What bothers severe asthma patients most? A paired patient–clinician study across seven European countries

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Shareable abstract (@ERSpublications)
A paired study of patients and their clinicians across seven severe asthma centres in Europe found that patients and clinicians viewed the "most bothersome" aspect of their asthma differently. Efforts to align these views will improve asthma treatment. https://bit.ly/3mogXYZ

Abstract

Introduction Severe asthma is a complex, multidimensional disease. Optimal treatment, adherence and outcomes require shared decision-making, rooted in mutual understanding between patient and clinician. This study used a novel, patient-centred approach to examine the most bothersome aspects of severe asthma to patients, as seen from both perspectives in asthma registries.

Methods Across seven countries, 126 patients with severe asthma completed an open-ended survey regarding most the bothersome aspect(s) of their asthma. Patients' responses were linked with their treating clinician who also completed a free-text survey about each patient's most bothersome aspect(s). Responses were coded using content analysis, and patient and clinician responses were compared. Finally, asthma registries that are part of the SHARP (Severe Heterogeneous Asthma Research collaboration, Patient-centred) Clinical Research Collaboration were examined to see the extent to which they reflected the most bothersome aspects reported by patients.

Results 88 codes and 10 themes were identified. Clinicians were more focused on direct physical symptoms and were less focused on "holistic" aspects such as the effort required to self-manage the disease. Clinicians accurately identified a most bothersome symptom for 29% of patients. Agreement was particularly low with younger patients and those using oral corticosteroids infrequently. In asthma registries, patient aspects were predominantly represented in questionnaires.

Conclusions Results demonstrated different perspectives and priorities between patients and clinicians, with clinicians more focused on physical aspects. These differences must be considered when treating individual patients, and within multidisciplinary treatment teams. The use of questionnaires that include multifaceted aspects of disease may result in improved asthma research.

Lessons for clinicians
- This patient-led study found that clinicians were not very accurate at identifying what bothered their patients most.
- Patients cared much more about the effort of self-management, and much less about the direct physical symptoms, than their clinicians thought.
- Aligning patient and clinician perspectives during consultations, and understanding the aspects of asthma that patients are bothered by, may improve severe asthma outcomes.

Introduction

Severe asthma, defined as asthma that requires treatment with high-dose inhaled corticosteroids and additional controller medication to prevent it becoming uncontrolled or asthma that remains uncontrolled despite such treatment, is heterogeneous, and is associated with a substantial burden to patients and healthcare systems [1–4]. People with severe asthma have increased morbidity and mortality rates and are five times more likely to experience asthma exacerbations, compared to mild/moderate asthma, leading to substantially lower quality of life [5–7]. The complex nature of the disease and accompanying comorbidities (including allergic rhinitis, chronic rhinosinusitis, obesity, gastro-oesophageal reflux disease, anxiety and depression), as well as the effects of treatment/treatment responses, impacts patients both physically and emotionally [8] affecting family and social relationships, employment and education [9]. Therefore, management of severe asthma should be equally multifaceted, including appropriate medication and nonpharmacological therapies such as physiotherapy, supported self-management and psychological support [10].

Poorly controlled severe asthma remains common despite advances in treatment, especially the advent of biologics [11]. The combination of a high symptom burden and high treatment burden, including side-effects of oral corticosteroids (OCS), leads many patients to have low expectations of levels of asthma control [12], which often results in poor quality of life. Therefore, to improve asthma treatment outcomes, patients and clinicians must have similar understandings of the impact severe asthma has on people living with it, and the benefits of appropriate treatment [13]. The alignment of patient and clinician perspectives promotes trust and shared decision-making, in which both clinician and patient actively engage in treatment processes. This has been shown to improve adherence and quality of life in poorly controlled asthma [14].

Current evidence indicates that patient and clinician perceptions of asthma are often not aligned. A large-scale survey with patients and physicians reported significant discordance in the subjective perception of asthma control [15, 16], with evidence that patients perceive their own asthma as better controlled than their clinician does. Pertinently, clinicians tend to underestimate the effects on patients' daily lives, thus leading to worse asthma control [17, 18]. Recent survey data highlighted the need for patients and physicians to work together in order to better understand the nature of their disease: whether it is well controlled, and how it can be improved using treatment guidelines [19]. A better understanding of the impact of the varied symptoms experienced by patients will aid clinicians to provide supportive, personalised treatment for severe asthma [20].

Several studies have used questionnaires and interviews to explore aspects of severe asthma that negatively impact patients including physical and emotional asthma symptoms, symptoms from comorbidities and medication side-effects, to inform patient-reported outcomes that are used in severe asthma registries [21, 22]. Registries that collect important data on patients' asthma encourage standardised reporting of well-established measures. However, registry variables may also be "medicalised" and not reflect the multidimensional patient experience of severe asthma, hampering clinicians' ability to provide supportive, personalised treatment.

Therefore, this novel study used an inductive, patient-centred approach to compare the perceived impact of heterogeneous, multidimensional aspects of severe asthma, from both patient and clinician perspectives. Furthermore, the study aimed to explore whether discrepancies between patient and clinician perspectives differed within patient subgroups, and examined how well the most important aspects were reported in dedicated registries collecting clinical information on people with severe asthma.

Methods

Design

This observational qualitative study used online patient and clinician surveys developed through an iterative process of consultations with severe asthma patients, patient organisations, clinical asthma experts

and psychology experts (refer to the Guidance for Reporting Involvement of Patients and the Public report in the supplementary material).

Survey and recruitment

The cross-sectional survey was sent to clinicians from severe asthma clinics in seven European countries (Czech Republic, Denmark, Greece, the Netherlands, Slovenia, Portugal, the United Kingdom (UK)) recruited *via* the European Respiratory Society Severe Heterogeneous Asthma Research collaboration, Patient-centred (ERS SHARP) [23]. Clinicians completed the first part of the survey before eligible patients (age >18 years, clinician-diagnosed severe asthma according to local guidelines) completed a linked patient component. Eligible patients were identified through opportunistic recruitment to the study by clinicians. To avoid biased recruitment, participating clinicians were asked to consecutively recruit eligible patients once they started the study. The responses given by patient and the clinician responsible for their care were anonymously linked *via* a unique weblink to enable an assessment of agreement. Neither patients nor clinicians saw the others' responses.

After providing informed consent, patients answered questions about their demographics and current treatment before completing an open-ended survey (supplementary material) about "what bothers you most about your asthma?". Open-ended questions were used to collect new insights grounded in participant data. A follow-up question asked "Is there anything else that bothers you about your asthma and you would like to tell us?", but this was rarely completed and not used in the analysis. Clinicians answered similar questions about "the most bothersome aspect of [their patient's] asthma". There was no limitation to the number of bothersome aspects that patients and clinician could report.

Patient eligibility criteria were physician-diagnosis of severe asthma, with ⩾6 months' follow-up in an asthma clinic, as well as having internet access and the ability to complete the study independently. Clinicians who were significantly experienced in severe asthma patient care were eligible. Patient eligibility was confirmed by the paired clinician who invited them to take part in the study. Surveys were translated into each patient's native language by a professional translation agency, who translated responses back into English for analysis.

Qualitative data analysis

Free-text survey responses were analysed using conventional content analysis, a widely used method of qualitative inquiry in healthcare research in which textual data is inductively analysed by the research team [24, 25]. In this study, an experienced qualitative researcher (E. Chatburn) developed the initial codebook from an initial sample of 32 responses: after reading through and obtaining a sense of the data, "codes" were created that captured any bothersome aspects within the responses. These codes were clustered under higher-order headings, and then iteratively refined into "themes". For example, when participants reported feeling exhausted during their days, this was coded as "tiredness or fatigue". Similar codes, such as "tiredness or fatigue", "sleep problems" or "weight changes", were categorised under the theme of "indirect physical consequences of asthma and asthma treatments". Further details of how the themes were constructed are discussed later.

The process of coding and categorisation was discussed with the research team throughout, and data credibility and trustworthiness were further strengthened by frequent dialogue with patients and clinicians.

The final categorisation of the patient data was reviewed and approved by additional patients. The researcher then applied the codebook from patient responses to clinician responses. Where any novel codes were present in the clinician responses, these were added to the codebook.

Once initial coding and categorisation was completed with sample responses, any remaining patient responses were coded using the initial codebook. New codes were added during the coding of the remaining responses, and the initial 32 sample responses were recoded at the end, using the full codebook to ensure nothing was missed.

Analysis

Patient and clinician answers were compared at the theme level, by examining the proportion of responses in which each theme was present. Significant differences between patient/clinician responses were identified using Fisher's exact test.

Responses were categorised by subgroup by patient age (⩾55 years *versus* <55 years), patient gender (male *versus* female), patient OCS use (every few months/few per year/annual *versus* every few weeks/daily). Patient and clinician responses were compared within patient subgroups.

Clinician responses were viewed as "in agreement" with patients if a theme identified in a patient response was also present in the clinician response. Agreement was also examined within patient subgroups at a theme level (gender: male *versus* female; age: <55 years *versus* ⩾55 years; OCS use: high (every few months or less) *versus* low (every few weeks or more)).

Registry comparison

All variables from 10 accessible national and regional severe asthma registries from the SHARP network were compiled and reviewed. Registries included were from severe asthma clinics in Belgium, Denmark, Germany, Spain, France, Greece, Italy, Portugal, the UK and the SHARP Central Registry. Each variable was compared qualitatively against the codes and themes from the survey codebook to determine if a variable reflected any identified code or theme. For patient-reported outcome measures with multiple questions, each question was reviewed individually.

Ethics

The project received ethical approval from University of Bath research ethics committee (reference 20:251) with specific approvals for each international site (supplementary material). Anonymous datasets from the project are available in the online repository: https://doi.org/10.6084/m9.figshare.20349138.

Results

Participants

128 patients and 24 clinicians from seven countries participated in the survey, with 126 patients having corresponding clinician data. Among the 126 patients included in the analysis, 70% were female (in line with previous sex differences observed in severe asthma prevalence [26]), and the majority (56%) were aged 45–64 years. 46 patients reported using OCS daily and 67% were current users of biological therapy for their asthma (table 1).

Codes and themes

From 88 codes, 10 themes were identified: direct physical symptoms of asthma; indirect physical consequences of asthma; limitations on daily life; sensitivity to triggers; effort required to self-manage asthma; burden of medication and side-effects; fears, worries and distress; stigma; interactions with healthcare providers; and "nothing bothers me" (table 2). A full codebook, including all codes and example quotes for each, is available in the supplementary material.

Patient and clinician perspectives of most bothersome aspects of severe asthma

Overall, patients reported more bothersome aspects of severe asthma in their responses (total 436 codes, mean 3.5 per participant, range 1–19) than clinicians (total 213, mean 1.7, range 1–5).

When responses were allocated into different themes, patient responses included between one and six themes each (figure 1). In total across patients, 278 themes were selected (mean 2.21 per patient). For clinicians, there were 188 entries in total (mean 1.49 per physician, range 1–3). The proportion of total responses from patients and clinicians in which each theme was identified were compared (figure 2).

Just 29% (82 out of 278) of the themes identified in patient responses were also present in the paired clinician response. In 46% (58 out of 126) of patients, no themes were agreed between patients and clinicians.

Both patients and clinicians reported "direct physical symptoms of asthma" most frequently, followed by "indirect physical consequences" and "limitations on daily life" (table 3). Thereafter, patients reported "sensitivity to triggers", followed by "effort required to self-manage". In contrast, only three clinician responses concerned effort required to self-manage. For clinicians, fourth- and fifth-ranked themes were "burden of medication" followed by "sensitivity to triggers".

Compared with patients, clinicians reported "direct physical symptoms of asthma" more frequently (OR 1.71, 95% CI 1.11–2.65; p=0.014), although both patients and clinicians reported this most often. Notably, clinicians reported the effort required to self-manage asthma less frequently than patients (OR 0.15, 95% CI 0.03–0.50; p<0.001). The frequency of other themes such as indirect physical consequences and limitations on daily life were broadly similar between patients and clinicians; however, interestingly, stigma was mentioned only by patients and not at all by clinicians.

TABLE 1 Participant demographics	
Patients[#]	126
Country	
Czech Republic	21 (17)
Denmark	19 (15)
Greece	19 (15)
The Netherlands	17 (14)
Slovenia	18 (15)
Portugal	20 (16)
United Kingdom	12 (10)
Gender	
Female	88 (71)
Male	36 (29)
Age, years	
⩽34	13 (10)
35–44	21 (17)
45–54	34 (27)
55–64	36 (29)
⩾65	20 (16)
OCS use	
Annual	47 (38)
Few per year	22 (18)
Every few months	6 (5)
Every few weeks	3 (2)
Daily	46 (37)
Current use of biologics	
Yes	84 (68)
No	23 (19)
Not sure	17 (14)
Clinicians	24
Gender	
Female	13 (54)
Male	11 (46)
Mean age, years[¶]	47.5
Experience in clinical practice, years	
0–9	4 (17)
10–19	9 (38)
⩾20	11 (46)

Data are presented as n or n (%). For subgroup analysis, demographic data were divided into the following comparisons: young (age ⩽34/35–44/45–54 years) *versus* old (age 55–64/⩾65 years), male *versus* female, low oral corticosteroid (OCS) use (every few months/few per year/annual) *versus* high OCS use (every few weeks/ daily). [#]: two patients did not provide complete demographic data and have not been included in summary percentages; [¶]: standard deviation of clinicians' age could not be calculated, as some sites only provided summary data.

Patient and clinician perspectives in subgroups

Differences between clinician and patient response proportions within subgroups of patients by age, gender and OCS use were evaluated (figure 3). Complete comparisons (including patient *versus* patient and clinician *versus* clinician comparisons) are presented in the supplementary material.

The accuracy of clinician responses only varied slightly across patient gender (female 29%, male 31%), but clinicians were more accurate for older patients (age ⩽55 years, 26%; >55 years, 35%) and those who used OCS more often (low use, 26%; high use, 34%).

Comparison with registry variables

All themes, except "effort required to self-manage asthma", were addressed by at least one registry variable (table 4). At a code level, 67% of codes were represented, although the breadth of coverage varied by theme: 100% of codes in the theme of direct physical symptoms were well covered in the registry variables, while 54% of indirect physical consequences were captured, and 0% of "effort required to self-manage asthma".

TABLE 2 Identified themes and codes from patients and clinician responses	
Themes (number of codes)	**Codes**
Direct physical symptoms of asthma (6)	Breathing difficulties, shortness of breath Coughing Chest tightness Mucus and phlegm Asthma attacks, flare ups, exacerbations Noisy breathing
Indirect physical consequences of asthma and asthma treatments (13)	Tiredness or fatigue Sleep problems Susceptibility to respiratory infections Nose, throat or sinus problems Pain Weight changes Poor physical fitness or stamina Weakness Palpitations Headaches Dizziness Eczema Allergic complaints
Limitations on daily life (missing out) (13)	Unable to do activities you want to do Walking and climbing stairs Sports, exercise, active leisure Family life, partner, caregiving Work life Social life Normal daily life is not possible Time outdoors Hobbies Poor quality of life in general Personal care Household tasks Sex life
Sensitivity to triggers (4)	Physical exertion as trigger Environmental triggers Stress as trigger Monitoring for and avoiding triggers
Effort required to self-manage asthma (11)	Managing activities: level, timing or setting Having to plan, anticipate, organise Unpredictability of symptoms, uncertainty Need to pause to rest, slow down, recover Think about asthma every day, managing it takes up time Enhanced hygiene routines Unable to make a plan or sudden need to change plans Explaining things or training others Symptoms never completely go away Masking or hiding asthma symptoms Doing breathing exercises
Burden of medications and their side-effects (6)	Dependence on medications taken Corticosteroid side-effects Amount of medications taken Need to always carry medications Medications ineffective Remembering to take meds, restock meds
Fears, worries and distress (8)	Specific fears about asthma General distress about having asthma Anxiety Worries about asthma medications Impact on mood Impact on self-esteem, feeling useless, no freedom Fears about asthma and COVID-19 Having panic attacks

TABLE 2 Continued	
Themes (number of codes)	**Codes**
Stigma (4)	Attracting attention, others think you are contagious
	People do not understand
	Asthma is stigmatising
	Feeling different to others
Interactions with healthcare providers (and hospital treatment) (5)	Unanswered questions, not listened to
	Not happy with care provision
	Not understood by doctors
	Need for surgeries
	Need for hospital admission
Nothing bothers me about asthma	
COVID-19: coronavirus disease 2019.	

There were 13 questionnaires included across the registries (mean 4.3, range 1–8). When the questionnaires were excluded, the coverage for the most bothersome symptoms was significantly decreased (16% overall). None of indirect physical consequences; fear, worries and distress; or stigma were addressed by the registry variables.

Discussion

Summary of findings

This study investigated patients' views on the most bothersome aspects of severe asthma by asking open-ended questions with a free-text response. This enabled patients to consider various aspects of discomfort or inconvenience due to their asthma, not limited to clinical symptoms. Consequently, many patients responded that much broader aspects of living with severe asthma were most bothersome.

This is the only study to evaluate the most bothersome aspects of severe asthma through a paired survey between patients and clinicians. This unique approach allowed comparison of views between individual
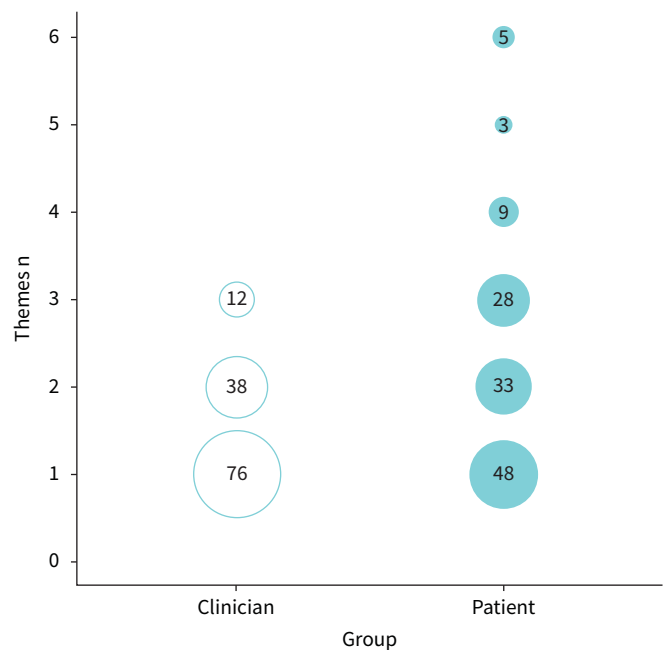
FIGURE 1 Distribution of responses by the number of distinct themes reported by patients *versus* clinicians. The size of each bubble represents the number of responses and the numbers within each bubble indicate the number of responses. For example, clinicians reported only one theme for 76 of the patients. By contrast, 48 patients reported only one theme.
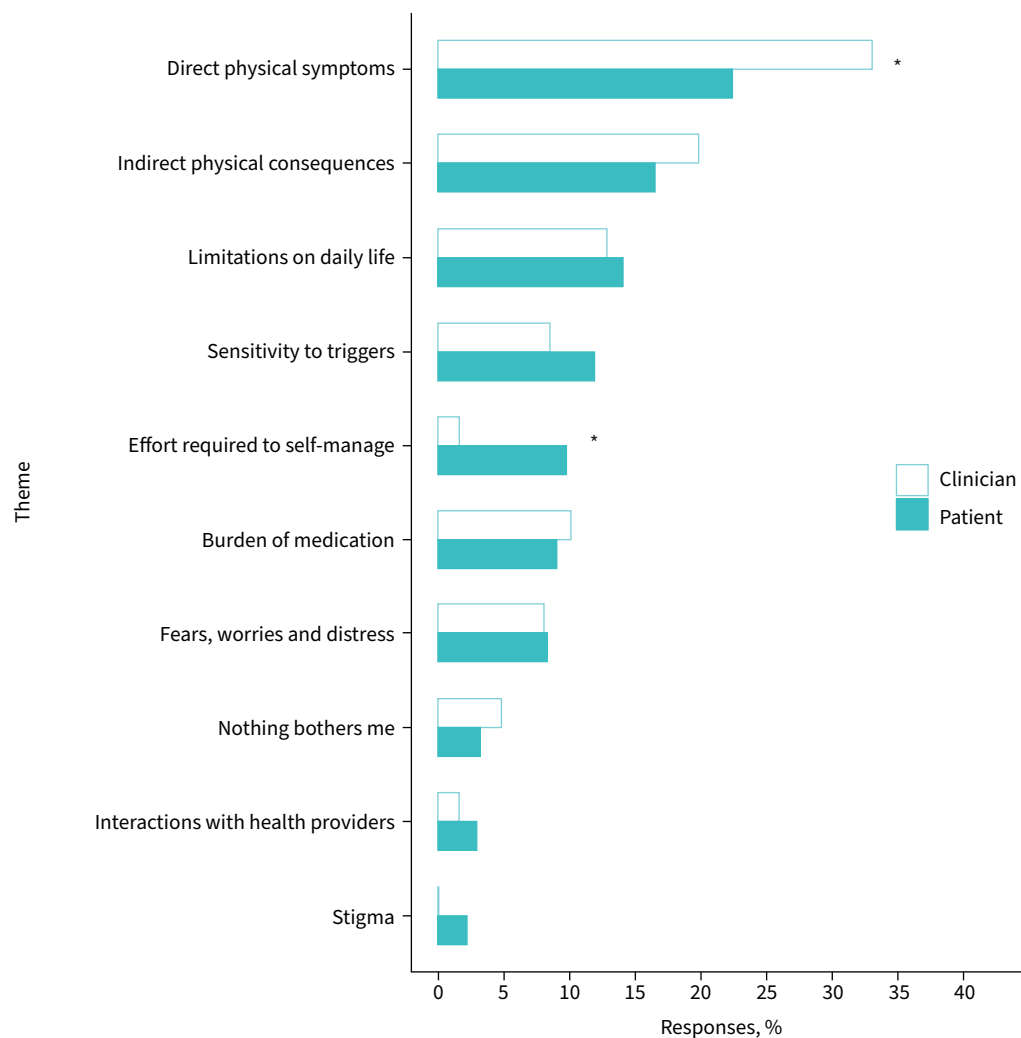
FIGURE 2 A comparison of the percentage of responses for each theme, by responder group. For more detail on how the themes were defined, refer to the supplementary material. *: p<0.05.

patients and their clinicians. Our study found that patients were less likely than clinicians to report the direct physical aspects of their disease as the most bothersome (22% *versus* 33%), and more likely than clinicians to find the effort of self-managing their disease most bothersome (10% *versus* 2%). This was observed across almost all subgroups, irrespective of the patient's age, gender and OCS use. The agreement between patient and clinician responses was poor (only 29% of aspects identified by patients were also identified by the clinician looking after them), although agreement was slightly higher for females, older patients and patients with high OCS use. This may reflect more agreement where clinicians have greater familiarity with particular groups of patients, such as female patients who are more common in severe asthma cohorts [27]. Previous research has observed more patient-centred interactions between patient and clinician when patients were older, which was associated with better patient satisfaction [28]. Finally, many aspects that patients considered important were only partially represented in clinical registry databases, mainly through standard patient-reported outcomes collected in the existing severe asthma registries.

These findings are in line with previous evidence in other disease areas that clinician and patient experiences of disease do not always align [29], and that broader healthcare outcomes that encompass holistic aspects such as social and psychological elements, are often at, or near the top of, patient priorities [30].

TABLE 3 Frequency of themes on most bothersome aspect compared between patients and clinicians				
	Patient[#]	Clinician[#]	OR[¶] (95% CI)	p-value[+]
Participants, n	278	188		
Theme				
Direct physical symptoms of asthma	22.3	33.0	1.71 (1.11–2.65)	0.014
Indirect physical consequences of having asthma and asthma treatment	16.5	19.7	1.24 (0.74–2.05)	0.391
Limitations on daily life (missing out)	14.0	12.8	0.90 (0.50–1.60)	0.783
Sensitivity to triggers	11.9	8.5	0.69 (0.34–1.34)	0.283
Effort required to self-manage asthma	9.7	1.6	0.15 (0.03–0.50)	<0.001
Burden of medications and their side-effects	9.0	10.1	1.14 (0.57–2.23)	0.747
Fears, worries and distress	8.3	8.0	0.96 (0.45–1.99)	1.000
Nothing bothers me about asthma	3.2	4.8	1.50 (0.52–4.36)	0.465
Interactions with health providers and hospital treatment	2.9	1.6	0.55 (0.09–2.32)	0.537
Stigma	2.2	0.0	0.00 (0.00–1.25)	0.086

Data are presented as %, unless otherwise stated. [#]: percentage of total responses, allocated to each theme, by response group; [¶]: represents clinicians (numerator) *versus* patients (denominator); [+]: compared using Fisher's exact test.

Study implications

Our study supports the reported substantial impacts of severe asthma on many aspects of a patient's life, highlighting the need for clinicians to understand and treat such complex diseases with multidisciplinary approaches.

Clinicians may have a different perspective on the most bothersome aspects of disease because they have different priorities, such as reducing symptoms and exacerbations, rather than the impact of asthma on a patient's daily life and emotions [31]. Although symptomatic improvement is an important treatment goal, patients frequently reported such nonclinical aspects as most bothersome. Therefore, the nonclinical bothersome aspects (such as the substantial effort required to appropriately self-manage severe asthma) may have more impact on patient wellbeing. These findings highlight the importance of integrative and inclusive multidisciplinary care teams to support all aspects of care of people with severe asthma, requiring close and integrative collaboration from different healthcare professionals (including physicians, nurses, pharmacists, physiotherapists and psychologists) to provide multidimensional support [32, 33].

Registries that collect data on patients are increasingly used to understand the impact of disease and treatment on patients. As demonstrated by our analysis, the multifaceted nature of severe asthma is not well reflected in severe asthma registry variables across Europe. Data capture was inconsistent across registries. All registries had different combinations of questionnaires, with some using multiple questionnaires to address some aspects of disease while not capturing patients' most bothersome aspects, or capturing bothersome aspects with a single item within a questionnaire. Therefore, when interpreting a questionnaire, patients' responses to each question should be carefully reviewed. The findings highlight the need to use varied clinical tools, including questionnaires, to address the aspects of severe asthma that are most important for patients.

Improving the concordance between patient and clinician perceptions is crucial to improved asthma outcomes, particularly given the key importance of quality of life for people with severe asthma [34, 35]. Treatment adherence in people with severe asthma is frequently suboptimal and may be improved by shared decision-making centred around outcomes that are important to individual patients [14]. Adherence may be improved through use of a common, agreed goal between patient and clinician, identified through explicitly confirming individual patient priorities ("what has been bothering you?") rather than focusing on symptom-focused discussions ("how have you been?") during consultations. Such approaches may be particularly important for particular patient subgroups [36, 37], such as males, those with lower OCS use and younger patients. Future work should explore how these groups can be offered personalised, supportive treatment that maintains an appropriate therapeutic partnership [38].

Study strengths and limitations

A clear strength of the study is the extensive involvement of patient representatives at every stage of this international collaborative study, including conception, design, analysis, interpretation and reporting. This
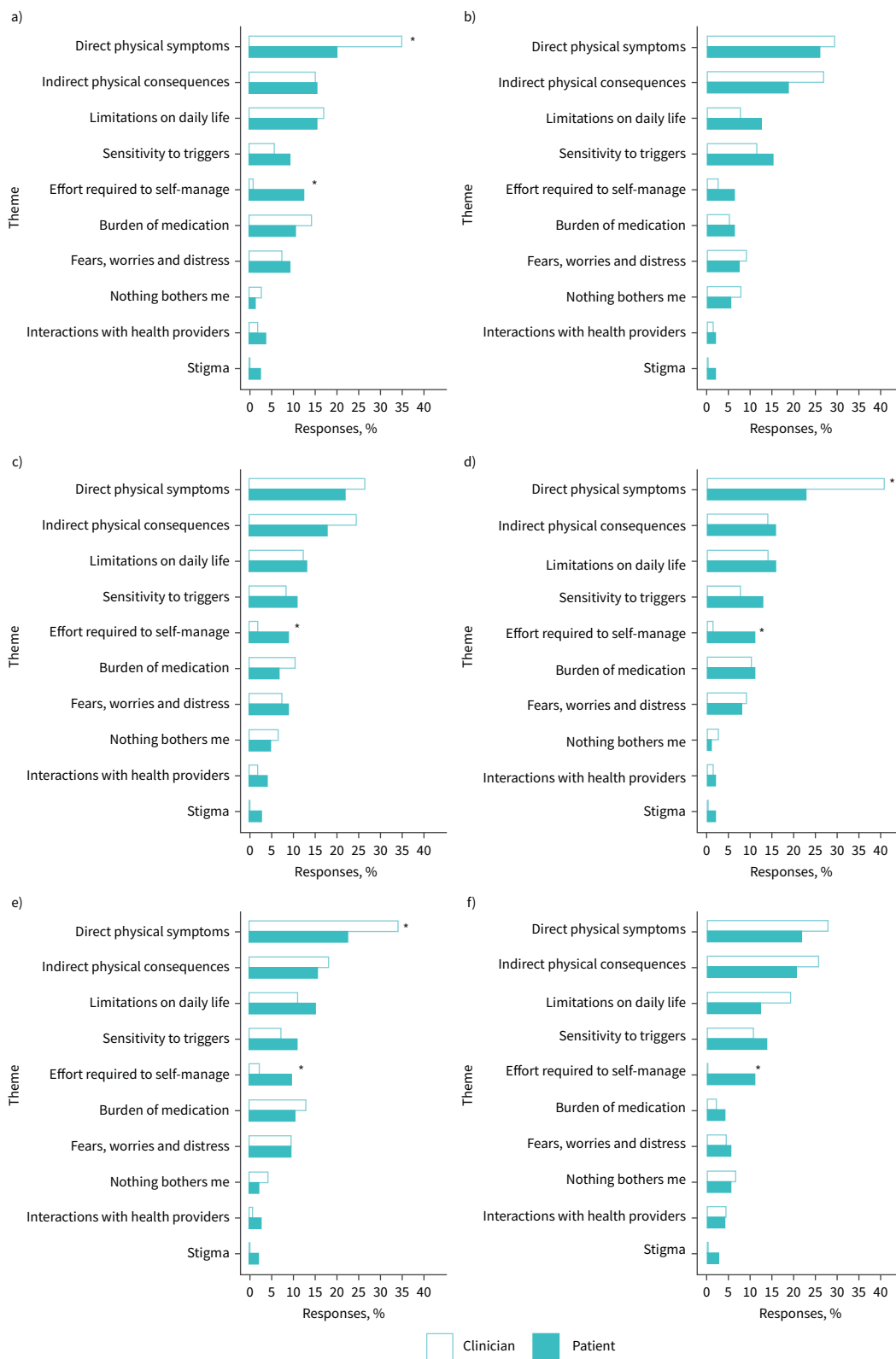
FIGURE 3 Percentage of responses for each theme, by patient subgroup: a) age <55 years (68 patients; 161 patient responses; 106 clinician responses); b) age ⩾55 years (56 patients; 113 patient responses; 79 clinician responses); c) female (88 patients; 200 patient responses; 138 clinician responses); d) male (36 patients; 74 patient responses; 47 clinician responses); e) oral corticosteroid (OCS) low use (75 patients; 146 patient responses; 106 clinician responses); f) OCS high use (49 patients; 128 patient responses; 79 clinician responses). *: p<0.05.

TABLE 4 Themes and codes covered by registry variables in each theme including and excluding questionnaires

	Codes	Codes covered by registry variables	Codes covered by registry variables excluding questionnaires
Direct physical symptoms of asthma	6	6 (100)	6 (100)
Indirect physical consequences of asthma and asthma treatments	13	7 (54)	0 (0)
Limitations on daily life (missing out)	13	12 (92)	1 (8)
Sensitivity to triggers	4	3 (75)	2 (50)
Effort required to self-manage asthma	11	0 (0)	0 (0)
Burden of medications and their side-effects	6	6 (100)	1 (17)
Fears, worries and distress	8	7 (87.5)	0 (0)
Stigma	4	2 (50)	0 (0)
Interactions with healthcare providers (and hospital treatment)	5	4 (80)	1 (20)
Nothing bothers me about asthma	NA	NA	NA
Overall total	70	47 (67)	11 (16)

Data are presented as n or n (%). Identified patient-reported outcomes: Asthma Control Test, Asthma Control Questionnaire, Asthma Quality of Life Questionnaire (AQLQ)/mini-AQLQ, Control of Allergic Rhinitis and Asthma Test, Epworth Sleepiness Scale, EQ-5D, Hospital Anxiety and Depression scale, Nijmegen questionnaire, Pittsburgh Vocal Cord Dysfunction Index, St George's Respiratory Questionnaire, Sino-Nasal Outcome Test-22, Dyspnoea visual analogue scale, Work Productivity and Activity Impairment Questionnaire. NA: not applicable.

ensured that the study findings are important for patients and, therefore, important for researchers and clinicians. Additionally, unlike previous studies, the "bottom-up" reflexive content analysis meant that the impact of existing clinical and research biases was reduced, although the inherent subjective nature of the qualitative methods should be acknowledged.

While a few studies have investigated patient and clinician treatment priorities [37], the novel design of pairing patient and clinician responses allowed the assessment of agreement for each individual patient. This showed not only differences between patient and clinician priorities, but also whether clinicians are able to understand what is important for their individual patients during treatment.

The study has some limitations. Firstly, it must be recognised that the patient sample is from severe asthma centres in only seven countries. While large and seemingly broadly representative of severe asthma prevalence in European patient groups [26], our qualitative findings may not be representative of all patients, such as patients treated outside of severe asthma centres, and underserved groups who are less likely to respond to voluntary surveys. Secondly, the sample size within each separate site was too small to determine any patterns within each site. Thirdly, the study data are self-reported and would be strengthened by including objective, physiological measures (such as lung function) and clinical measures (such as comorbid conditions) in order to further understand patient perceptions across heterogeneous characteristics. Future research should look to understand how contextual factors (such as the provision of psychological/behavioural support to develop adaptive coping strategies, or socioeconomic factors) can influence the patient–physician partnership, and understand their impact on relevant outcomes such as asthma control.

Conclusions

Patients and clinicians had different views on the most bothersome aspects of severe asthma in daily life. While both groups reported physical symptoms, most patients shared a wide variety of aspects related to quality of life that frequently included the substantial effort required to self-manage their condition. During clinical consultation, physicians should respect the importance of their patients' most bothersome symptom and ensure that it is addressed, recognising that it may change from consultation to consultation, alongside other clinically relevant issues. Such an approach would enhance trust and strengthen the patient–clinician partnership. Using questionnaires that include multifaceted aspects of disease, within research, clinical practice and disease registries, may result in improved asthma treatments.

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