

1 **Patient perceptions of living with severe asthma: challenges to effective**
2 **management**

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50 **ABSTRACT**

51

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

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

58 **Methods:** Participants were recruited from a specialist Difficult Asthma Service. Semi-
59 structured interviews were conducted by researchers independent of the patient's care.
60 Interviews were transcribed verbatim and inductive Thematic Analysis was performed.

61 **Results:** Twenty-nine participants [13 male, mean (SD) age 49.5 (13.6) years, mean Asthma
62 Control Questionnaire 2.2 (1.2)] participated in an interview. Analysis resulted in four major
63 themes describing the experience and challenges to managing severe asthma: Understanding
64 of severe asthma, emotional impact of living with severe asthma (sub-theme: fear of
65 hospitalisation), public perceptions of asthma, and concerns about medications.

66 **Conclusion:** Healthcare professionals need to consider and discuss with patients their
67 perceptions of severe asthma and the relevant treatments; particular attention should focus
68 around education of disease control and actively exploring thoughts around hospitalisation.
69 Our data highlights the potential for psychological and social support to enhance self-
70 management by directly addressing the wide-ranging individual challenges patients face.
71 There is also a need for greater public awareness and education about severe asthma to
72 minimise patient distress particularly in the work environment.

73

74

75 **What is already known about this topic?**

76 Symptom and treatment burden of severe asthma can impact daily life and psychological
77 wellbeing, but the variety of individual challenges around disease-management decisions is
78 unknown.

79 **What does this article add to our knowledge?**

80 We report a wide range of challenges for patients to effectively manage severe asthma and a
81 currently unmet need to address these, including psychological and social factors which
82 influence treatment decisions and disease management behaviours.

83 **How does this study impact current management guidelines?**

84 Novel individualised patient education approaches are needed to address perceptions and
85 priorities which inform decisions relating to self-management. Identification of psychological
86 and social support needs alongside improved public awareness of severe asthma is warranted.

87

88 **Keywords:** severe asthma, difficult asthma, qualitative, interview, disease management

89

90 **Abbreviations**

91 ACQ - Asthma Control Questionnaire

92 AQLQ – Asthma Quality of Life Questionnaire

93 BMI – Body Mass Index;

94 BTS – British Thoracic Society

95 FEV₁ - Forced Expiratory Volume in one second;

96 HADS – Hospital Anxiety & Depression Scale

97 ICS – Inhaled Corticosteroids

98 LABA – Long Acting Beta Agonists

99 MRC- Medical Research Council Dyspnoea Scale Grade

100 OCS – Oral corticosteroids

101 SIGN – Scottish Intercollegiate Guidelines Network

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103

104 **INTRODUCTION**

105

106 Management of severe asthma poses a significant challenge to the individual sufferer,
107 healthcare professionals and the healthcare system. Although representing only
108 approximately 10% of the whole asthma population,^{1,2} 50-60% of the healthcare costs
109 associated with asthma are attributed to those with severe asthma³. The management of
110 severe asthma is multifaceted, comprising pharmacological therapy, patient education and
111 self-management.⁴

112 Effective self-management for chronic illness has been described to encompass three sets of
113 tasks: those relating to medical management for example taking medication, those relating to
114 role management for example change in roles and emotional management.⁵ For asthma in
115 general the focus is on the avoidance of known triggers, adherence to medication and
116 adjustment of treatment in the face of exacerbations or changing disease control. Whilst such
117 strategies have been effective in general asthma,^{6,7} adherence to self-management plans is
118 nevertheless poor in the context of everyday life, seen by low levels of adherence to regular
119 peak flow monitoring and preventor medication use.^{4,8} Current approaches to self-
120 management when asthma is severe are a challenge for many patients, demonstrated by
121 suboptimal adherence (<80% of prescriptions issued) to inhaled corticosteroids and oral
122 corticosteroids in 65% and 26% of patients, respectively.⁹ Gamble (2009) demonstrated that
123 35% of patients filled fewer than 50% of prescriptions for inhaled combination therapy.¹⁰
124 Non-adherence to inhaled (preventer) therapies has been linked to an increased likelihood of
125 hospitalisations in previous 12 months¹⁰ as well as lower FEV1 and higher % sputum
126 eosinophil counts.⁹ For clinicians, clinical outcomes are clearly defined, yet patient-related
127 outcomes such as the psychological impact are poorly defined,^{11,12} with heterogeneity across
128 patient's perceptions, needs and participation in decision-making.^{11,13,14} This poses a
129 challenge for collaborative working between patient and healthcare professionals.
130 Psychosocial morbidity is often associated with severe asthma and alongside financial and
131 employment problems has been associated with an increased risk of death.^{15,16} Those with
132 poorer mental health have greater educational, support and training needs specific to asthma
133 management, further complicating the application of such strategies.¹⁷ Many of these factors
134 could be considered potentially modifiable, yet attempts to address psychosocial
135 complications have been limited. Psycho-educational programmes targeting patients with
136 severe asthma have shown short-term improvements in health-related quality of life and
137 hospital admissions, but evidence is limited in those with multiple risk factors.¹⁸ A recent

138 qualitative study has described the impact of severe asthma, impacting on all areas of daily
139 life, including daily activities, independence, parenting and employment, highlighting unmet
140 emotional support needs.¹⁹

141 It is important to recognise that behaviours related to adherence and asthma management
142 exist within a wider context of living with chronic illness that go beyond disease-related
143 tasks, and should therefore also take account of emotional adaptation, and illness and
144 treatment perceptions.²⁰⁻²² Whilst a small number of qualitative studies have explored the
145 perspective of those living with severe asthma,^{19,23-25} a greater understanding is needed of the
146 self-management practices and desires of those living with severe asthma. Considering the
147 higher symptom and treatment burden identified for those living with severe asthma,^{19,23} it is
148 important to understand the experience of these individuals which is likely to differ from
149 those with milder asthma. To better understand the factors that support or prevent successful
150 management of severe asthma, further attention needs to be given to the patient perspective.
151 We aimed to explore the attitudes of patients with severe asthma about their condition, their
152 experiences of asthma management and identify individual challenges and influences with
153 respect to self-management. We aimed to highlight patients' experiences with a view to better
154 understanding the support that might promote more effective self-management for severe
155 asthma.

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158

159 **METHODS**

160

161 We conducted a qualitative study investigating perceptions of living with severe asthma and
162 its management using semi-structured interviews. Qualitative research is a well-established
163 approach for better understanding the experience of living with chronic illness and the
164 barriers for self-care. Such an approach allows emphasis to be given to views and
165 experiences which are recognised as a necessary component of robust applied health
166 research.²⁶ The interviews were part of a larger feasibility study investigating Asthma
167 Tailored Pulmonary Rehabilitation for severe asthma²⁷.

168

169 **Participants:**

170 Patients were recruited from an adult Difficult Asthma Service and patients were eligible if
171 they had been under the care of the service for at least six months, and after evaluation had
172 severe asthma defined by step 4 or 5 of the British Thoracic Society (BTS) / Scottish
173 Intercollegiate Guidelines Network (SIGN) Asthma Management Guideline 2014²⁸(i.e.
174 patients require at least 2000mcg of inhaled corticosteroids daily). Patients were excluded if
175 they had fixed airflow obstruction and >10 pack years smoking history to exclude those with
176 COPD.

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

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

188

189 **Data collection:**

190 Face-to-face semi-structured interviews were conducted with patients following informed
191 consent. Participants could choose for the interview to take place at home or at the hospital.

192 The interview guide was developed, considering previous literature, in collaboration with the
193 wider multi-disciplinary research team and a patient and public advisory group (Figure E1).
194 Interviews were recorded and transcribed verbatim and were conducted by one of two
195 researchers (LA/SH), who were not involved in patient care and were not previously known
196 to the participants.

197 Participant's demographic data and questionnaires routinely collected in clinic were recorded.
198 The latter included the Hospital Anxiety & Depression Scale (HADS),²⁹ Asthma Control
199 Questionnaire (ACQ)³⁰ and the Asthma Quality of Life Questionnaire (AQLQ).³¹ The HADS
200 is a screening tool to identify symptoms of anxiety and depression. Scores are presented out
201 of a total of 21 for both anxiety and depression, with higher scores reflecting higher symptom
202 burden. The ACQ aims to measure adequacy of asthma control. A score of less than 0.75
203 represents well-controlled asthma and scores above 1.5 represent inadequately controlled
204 asthma. The AQLQ aims to measure disease related quality of life in patients with asthma in
205 four domains including symptoms, activity limitation, emotional function and environmental
206 stimuli. Patients respond to 32 items on a 7-point scale and the mean (SD) is calculated. A
207 score of 1 indicates severe impairment and a score of 7 indicates no impairment at all.

208 Further, participant postcodes were used to calculate the Index of Multiple Deprivation,
209 which is a measure of deprivation across small areas based on seven domains of deprivation
210 (income; employment; education, skills and training; health deprivation and disability; crime;
211 barriers to housing and services; living environment). The index scores small areas 1-10 (with
212 1 being in the most deprived 10% of areas and 10 being the least deprived 10% of areas in
213 England).

214

215 **Analysis:**

216 Data were analysed using inductive Thematic Analysis³² supported by NVivo software
217 (version 10; QSR International, Doncaster, Australia) and led by LA.

218 Analysis followed the six stages as outlined by Braun & Clarke: familiarisation with data,
219 generating initial codes, searching for themes, reviewing themes, defining and naming
220 themes, and producing the report.³²

221 Starting with a thorough familiarisation of the transcripts, initial coding was undertaken by
222 LA. Samples of transcripts (anonymised and uncoded) were also distributed amongst the
223 wider multi-disciplinary research team. The purpose of this method was to verify the initial
224 codes, to establish reliability in the coding method, to consider the data from multiple
225 perspectives, and to aid the development of themes. There were two subsequent meetings

226 with the wider research team to agree themes and interpretations and explore themes with the
227 patient advisory group to further validate interpretations. Themes were checked against the
228 original data set leading to the development of final themes. The final stage of analysis is to
229 describe, evidence and present the data in accordance with these themes.

230 **Ethics:**

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

234

235 RESULTS

236

237 Between December 2013 and November 2014, 88 patients were given information about the
238 study: three did not meet the inclusion criteria, 56 declined or were unable to be contacted
239 and 29 gave their consent and attended a semi-structured interview (Table 1 shows their
240 characteristics). The recruitment rate is consistent with other qualitative research reporting
241 less than 50% uptake.³³⁻³⁵ All interviews took place at the hospital at a time convenient to the
242 participant, except for one which took place in the participant's home at their preference. The
243 average length of interviews was 42 minutes, with a range of 20-62 minutes.

244 During data collection efforts were made to address an emerging lack of representation from
245 male patients and those of minority ethnic origin; gaps which were unrepresentative of the
246 local clinical service, which reports 56% female and 82% white.³⁶ Whilst these efforts
247 increased the number of males recruited to the study (44%), those from minority ethnic
248 groups remained under-represented (3%).

249 Data are presented under the following themes: Understanding of severe asthma, emotional
250 impact of living with severe asthma (sub-theme: fear of hospitalisation), public perceptions of
251 asthma, and concerns about medications (see Tables 2-5). To represent the consistency or
252 frequency of reports, specific phrases will be used to represent the proportion of participants
253 (as a percentage). These will be 'many' to imply more than 65% of participants, 'some' to
254 imply up to 65% and 'few' to imply less than 20%, as described by Sandelowski (2001)³⁵.

255

256 **Understanding of severe asthma (Table 2)**

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

261 A perceived lack of understanding about the disease was felt to have implications for the
262 decisions individuals made about daily management of asthma. The focus was often on acute
263 asthma incidents as opposed to consideration of on-going disease and few talked about wider
264 management practices in between the acute events. Participants discussed their asthma action
265 plans, some stating confidence to monitor peak flow, symptoms and respond accordingly.
266 However, recommendations from healthcare professionals to manage symptoms at home could
267 have unintended consequences for individuals. One participant described an initial reluctance
268 to follow the recommendation to monitor peak flow regularly for fear of increasing anxiety

269 about asthma. Experience with self-monitoring as well as a positive impact of self-monitoring
270 were described as easing initial concerns. Some participants lacked confidence that self-
271 monitoring was sufficient to fully help them manage their condition, due to unpredictable
272 variations in the severity, which at times left them fearful when symptoms arose. The
273 uncertainty of asthma and its evolving management through contact with clinicians posed
274 additional complexity for participants attempting to monitor and manage symptoms.

275

276 **Emotional impact of severe asthma (Table 3)**

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

288 ***Concerns about hospitalisation***

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

297 For some participants, hospitalisation provoked thoughts and feelings about the severity of
298 asthma and their own future health. One participant was able to relate back to a previous
299 admission they had and the realisation that their condition was worsening. Whereas another
300 reflected on the impact of seeing other patients he viewed as worse than himself. This raised
301 concerns about potential future decline, a prospect that was difficult to cope with and as a
302 result contributed to the dislike of the hospital environment.

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

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

317

318 **Public perceptions of asthma (Table 4)**

319 Interviews highlighted concerns about how other people perceived asthma which included a
320 discussion about challenges experienced in the workplace. Many participants faced personal
321 conflict when recognising that asthma could be a serious condition, and this conflict could be
322 mirrored by those around them. These participants felt that the public perceived asthma as a
323 mild condition and felt that sometimes others did not understand how much they were
324 suffering, causing frustration.

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

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

335 Practical support in the workplace was available, for example, flexible working hours, time off
336 for medical appointments or having a desk near a window or a fan to help regulate room

337 temperature. However, some found that this had created conflict with managers or immediate
338 colleagues who did not understand the necessity for this. Time off work for asthma-related
339 illness could also be a source of problems as the amount of time absent at work was not in line
340 with colleagues' expectations of asthma and its severity. For some participants, this had led to
341 unhappy working conditions and further distress.

342

343 **Concerns about medications (Table 5)**

344 Participants' discussions about medications centred largely on concerns about oral
345 corticosteroids (OCS) despite this treatment not being a specific focus of interviews.

346 Concerns about the long-term side-effects of OCS were expressed by many and included
347 concerns relating to bone, skin and liver health, diabetes, weight gain, depression and other
348 mood changes. There were also more general concerns expressed in relation to high doses of
349 OCS for prolonged periods of time, potential unknown effects to be seen longer-term and
350 continued reliance on steroids.

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

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

367

368

369 **DISCUSSION**

370 We aimed to understand the experience of asthma management and its challenges from the
371 perspective of patients with severe asthma. Participants in this study described an impact from
372 asthma that ranged from the interference with daily activities to managing symptoms in the
373 workplace, yet descriptions of its management focussed largely on acute events. Strong
374 emotive reactions to severe asthma and hospitalisation were described, influencing
375 participant's willingness to accept hospitalisation when symptoms became severe. Treatment
376 concerns were overwhelmingly focussed on OCS, highlighting a decision-making process that
377 balanced the necessity of OCS against the concerns. Whilst previous studies have described
378 the impact of living with severe asthma, encompassing personal and social effects,^{19,23} the
379 detailed descriptions from participants in this study also describe the emotional effect of the
380 disruption to daily living and the multiple challenges to disease management faced by those
381 with severe asthma. This further extends the wider psychological and social support needs that
382 have been identified for severe asthma.¹⁹ Multi-disciplinary approaches for the management of
383 severe asthma, including consideration of co-morbidities and psychosocial factors, have had
384 positive outcomes for asthma control³⁸⁻⁴⁰ and our data highlights the importance of these
385 approaches to include consideration of psychological and social support needs.

386 Management of asthma was described by some in terms of adaptations in the workplace and
387 restricting physical activity, however it was predominantly described by participants in terms
388 of responding to the acute events. This has similarly been described in mild-moderate asthma,
389 where asthma is reported as an acute or episodic condition by patients and further linked to
390 poor treatment adherence and engagement with preventive strategies.^{22,41,42} This relates to the
391 'shifting perspectives' model of chronic illness in which the perception of chronic illness
392 includes elements of illness and wellness and that the focus of attention (i.e. illness or wellness)
393 can continually shift depending on disease factors as well as the personal and social context,
394 for example, family factors or disease acceptance.⁴³ Depending on whether illness or wellness
395 is in the foreground will likely influence patient's responses to their disease and their
396 environment.³² Adjustment and a shift in perspective may be important for successful self-
397 management and has been linked to disease management behaviours in asthma^{25,44}.

398 Emotive reactions such as fear and anxiety were expressed by participants. Increased
399 psychological morbidity has been reported in severe or difficult-to-control asthma⁴⁵⁻⁴⁷ and has
400 been linked to increased healthcare costs⁴⁸ and asthma deaths¹⁵. Emotional factors such as
401 panic or fear are an important element of asthma control, as perceived by the patient, though

402 often neglected in clinical guidelines.¹² Yet participants in this study discussed many areas
403 of their life they had adapted to manage their symptoms. The daily impact of managing asthma
404 had an emotional impact also, in which participants felt unhappy about the restrictions they
405 faced but a perception that they were necessary to ameliorate anxiety about worsening
406 symptoms. The need for psychological support and services that provide multi-disciplinary
407 working for patient benefit has been called for^{41,42} to improve coping and disease-related
408 behaviour.

409 A striking feature of the interviews in this study was a concern about symptoms leading to
410 hospitalisation, which contrasts with previous work where hospitals were perceived as safe by
411 those with moderate-severe asthma.⁴² Participants described delaying help-seeking, which has
412 similarly been described by those with severe asthma^{19,23} and those attending emergency
413 departments for life-threatening asthma.⁵¹ Similar competing priorities were reported such as
414 work, childcare and a desire to self-manage, mirroring findings by Foster (2017) that help
415 seeking was delayed to prevent the disruption caused by hospitalisation. Our data also saw an
416 emotive reaction to hospitalisation, inducing fear and avoidance in some. Those who delay
417 help-seeking are likely to repeat this behaviour rather than prompting a change in self-
418 management.⁵¹ It is important that discussions between patients and healthcare professionals
419 elicit concerns about potential admission and encourage forward planning.

420 Many participants expressed concerns about OCS side-effects, above any other treatment
421 including inhaled corticosteroids, which is common in this group of patients.^{23,52} Individuals
422 with severe asthma express difficulties in managing the side-effects^{19,23,52}, identifying a clear
423 treatment burden, in addition to symptoms, leading to ambivalence towards treatments.¹⁹
424 Participants decision-making processes balanced concerns about side-effects against the
425 perceived need of OCS for asthma control, a process also observed by Gamble (2007)⁵². This
426 description lends further support to the necessity-concerns framework,^{22, 53} a well-established
427 model that places patients as active decision-makers who consider the necessity of treatment
428 against concerns. Stronger concerns (outweighing the perceptions of benefit) are associated
429 with decreased adherence and as such are stronger predictors of reported adherence than
430 clinical and socio-demographic factors for many chronic conditions, including asthma.^{22, 53}

431 Additional to these findings, many participants in this study felt a burden from perceptions in
432 the public domain that asthma is a mild condition. This created problems in the workplace and
433 other social situations. With an increasing number of public awareness campaigns for many
434 chronic conditions, such as stroke, heart disease and diabetes, it is important that similar

435 approaches are taken for asthma which also has the potential to be life threatening. This further
436 supports the need for public messages to effectively enable such misunderstandings to be
437 challenged.¹⁹

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

450 Utilising qualitative methodology, we have been able to provide a rich account of the
451 challenges of effective management for adults with severe asthma. We aimed to recruit a
452 wide representative sample but despite targeted efforts during recruitment those from a
453 minority ethnic background remained under-represented and therefore their experiences are
454 not adequately represented. The discrepancy in this sample of 3% compared with 18% from
455 an ethnic minority background in the local service³⁶, despite targeted efforts, suggests that
456 further recruitment strategies are needed to engage different ethnic minorities. A limitation of
457 this study was that two researchers carried out interviews which can potentially lead to
458 variation during the interview process. However, transcripts were reviewed by both
459 researchers and discussion took place to ensure that the interview schedule was adhered to
460 and that amendments could be made if needed. Participants were recruited from one severe
461 asthma service covering the East Midlands, UK so our findings may not be completely
462 transferable to other geographical areas. However, our region includes a wide range of social
463 deprivation from least to most deprived represented in our cohort.

464

465 **Conclusion**

466 A wide range of challenges to effectively manage severe asthma have been identified and
467 highlight psychosocial factors that influence individual decision-making about treatments and

468 disease management behaviours. Identification of these challenges and psychosocial factors
469 is needed to support education relating to asthma management overall with consideration of
470 treatment perceptions including hospitalisation. Individualised patient education should
471 include elements that address patients' perceptions and priorities to resolve ambivalence
472 towards treatment and self-management practices. Psychological and social support, and
473 greater public awareness need further consideration to better support self-management.

474

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658 **Table 1: Demographic characteristics of participants attending qualitative interview**
659 Mean (SD) unless * = frequency or ** median (range)
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Demographics	Patients with severe asthma (BTS steps 4 and 5)
Age (years)	49.4 (13.6)
Sex (M/F)*	13/16
BMI (kg/m ²)	31.6 (5.5)
Asthma duration (months),	297.4 (244.6)
Duration in difficult Asthma clinic (months),	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. hospitalised prior 12 months*	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 anti-depressants*	4
Current smokers*	4
Age left education (years)	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

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BMI – Body Mass Index; FEV₁ Forced Expiratory Volume in one second;; MRC- Medical Research Council Dyspnoea Scale Grade, ICS – Inhaled Corticosteroids, LABA – Long Acting Beta Agonists, HADS – Hospital Anxiety & Depression Scale,

664 **Table 2: Understanding of severe asthma**

<p>Seriousness of asthma</p>	<p><i>“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></p>
<p>Management of asthma</p>	<p><i>“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.</i></p> <p><i>“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.</i></p> <p><i>“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.</i></p>
<p>Understanding of severe asthma</p>	<p><i>“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.</i></p> <p><i>“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.</i></p> <p><i>“...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.” 102, female, aged 54.</i></p>

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Table 3: Emotional impact of severe asthma

Restricted activities	<p><i>“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.</i></p>
Concern about hospitalisation	<p><i>“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.</i></p>
	<p><i>“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></p>
	<p><i>“... 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></p>
	<p><i>“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.</i></p>
	<p><i>“...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></p>
	<p><i>“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.” 125, male, aged 43.</i></p>
	<p><i>“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.” 124, female, aged 30.</i></p>
	<p><i>“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></p>
	<p><i>“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></p>

	<i>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.</i>
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Table 4: Public perceptions of asthma

<i>Asthma as a mild condition</i>	<p><i>"... 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." 106, female, aged 45.</i></p> <p><i>"...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.</i></p> <p><i>"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.</i></p>
<i>Misunderstanding</i>	<p><i>"...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." 106, female, aged 45.</i></p>
<i>Challenge in the work environment</i>	<p><i>"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.</i></p> <p><i>"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.</i></p> <p><i>"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'." 103, female, aged 56.</i></p> <p><i>"... 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.</i></p>

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Table 5: Concerns about medications

<p><i>Side-effects</i></p>	<p><i>“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</i></p> <p><i>“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.</i></p>
<p><i>Decision-making for steroids</i></p>	<p><i>“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.</i></p> <p><i>“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.</i></p>
<p><i>Reducing steroids</i></p>	<p><i>“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.</i></p> <p><i>“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.</i></p> <p><i>“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></p> <p><i>“... 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</i></p>

	<p><i>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."</i> 128, male aged 49</p>
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