require at least 2000 mcg of inhaled corticosteroids daily). Patients were excluded if they had fixed airflow obstruction and >10 pack-years of smoking history to exclude those with chronic obstructive pulmonary disease.

In line with established methods, purposive sampling occurred to ensure a maximum variation of gender, age, ethnicity, and social factors amongst interviewees. To achieve this, a matrix of key variables (gender, age, ethnicity, and social deprivation) was created and patient recruitment was tracked against this with targeting of specific categories to achieve maximum variation. The service provides care to individuals from across the East Midlands area that includes areas representing the least to the most deprived.

The Difficult Asthma Service provides patients with a consultant specialist assessment and review, consultant pharmacist support, and assessment of drug adherence. Specialist nurse support included education, personal asthma action plans, inhaler technique support, and clinical assessment. Further physiotherapy and speech and language support is also accessed.

Data collection

Face-to-face semistructured interviews were conducted with patients after informed consent. Participants could choose for the interview to take place at home or at the hospital.

The interview guide was developed, considering previous literature, in collaboration with the wider multidisciplinary research team and a patient and public advisory group (Figure E1, available in this article's Online Repository at www.jaci-inpractice.org).

Interviews were recorded and transcribed verbatim and were conducted by one of 2 researchers (L.D.A. and S.C.), who were not involved in patient care and were not previously known to the participants.

Participants' demographic data and questionnaires routinely collected in clinic were recorded. The latter included the Hospital Anxiety & Depression Scale (HADS),²⁹ Asthma Control Questionnaire (ACQ),³⁰ and the Asthma Quality of Life Questionnaire (AQLQ).³¹ The HADS is a screening tool to identify symptoms of anxiety and depression. Scores are presented out of a total of 21 for both anxiety and depression, with higher scores reflecting higher symptom burden. The ACQ aims to measure adequacy of asthma control. A score of less than 0.75 represents well-controlled asthma and scores above 1.5 represent inadequately controlled asthma. The AQLQ aims to measure disease-related quality of life in patients with asthma in 4 domains including symptoms, activity limitation, emotional function, and environmental stimuli. Patients respond to 32 items on a 7-point scale and the mean (standard deviation) is calculated. A score of 1 indicates severe impairment and a score of 7 indicates no impairment at all. Furthermore, participant postcodes were used to calculate the Index of Multiple Deprivation, which is a measure of deprivation across small areas based on 7 domains of deprivation (income; employment; education, skills, and training; health deprivation and disability; crime; barriers to housing and services; living environment). The index scores small areas 1 to 10 (with 1 being in the most deprived 10% of areas and 10 being the least deprived 10% of areas in England).

Analysis

Data were analyzed using inductive thematic analysis³² supported by NVivo software (version 10; QSR International, Doncaster, Australia) and led by LDA.

Analysis followed the 6 stages as outlined by Braun and Clarke³²: familiarization with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.

Starting with a thorough familiarization of the transcripts, initial coding was undertaken by LDA. Samples of transcripts (anonymized and uncoded) were also distributed amongst the wider multidisciplinary research team. The purpose of this method was to verify the initial codes, to establish reliability in the coding method, to consider the data from multiple perspectives, and to aid the development of themes. There were 2 subsequent meetings with the wider research team to agree on themes and interpretations and explore themes with the patient advisory group to further validate interpretations. Themes were checked against the original data set leading to the development of final themes. The final stage of analysis is to describe, evidence, and present the data in accordance with these themes.

Ethics

This study was approved by East Midlands Research Ethics Committee (13/EM/0323), and all patients gave written informed consent. The ISRCTN Registry number is ISRCTN96143888.

RESULTS

Between December 2013 and November 2014, 88 patients were given information about the study: 3 did not meet the

TABLE I. Demographic characteristics of participants attending qualitative interview

Demographics	Patients with severe asthma (BTS steps 4 and 5)
Age (y)	49.4 (13.6)
Sex (M/F)*	13/16
BMI (kg/m ²)	31.6 (5.5)
Asthma duration (mo)	297.4 (244.6)
Duration in difficult asthma clinic (mo)	50.9 (42.3)
FEV ₁ (L)	2.2 (0.9)
FEV ₁ (% predicted)	72.0 (23.4)
No. at MRC 3 and above	10
No. hospitalized before 12 mo*	14
Exacerbations in last year [†]	3 (0-24)
No. taking oral steroids*	15
Steroid dose (mg)	11.2 (8.6)
No. taking ICS/LABA*	26
No. taking antidepressants*	4
Current smokers*	4
Age left education (y)	17.2
HADS score anxiety, mean (SD)	8.9 (5.5)
HADS score depression, mean (SD)	6.8 (4.6)
Asthma Quality of Life Questionnaire total, mean (SD)	4.31 (1.23)
Asthma Control Questionnaire Score, mean (SD)	2.3 (1.2)
Index of multiple deprivation (*)	
1	3
2	4
3	2
4	2
5	2
6	3
7	3
8	4
9	3
10	3

BMI, Body mass index; BTS, British Thoracic Society; FEV₁, forced expiratory volume in 1 s; HADS, Hospital Anxiety & Depression Scale; ICS, inhaled corticosteroids; LABA, long-acting β -agonists; MRC, Medical Research Council Dyspnoea Scale Grade.

Mean (SD) unless *frequency or [†]median (range).

inclusion criteria, 56 declined or were unable to be contacted, and 29 gave their consent and attended a semistructured interview (Table I shows their characteristics). The recruitment rate is consistent with other qualitative research reporting less than 50% uptake.³³⁻³⁵ All interviews took place at the hospital at a time convenient to the participants, except for one that took place in the participants' home at their preference. The average length of interviews was 42 minutes, with a range of 20 to 62 minutes.

During data collection, efforts were made to address an emerging lack of representation from male patients and those of minority ethnic origins, unrepresentative of the local clinical service: 56% female and 82% white.³⁶ Although these efforts increased the number of males recruited to the study (44%), those from minority ethnic groups remained under-represented (3%).

TABLE II. Understanding of severe asthma

Seriousness of asthma	“So it’s almost the good days when I don’t realise I’ve got asthma...I don’t think about it because I don’t have to take any medication.” ID122, female, aged 40. “I didn’t think [it was serious]. It’s not like something like... people have cancer and you read their stories, it’s in everyday life, whereas I don’t think asthma is really. It’s just a bit of a bad chest. A bit of a wheeze and a bad cough.” ID 124, female, aged 30. “So when I was bad I was shocked, I mean I thought, I definitely didn’t think asthma could kill people, I mean that’s ridiculous. And then so when the doctors said to me that this could kill me I was really taken aback.” ID105, male, aged 51.
Management of asthma	“I don’t really manage the symptoms as such other than take the medication and the inhalers and the SMART plan for the inhalers... if I’m struggling a particular day I might take a little bit more.” ID108, male, aged 44.
Understanding of severe asthma	“Initially when they asked me to do it [monitor peak flow] and keep a record, I was too scared to do it, because I kept thinking if it wouldn’t improve, again I’d get anxious about it. But when I started to feel much better, I started to do it on a regular basis, and I can usually tell well in advance if I’m going to be ill, so I can then do something about it.” ID114, male, aged 67. “When I saw [Consultant] he said your eosinophils are raised. I said oh that’s strange because my peak flow hasn’t moved...And that did really throw me a bit, I must admit, in that I’d always relied on the peak flow to be the marker of when to start taking steroids.” ID114, male, aged 67. “...but I know a part of me does wonder whether maybe the fact that I don’t do it [exercise] has contributed to some of the breathlessness. So I mean I do have days where I wonder whether my breathlessness is to do with the fact I’m unfit or to do with my chest if that makes sense.” ID102, female, aged 54.

Data are presented under the following themes: understanding of severe asthma, emotional impact of living with severe asthma (subtheme: fear of hospitalization), public perceptions of asthma, and concerns about medications (see [Tables II-V](#)). To represent the consistency or frequency of reports, specific phrases will be used to represent the proportion of participants (as a percentage). These will be “many” to imply more than 65% of participants, “some” to imply up to 65%, and “few” to imply less than 20%, as described by Sandelowski.³⁷

Understanding of severe asthma ([Table II](#))

Perceptions about how serious asthma could be were variable. Many participants felt ill-informed about asthma, its severity, and therefore felt unsure about what they should do to manage it. For a few participants, the seriousness of the condition was not apparent until an admission to hospital or the experience of a severe attack.

A perceived lack of understanding about the disease was felt to have implications for the decisions individuals made about daily management of asthma. The focus was often on acute asthma incidents as opposed to consideration of ongoing disease, and few talked about wider management practices in between the acute events. Participants discussed their asthma action plans, some stating confidence to monitor peak flow, symptoms, and respond accordingly.

However, recommendations from health care professionals to manage symptoms at home could have unintended consequences for individuals. One participant described an initial reluctance to follow the recommendation to monitor peak flow regularly for fear of increasing anxiety about asthma. Experience with self-monitoring and a positive impact of self-monitoring were described as easing initial concerns. Some participants lacked confidence that self-monitoring was sufficient to fully help them manage their condition, due to unpredictable variations in the severity, which at times left them fearful when symptoms arose. The uncertainty of asthma and its evolving management through contact with clinicians posed additional complexity for participants attempting to monitor and manage symptoms.

Emotional impact of severe asthma ([Table III](#))

Participants had an emotional response to living with asthma. For many participants, being aware of symptoms led to personal adaptations and restriction of activities, either by personal choice or health care professional advice, including reduced exposure to situations or places they were concerned could trigger an “attack” of symptoms or were fearful that asthma could limit their abilities, for example, holidays, sports, or other physical activities. Although in many cases such changes in daily life were viewed as necessary to feel safe, this often had a negative emotional impact. Emotions and behavior were linked as feelings of fear and anxiety affected the daily decisions participants would make about activities in which they engaged. Participants felt dissatisfied with the restrictions that living with asthma sometimes imposed on them. Patients also discussed the complexity of understanding whether symptoms were related to asthma particularly exertional breathlessness.

Concerns about hospitalization. Participants’ feelings about hospitalization in the context of severe asthma represented a prominent subtheme that was distinct from the general emotional impact of severe asthma described above. Some participants discussed a reluctance to be admitted to hospital. This was either due to a strong dislike of the environment or, in some cases, due to a fear of the likelihood of hospitalization. In the latter, a strong fear that worsening symptoms could leave them little control over hospitalization became a source of stress in itself. It was not always clear what drove concern about hospitalization even with prompting with many reporting “I just don’t like hospitals.”

For some participants, hospitalization provoked thoughts and feelings about the severity of asthma and their own future health. One participant was able to relate back to a previous admission and the realization that his condition was worsening, whereas another reflected on the impact of seeing other patients he viewed as worse than himself. This raised concerns about potential future decline, a prospect that was difficult to cope with and as a result contributed to the dislike of the hospital environment.

TABLE III. Emotional impact of severe asthma

Restricted activities	“If people are going to do anything where I think it might be a bit strenuous I’ll say no. So I’m always thinking ahead. If my kids are planning something and I think I might be out of breath, I’ll think of excuses not to do it.” ID128, male, aged 49. “It affects me all the time, because I don’t do anything. I have got two dogs and I used to walk all the time. I haven’t actually walked them this year, because I’m too scared to go — it sounds so pathetic that you’re too scared to go out. I’m just so scared of getting into a situation and not being able to deal with it. We keep saying we’re going to go out, but then I keep finding excuses not to.” ID111, female, aged 45.
Concern about hospitalization	“I know, I’m an intelligent person, I know I should come in. I mean last year, if they [HCP’s] had their own way I would have been admitted three, four times last year, but I said no. I just don’t like hospitals.” ID120, female, aged 38. “... I don’t want to go back in there again! Because when I first went in, to me that was the beginning of the end...it was the first time I had to go in hospital and it made me realise that I was getting worse.” ID103, female, aged 56. “I don’t always get to follow it [Action Plan] as I should obviously because I’m a single mum ... There are times, it’s like I’m blowing peak flows of like 120 and they [HCP’s] say that if I get to 150 that’s when I should ring 999, but I just sit up in a locked room... with my ioniser and my steroids and my Ventolin just trying to not take deep breaths.” ID113, female, aged 39. “...but once I feel fine, I just want them [hospital staff] to say go home, I’d sooner just stay at home, even if, you know, like sitting around at home and don’t do anything. Well at least you know your own comfort and you can sleep.” ID 117, male, aged 50. “I don’t like coming to hospitals and I don’t like coming to doctors surgeries, particularly don’t like coming here [hospital], because I kind of look around and sort of see the future me. And I don’t want to be like that... I’d do anything not to be like that, and that does bring me down quite a lot.” ID125, male, aged 43. “I worry about getting stressed...because it scares me, I don’t want to go back into hospital again. When I went to the GP last week, my peak flow was 150, and on my card it says I have to go straight to [hospital], and I said to the nurse I can’t, I haven’t got time to. But I think it was more a fear of going back in, so...my mum had my youngest and I just relaxed as much as I could, let the tablets run its course, and that’s really it.” ID124, female, aged 30. “I’d ring them[ambulance] just before I’d lost my breath or I can’t talk. I probably leave it sometimes a bit later than I should, but that’s my way of coping to go into hospital. I hate hospitals.” ID107, female, aged 55. “I just don’t like hospitals...The way I look at it, I’ve got the nebuliser at home, I’ve got the medication given me here anyway, I’ve got the peak flow. I can do everything in the comfort of my own home.... The only thing that I don’t have at home is people coming round every three hours taking blood out of me, which I don’t like needles.” ID120, female, aged 38.

For 2 female participants, there was a conflict between responding to worsening asthma symptoms and their family roles and responsibilities if they were admitted to hospital with concerns about childcare or further pressure on a partner or work. This sometimes led to situations where participants prioritized their other responsibilities and delayed seeking help when symptoms worsened or delayed hospitalization. These examples highlight how participants negotiate risk in relation to their asthma. A finely tuned balance of assessing the risk of symptoms or a flare up against when to accept the need for health care intervention was apparent. This led to a heightened awareness of the need to self-monitor as participants considered what action was required.

A few participants also expressed that they felt better in their own home, believing that treatment could be replicated at home, with the advantage of improved sleep and be undisturbed thereby aiding recovery. As a result, there was also a perception that if a hospital admission was necessary, it could be shortened by being allowed to return home once emergency intervention had been received.

Public perceptions of asthma (Table IV)

Interviews highlighted concerns about how other people perceived asthma, which included a discussion about challenges experienced in the workplace. Many participants faced personal

conflict when recognizing that asthma could be a serious condition, and this conflict could be mirrored by those around them. These participants felt that the public perceived asthma as a mild condition and felt that sometimes others did not understand how much they were suffering, causing frustration.

However, it was felt that members of the broader community were not necessarily to blame for these misperceptions of asthma. Participants felt that although the prevalence of asthma was increasing and considered much more common, perceptions regarding it as a “mild condition” presented a challenge for those living with severe asthma. Participants appreciated that severe asthma could be difficult to understand, but maybe more could be done to increase public awareness.

For some participants, perceptions of asthma by others posed challenges in the workplace. Participants found themselves hiding symptoms or felt concerned that a regular cough was irritating to coworkers. Some felt that their colleagues perceived asthma as a mild condition and therefore did not understand the difficulties individuals faced in the workplace.

Practical support in the workplace was available, for example, flexible working hours, time off for medical appointments, or having a desk near a window or a fan to help regulate room temperature. However, some found that this had created conflict with managers or immediate colleagues who did not understand the necessity for this. Time off work for asthma-related illness

TABLE IV. Public perceptions of asthma

Asthma as a mild condition	"...you've not got a bandage on your head have you? I think sometimes it's frustrating because they think, well if you're sat there talking to somebody, they think well you look perfectly fine to me...They didn't see you 10 minutes before struggling." ID106, female, aged 45. "...when you say to people you've got asthma, they're oh everybody's got asthma! Yeah, that's a joke." ID107, female, aged 55. "Because you've got all these booklets about diabetes and lung cancer....you can die from cancer and that, but also you can die from having an asthma attack. So the more you... leaflets out trying to get people to understand more people might." ID 117, male, aged 50. "...you realise that it's not their fault because... I would probably be the same if I didn't have asthma and I knew somebody with asthma. If I didn't see them all the time, I would probably think the same." ID 106, female, aged 45.
Misunderstanding	"A lot of people don't know a lot about it, do they? I suppose when you're coughing a lot and all that kind of thing, they think you've got a cough, but you've not. It's just that you have to cough to try and get the stuff off your chest, and they think ooh, I'm not going near him, he's got a cough - and that puts you off a bit." ID118, male, aged 62.
Challenge in the work environment	"I feel there is a bit of a stigma attached to having it and I don't like to let people know if I'm not well. I mean a lot of my colleagues know if I'm not very well, they can see it. But I try to disguise it as much as I can." ID102, female, aged 54. "Yeah, because I'm under the doctors... then I had to see a works doctor and they were saying 'but we don't see why your asthma should make you have flexible hours'." ID 103, female, aged 56. "... it got a bit strained while I was off [work] for the six months because I think with asthma people just assume you've just a mild form of asthma like most people have and it's oh what's wrong with you, you've only got a bit of asthma!" ID122, female, aged 40.

could also be a source of problems as the amount of time absent at work was not in line with colleagues' expectations of asthma and its severity. For some participants, this had led to unhappy working conditions and further distress.

Concerns about medications (Table V)

Participants' discussions about medications centered largely on concerns about OCS despite this treatment not being a specific focus of interviews. Concerns about the long-term side effects of OCS were expressed by many and included concerns relating to bone, skin, and liver health, diabetes, weight gain, depression, and other mood changes. There were also more general concerns expressed in relation to high doses of OCS for prolonged periods of time, potential unknown effects to be seen in the long term, and continued reliance on steroids.

Despite many concerns about OCS, only 1 participant reported intentional nonadherence, with the others reporting good adherence leading to a discussion during interviews about participants' decision-making processes regarding treatment. Strong concerns about the side effects of OCS were discussed above any other treatments including inhaled steroids that were rarely mentioned. Yet, for some the view prevailed that OCS were necessary to stay well. A few participants recalled discussing these concerns with health care professionals where the same message of necessity was often the conclusion reinforcing participants' attitudes that the necessity outweighed the concerns.

OCS were, to a degree, accepted as part of life with severe asthma. However, participants continued to discuss a strong aspiration that one day they would no longer need these medications. For many, the goal of asthma treatment was to decrease or stop OCS without compromising asthma control. However, the perception that OCS were necessary was a constant process of weighing up of concerns against necessity. As a result, 2 participants described how on occasion their concerns led to reduced adherence to steroids, including instances when OCS had been

intentionally stopped without medical guidance, prompting acute symptoms.

DISCUSSION

We aimed to understand the experience of asthma management and its challenges from the perspective of patients with severe asthma. Participants in this study described an impact from asthma that ranged from the interference with daily activities to managing symptoms in the workplace, yet descriptions of its management focused largely on acute events. Strong emotive reactions to severe asthma and hospitalization were described, influencing participants' willingness to accept hospitalization when symptoms became severe. Treatment concerns were overwhelmingly focused on OCS, highlighting a decision-making process that balanced the necessity of OCS against the concerns. Although previous studies have described the impact of living with severe asthma, encompassing personal and social effects,^{19,23} the detailed descriptions from participants in this study also describe the emotional effect of the disruption to daily living and the multiple challenges to disease management faced by those with severe asthma. This further extends the wider psychological and social support needs that have been identified for severe asthma.¹⁹ Multidisciplinary approaches for the management of severe asthma, including consideration of comorbidities and psychosocial factors, have had positive outcomes for asthma control³⁸⁻⁴⁰ and our data highlight the importance of these approaches to include consideration of psychological and social support needs.

Management of asthma was described by some in terms of adaptations in the workplace and restricting physical activity; however, it was predominantly described by participants in terms of responding to the acute events. This has similarly been described in mild-moderate asthma, where asthma is reported as an acute or episodic condition by patients and further linked to poor treatment adherence and engagement with preventive

TABLE V. Concerns about medications

Side-effects	"I suppose the fact that the steroids, I know that I've got slight cataracts, ...a lot of my bones are thin, the side effects of the steroids, the long-term use of steroids concerns me. And I recently had a course of itraconazole and my liver function's not wonderful so.. you rob Peter to pay Paul on there." ID102, female, aged 54. "Well, I don't like steroids. Obviously they work extremely well to reduce the inflammation but with side effects. I do bruise easily, my skin is extremely thin and the potential for perhaps developing diabetes, which one of my friends did, and also glaucoma as well or cataracts rather, doesn't fill me full of joy and excitement really!" ID114, male, aged 67. "And it did concern me that I was on, pumping my system with all this stuff, and I remember talking to my GP about my concerns and he said well the answer is simply you either want to breathe or you want to be slim, which would you rather have? I was worried about my weight increase, he said it's either one or the other, what would you rather do, breathe or be a normal weight? And it's like well breathe, you know, but it was really difficult to watch myself disappear with being on steroids, like I couldn't, lost my cheekbones, and I remember looking in the mirror one day and the only part of me I could recognise was my hair colour and my eye colour, and everything else about me I couldn't." 109, female, aged 40.
Decision making for steroids	"But without them [OCS] I wouldn't be here... So it's weighing those...If I didn't have them I might not be here might I? So that's how I look at it and I could be dead if I didn't take them." ID102, female, aged 54. "it [steroids] gives you a better quality of life, although sometimes the side effects reduce your quality of life! You suddenly get a bad tummy for a week and think oh God it's those damn steroids again. But yeah, it's swings and roundabouts I think, but the control of asthma is the important one because obviously that does reduce your quality of life and what you can do really on a day to day basis." ID114, male, aged 67.
Reducing steroids	"I wouldn't mind getting off some of my drugs. And that's a boost for me. I mean to me it sounds small, but the goal for me is that I've got down to about 10, 15mgs on my steroids. Where I used to be like 20 and that. So it's only gone down 5, 10 or whatever, but it's still gone down, so it's a bit of an improvement to me." ID117, male, aged 50. "The only thing that... which is the thing I'm waiting for now, is to be put onto this course of injections rather than taking this...it won't be rather than taking the steroids but with a view to reducing the steroid dose. That will be my ultimate aim." ID114, male, aged 67. "... I didn't realise by just stopping your steroids, the effect it would have on my body and I started deteriorating and I just thought I'll keep taking it and I'll get over it, and ended up collapsing and in hospital for a week. And then I think it's Dr [name] I think it was, from the asthma clinic, she was on the ward at the time and she gave me a right roasting and explained to me what happens with the steroids and the effect it had. So I've never done that again. And a couple of years ago when I started to wean myself off them the weight dropped off me, I was exercising, I felt better in myself and I just thought, you know what, I could see a light at the end of the tunnel. But I didn't realise until I come back to clinic that they said yeah but you've still got the steroids, the ones you've been taking for years are still in your body. It will take a while before your body starts to realise it's got to produce it itself and all of a sudden that's what's happened, it's probably hit a brick wall and stopped." 128, male aged 49.

strategies.^{22,41,42} This relates to the "shifting perspectives" model of chronic illness in which the perception of chronic illness includes elements of illness and wellness and that the focus of attention (ie, illness or wellness) can continually shift depending on disease factors as well as the personal and social context, for example, family factors or disease acceptance.⁴³ Depending on whether illness or wellness is in the foreground will likely influence patients' responses to their disease and their environment.³² Adjustment and a shift in perspective may be important for successful self-management and has been linked to disease management behaviors in asthma.^{25,44}

Emotive reactions such as fear and anxiety were expressed by participants. Increased psychological morbidity has been reported in severe or difficult-to-control asthma⁴⁵⁻⁴⁷ and has been linked to increased health care costs⁴⁸ and asthma deaths.¹⁵ Emotional factors such as panic or fear are an important element of asthma control, as perceived by the patient, though often neglected in clinical guidelines.¹² Yet participants in this study discussed many areas of their life they had adapted to manage their symptoms. The daily impact of managing asthma had an emotional impact also, in which participants felt unhappy about the restrictions they faced but a perception that they were necessary to ameliorate anxiety about worsening symptoms. The need for psychological support and services that provide

multidisciplinary working for patient benefit has been called for^{49,50} to improve coping and disease-related behavior.

A striking feature of the interviews in this study was a concern about symptoms leading to hospitalization, which contrasts with previous work where hospitals were perceived as safe by those with moderate-severe asthma.⁴² Participants described delaying help seeking, which has similarly been described by those with severe asthma^{19,23} and those attending emergency departments for life-threatening asthma.⁵¹ Similar competing priorities were reported such as work, childcare, and a desire to self-manage, mirroring findings by Foster et al¹⁹ that help seeking was delayed to prevent the disruption caused by hospitalization. Our data also saw an emotive reaction to hospitalization, inducing fear and avoidance in some. Those who delay help seeking are likely to repeat this behavior rather than prompting a change in self-management.⁵¹ It is important that discussions between patients and health care professionals elicit concerns about potential admission and encourage forward planning.

Many participants expressed concerns about OCS side effects, above any other treatment including inhaled corticosteroids, which is common in this group of patients.^{23,52} Individuals with severe asthma express difficulties in managing the side effects,^{19,23,52} identifying a clear treatment burden, in addition to symptoms, leading to ambivalence toward treatments.¹⁹ Participants

decision-making processes balanced concerns about side effects against the perceived need of OCS for asthma control, a process also observed by Gamble et al.⁵² This description lends further support to the necessity-concerns framework,^{22,53} a well-established model that places patients as active decision makers who consider the necessity of treatment against concerns. Stronger concerns (outweighing the perceptions of benefit) are associated with decreased adherence and as such are stronger predictors of reported adherence than clinical and sociodemographic factors for many chronic conditions, including asthma.^{22,53}

Additional to these findings, many participants in this study felt a burden from perceptions in the public domain that asthma is a mild condition. This created problems in the workplace and other social situations. With an increasing number of public awareness campaigns for many chronic conditions, such as stroke, heart disease, and diabetes, it is important that similar approaches are taken for asthma that also has the potential to be life threatening. This further supports the need for public messages to effectively enable such misunderstandings to be challenged.¹⁹

Common across many of the themes identified in this study is a need for further education, improved decision making with health care professionals, and enhanced psychosocial support across the spectrum of care for severe asthma. Our study alongside the findings of others demonstrates the needs of patients to better understand asthma as a long-term condition requiring ongoing management and medication^{42,52} and for health care professionals to better understand the burden of treatments for those living with severe asthma.^{19,23} Participants described a daily burden of symptoms that included an emotional impact and, for some, fears about potential hospitalization. This influenced decisions relating to treatments and help seeking. Trust in health care professionals is an important factor for patients' inclusion in decision making¹³ and adherence to self-management strategies.²⁵ When health care professionals have prior knowledge of patients' perceptions of treatment, they are better equipped to initiate discussion, though further training is likely to be necessary.⁵⁴

Using qualitative methodology, we have been able to provide a rich account of the challenges of effective management for adults with severe asthma. We aimed to recruit a wide representative sample, but despite targeted efforts during recruitment, those from a minority ethnic background remained under-represented and therefore their experiences are not adequately represented. The discrepancy in this sample of 3% compared with 18% from an ethnic minority background in the local service,³⁶ despite targeted efforts, suggests that further recruitment strategies are needed to engage different ethnic minorities. A limitation of this study was that 2 researchers carried out interviews that can potentially lead to variation during the interview process. However, transcripts were reviewed by both researchers and discussion took place to ensure that the interview schedule was adhered to and that amendments could be made if needed. Participants were recruited from one severe asthma service covering the East Midlands, UK, so our findings may not be completely transferable to other geographical areas. However, our region includes a wide range of social deprivation from least to most deprived represented in our cohort.

CONCLUSIONS

A wide range of challenges to effectively manage severe asthma have been identified and highlight psychosocial factors that

influence individual decision making about treatments and disease management behaviors. Identification of these challenges and psychosocial factors is needed to support education relating to asthma management overall with consideration of treatment perceptions including hospitalization. Individualized patient education should include elements that address patients' perceptions and priorities to resolve ambivalence toward treatment and self-management practices. Psychological and social support, and greater public awareness need further consideration to better support self-management.

Acknowledgments

The authors' contributions are as follows. Conception and design: R. A. Evans, P. Bradding, N. Hudson, S. J. Singh, R. H. Green, L. D. Apps; recruitment and conduct of the study: R. A. Evans, L. D. Apps, S. Chantrell; research analysis and interpretation: R. A. Evans, L. D. Apps, S. Chantrell, S. Majd, R. H. Green, P. Bradding, S. J. Singh, N. Hudson, E. Eglinton, A. C. Murphy; drafting the manuscript: L. D. Apps, R. A. Evans; refining and approving the final manuscript: L. D. Apps, R. A. Evans, R. H. Green, P. Bradding, S. J. Singh, A. C. Murphy, S. Chantrell, N. Hudson, S. Majd.

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ONLINE REPOSITORY

To get us started, can you tell me a little bit about your asthma?

How do you feel about the medications or care you have received for your asthma?

What would good asthma control be like for you?

Do you feel you know enough about your asthma?

Do you get support for your asthma from anywhere/anyone else other than HCPs?

How would you describe having asthma to another person?

How do you think other people view asthma?

Does asthma affect the activities you take part in in any way – positively or negatively?

FIGURE E1. Interview schedule.