

Life Impact and Treatment Preferences of Individuals with Asthma and Chronic Obstructive Pulmonary Disease: Results from Qualitative Interviews and Focus Groups

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ABSTRACT

Introduction: The impact of asthma and chronic obstructive pulmonary disease (COPD) on individuals' lives may be substantial, yet clinical practice often focuses only on symptoms. We aimed to better understand the perspective of asthma or COPD patients and to identify condition-related burden, life impact, priorities, unmet needs, and treatment goals.

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Methods: Individuals aged at least 18 years with asthma or COPD were identified by a recruitment panel via clinical referrals, support groups, consumer networks, and a patient database. Interviews were carried out individually (by telephone) or in focus groups (with no more than five participants per group). A semi-structured interview guide was used with prespecified topics, informed by a literature review, that were considered impactful in asthma or COPD (symptoms and daily-life impact, satisfaction with current treatment, important aspects of treatment, adherence, and ideal treatment).

Results: Overall, 72 people participated in focus groups/individual interviews (asthma $n = 18/n = 21$; COPD $n = 15/n = 18$). "Shortness of breath" was the most frequently reported symptom; however, participants discussed the life impact of their condition more than symptoms alone. Reported physical impacts included the inability to sleep and socialize, while emotional impacts included "embarrassment, stigma, and/or self-consciousness", "fear and/or panic", and "sadness, anxiety, and/or depression". Coping mechanisms for normal activities included continuing at reduced pace and avoidance. Treatment preferences centered on resolving impacts; improved sleep, "speed of action", and "length of relief" were the most frequently reported ideal treatment factors.

Conclusion: Patients with asthma or COPD experience substantial quality of life limitations

and tend to focus on these in their expressions of concern, rather than symptoms per se. Life impacts of these conditions may have implications beyond those commonly appreciated in routine practice; these considerations will be applied to a future discrete choice experiment survey.

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Keywords: Asthma; Chronic obstructive pulmonary disease; Patient preference; Qualitative research; Quality of life; Respiratory

INTRODUCTION

Asthma and chronic obstructive pulmonary disease (COPD) are two of the most common respiratory conditions in the UK [1, 2]. An estimated 1 in 12 adults are currently receiving treatment for asthma (4.3 million [3]). More than 1 in 17 people are living with COPD (3 million in the UK), although only a third of these have been formally diagnosed [2].

Symptoms of asthma fluctuate and can include wheeze, dyspnea, chest tightness, cough, and variable expiratory airflow limitation [4], which can develop at any age. By contrast, COPD has a typical onset after the age of 40 [5, 6], is characterized by persistent airflow limitation, and is usually linked to tobacco-smoke exposure; however, occupational exposure to high levels of dust and fumes over a period of time can also cause COPD regardless of smoking status [2].

Although the measurement and management of symptoms tend to be the primary focus for clinical experts, patients with asthma or COPD are typically more concerned with the overall impact of their condition on their quality of life (QoL) [7, 8]. Clinical measurements (such as lung function) do not always correlate with how individuals feel [9]. This is particularly true for patients with asthma, for whom feelings of anxiety and loss of control are common [10, 11]. The irregular nature of asthma exacerbations also appears to affect the perception of asthma control, which is typically overestimated by many patients with asthma

(based on their ability to manage exacerbations, rather than their frequency of symptoms or exacerbations [12, 13]).

Living with sustained COPD symptoms incurs a physical and psychological burden [14], experienced as an acute effect at the time of an exacerbation and as a long-term impact on patients' lives [15]. Patients adapt to living with COPD in different ways; two common strategies may be classified as "hiding", where patients feel unable to continue with normal activities, and "battling", where patients struggle to continue normal activities [16]. In addition to the compromises and lifestyle adjustments made by individuals with COPD in order to cope with their condition, there can be a substantial impact on those who care for them [17], with many factors contributing to psychological distress [18].

Although there is some crossover between asthma and COPD treatment options, the goals of treatment vary between the conditions, as will patients' perceptions of these treatments. Treatment for asthma, for example, aims to achieve symptom control and minimize the risk of exacerbations and side effects [4]. As COPD represents a spectrum of disease phenotypes, a different treatment regimen may be required for each individual [2].

Many patients with asthma and COPD find it difficult to adhere to prescribed treatment [4, 19]. The most reliable predictor of adherence in asthma is whether or not patients have regular consultations with clinical experts [20]. However, improved adherence has also been associated with less complex treatment regimens in COPD [21] and, similarly, with once-daily regimens in mild-to-moderate asthma [22, 23]. To improve adherence, it is important to understand the value of therapeutic benefits from the perspective of patients with asthma or COPD.

This qualitative study is the first step of a research initiative to improve the management of asthma/COPD through understanding patients' perspectives and quantifying the impact/importance of patient-determined treatment benefits. In the study reported here, interviews and focus groups were conducted to explore the symptoms, impacts, and features of

treatment important to individuals with asthma or COPD. The objective was to identify COPD- or asthma-related factors (such as burden, priorities, individual unmet need, and treatment goals) that may be used to determine patient-defined treatment benefits. A small cohort of clinical experts were interviewed to reveal how their perceptions compare with those of individuals with COPD/asthma.

METHODS

Study Population

Participants with a self-reported physician diagnosis of asthma or COPD were recruited via a recruitment agency (Global Perspectives™, London, UK) from clinical expert referrals, support groups, consumer networks, and a database of individuals who had previously taken part in research or expressed interest in doing so. Key inclusion criteria were a current diagnosis of asthma or COPD, currently receiving treatment for asthma or COPD, age at least 18 years, current UK residency, adequate written and oral fluency in English, and ability to participate in a focus group or interview. Individuals were excluded if they had an acute illness, cognitive impairment, or comorbidity that would interfere with study requirements or inhibit the ability to provide informed consent or allow participation in an interview.

Recruited clinical experts were registered clinicians in the UK, specializing in respiratory medicine, currently treating patients with asthma and/or COPD, and without any financial interest in a pharmaceutical company. Clinical experts were recruited via Global Perspectives™, using a database of individuals who had previously taken part in research or expressed interest in doing so.

Institutional review board approval (Salus IRB, protocol number 0018-0637) was obtained prior to commencing recruitment. Informed consent was obtained from all participants; participants gave consent to be in the study and for anonymous quotes to be used in reporting of study results, prior to study initiation. The study was conducted in accordance with the applicable version of the Declaration of Helsinki [24].

Qualitative Telephone Interviews for Individuals and Clinical Experts

All individual interviews were conducted by telephone by an experienced interviewer (ICON PRO; based in Oxford, UK, at the time of the study), and lasted approximately 1 h.

Focus Groups

The focus groups were conducted face-to-face and lasted approximately 2 h. Participants were invited to attend one of two to three focus group sessions per condition (at most five participants in each focus group). One asthma focus group comprised people aged 18–23 years, to determine whether the experience and views of younger asthmatics reflected those of older participants with asthma. Each focus group was facilitated by an experienced interviewer and took place in person at UK research facilities in London ($n = 3$), Birmingham ($n = 2$), and Manchester ($n = 2$).

Data Collection from All Interviews and Focus Groups

Prior to individual interview questions, participants were asked sociodemographic and clinical background questions via paper-completed questionnaires. Interviews were conducted according to approved semi-structured interview guides, which included key questions and items that were identified from a preceding literature review. Interviewers were allowed the flexibility to adapt the questioning for each participant; consequently, some questions were not asked of every participant. Responses were collated for five main areas of interest: experience of symptoms and their impact on daily life, satisfaction with current treatment, aspects of treatment that are important, adherence to medication, and ideal treatment. A full description of the areas covered in the interviews is included in the Supplementary Appendix. Participants were financially compensated following the completion of each interview and focus group.

Individuals self-reported their disease severity for descriptive purposes only. All participants with asthma who completed the focus groups

and individual interviews were asked to complete the Asthma Control Test™ (ACT; GSK, Brentford, UK) [25]; due to licensing requirements of the test, participants were required to return it by post after their interview. The ACT scoring range is 0–25 with scores of 19 or less indicating poorly controlled asthma [26]. To assess the impact of COPD on quality of life, all participants with COPD, who took part in both the focus groups and individual interviews, were asked to complete the COPD Assessment Test™ (CAT; GSK, Brentford, UK) at the time of interview. The CAT scoring range is 0–40, with scores greater than 20 considered to represent high impact on individuals' health [27].

Analysis Methods

Interviews and focus groups were recorded and transcribed verbatim. Descriptive statistics were used to summarize the sociodemographic information. Thematic analyses were conducted using the qualitative data analysis software MAXQDA (<http://www.maxqda.com/>; VERBI GmbH, Berlin, Germany): data were coded to reflect interview and focus group content, codes were then grouped into themes and sub-themes. During the course of the analysis, data and coding were re-examined to confirm and identify additional themes as appropriate until themes were saturated (no formal theme saturation analysis was performed). Four separate analyses were conducted: for interviews and focus groups for asthma and COPD. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1964, as revised in 2013. Informed consent was obtained from all patients for being included in the study.

RESULTS

Participant Characteristics

Overall, 72 patients with a self-reported physician diagnosis of asthma or COPD participated

in the study: 39 participants had asthma, while 33 participants had COPD; participants' sociodemographic and clinical characteristics are presented in Table 1. The mean age of the asthma population was 35.5 (standard deviation [SD] = 13.4) years and the mean age of the COPD population was 60.2 (SD = 13.9) years. Most participants with asthma were non-smokers ($n = 26$; 67%), while most participants with COPD were current or ex-smokers ($n = 18$; 55%).

Most participants with asthma (77%) considered themselves to have at least moderate asthma. For participants who completed the five-item ACT [25] within 3 months of their interview or focus group ($n = 21$, 54%), the mean score was 16.95 (SD = 4.68), indicating that participants' asthma was poorly controlled [25]. For COPD, 91% of participants considered themselves to have at least moderate disease; the mean score on the eight-item CAT was 24.68 (SD = 9.06), indicating high COPD impact [28].

Participants with asthma were taking an average of 2.14 (SD = 1.15) medications to treat their condition; the most frequently taken medications were short-acting β_2 -agonists (SABAs; $n = 30$; 76.9%), inhaled corticosteroids (ICS)/long-acting β_2 -agonists (LABAs; $n = 16$; 41.0%), and ICS ($n = 13$; 33.3%). Participants with COPD were taking an average of 2.63 (SD = 0.94) medications to treat their condition; the most frequently taken medications were SABAs ($n = 25$; 75.8%), ICS/LABAs ($n = 17$; 51.5%), and long-acting muscarinic antagonists ($n = 14$; 42.4%).

Participant Responses

Four focus groups were conducted for asthma (18 participants in total) and three focus groups were conducted for COPD (15 participants in total). Individual interviews were conducted for 39 participants in total ($n = 21$, asthma; $n = 18$, COPD). Participants' quotes, from which themes were identified, are reported in full in Tables S1–S4.

Table 1 Participant characteristics

Characteristic	Focus groups		Individual interviews	
	Asthma (<i>n</i> = 18)	COPD (<i>n</i> = 15)	Asthma (<i>n</i> = 21)	COPD (<i>n</i> = 18)
Age, mean (SD)	33.83 (14.01)	54.47 (14.43)	36.86 (12.93)	65.88 (11.61)
Gender, <i>n</i> (%) female	9 (50.00)	8 (53.33)	14 (66.67)	10 (55.56)
Ethnicity, <i>n</i> (%) white	14 (77.78)	13 (86.67)	21 (100.00)	18 (100.00)
Employed full time, <i>n</i> (%)	10 (55.56)	5 (33.33)	8 (38.10)	4 (22.22)
Retired, <i>n</i> (%)	1 (5.56)	5 (33.33)	3 (14.29)	10 (55.56)
Smoking status, <i>n</i> (%)				
Smoker	3 (16.67)	4 (26.67)	2 (9.52)	1 (5.56)
Ex-smoker	4 (22.22)	2 (13.33)	4 (19.05)	11 (61.11)
Median year of diagnosis	1997	2010	1994	2011
Self-reported severity, <i>n</i> (%)		^a		
Mild	4 (22.22)	2 (14.29)	5 (23.81)	1 (5.56)
Moderate	9 (50.00)	7 (50.00)	11 (52.38)	11 (61.11)
Severe	5 (27.78)	5 (35.71)	5 (23.81)	6 (33.33)

COPD chronic obstructive pulmonary disease, SD standard deviation

^a *n* = 14

Symptoms: Participants with Asthma or COPD

“Breathing difficulties” was reported as the worst aspect of asthma by a fifth of participants, while “breathlessness” was reported by more than a quarter of individuals as the worst aspect of COPD (Fig. 1). These aspects were also amongst the most frequently reported symptoms by participants with asthma or COPD; “shortness of breath” was the most frequently reported symptom for both conditions (Table 2, Table S1).

Participants revealed more about their symptoms during an individual interview than in a focus group; for example, “shortness of breath” was reported at higher frequencies when assessed by qualitative interview, than by focus group (Table 2).

Of note, participants discussed the impact of symptoms, specifically the limitations or restrictions that these placed on their daily lives,

rather than the symptoms in isolation. These impacts are described in further detail below.

Physical Impact and Coping: Participants with Asthma or COPD

A number of QoL impacts were reported by participants with asthma or COPD (Table 3, Table S2); the most frequently reported areas of impact related to physical activities. Participants with asthma typically reported that any physical activity had to be done with a degree of moderation, or that they simply were not able to do things they might have done previously. Many participants with COPD perceived the worst aspect of their condition to be limitations in their ability to carry out physical activities, while a fifth of participants with asthma considered the need to moderate their behavior to be the worst aspect of their condition (Fig. 1).

Particular impacts of asthma included the ability to sleep, participation in physical

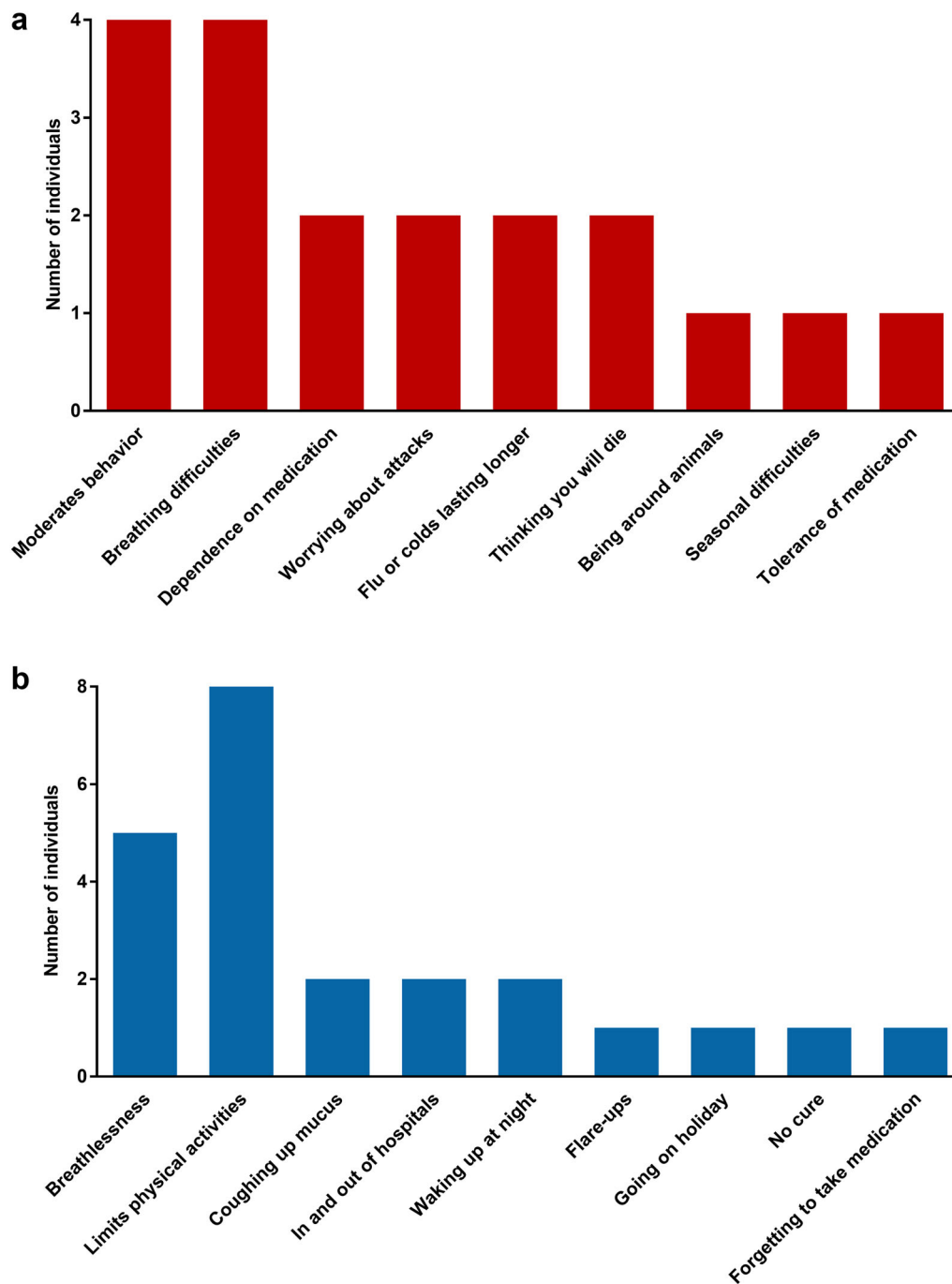


Fig. 1 Participants’ views of the worst aspect of **a** asthma ($n = 20$) and **b** COPD ($n = 18$)

activity, and the ability to socialize (Table 3). Particular areas impacted by COPD were the ability to sleep, everyday functioning (basic activities such as walking or climbing stairs), and the ability to socialize (Table 3).

There were some differences in the way that participants with asthma and those with COPD described the impact of their symptoms. For example, descriptions of shortness of breath (the most common symptom reported)

Table 2 Frequency of symptoms reported by participants

Symptom, <i>n</i> (%)	Focus groups		Individual interviews	
	Asthma (<i>n</i> = 18)	COPD (<i>n</i> = 15)	Asthma (<i>n</i> = 21)	COPD (<i>n</i> = 18)
Shortness of breath	7 (38.89)	9 (60.00)	20 (95.24)	18 (100.00)
Coughing	4 (22.22)	8 (53.33)	14 (66.67)	17 (94.44)
Coughing up mucus	0	7 (46.67)	3 (14.29)	13 (72.22)
Chest tightness	4 (22.22)	6 (40.00)	14 (66.67)	13 (72.22)
Wheezing	7 (38.89)	5 (33.33)	18 (85.71)	14 (77.78)
Tiredness	0	3 (20.00)	2 (9.52)	5 (27.78)
Lack of energy	0	2 (13.33)	2 (9.52)	5 (27.78)
Chest infections	0	0	2 (9.52)	12 (66.67)
Back/chest/lung pain	0	0	6 (28.57)	3 (16.67)
Flare-ups	0	0	12 (57.14)	0

COPD chronic obstructive pulmonary disease

reflected a greater physical impact with COPD but more unpredictability and anxiety with asthma. One participant with COPD talked about having to plan ahead to arrive at places early because they will be out of breath and another described being worried about getting out of breath very easily. Shortness of breath impacted the distance that participants with COPD could walk and also their everyday activities such as getting dressed, talking, or sleeping; illustrative quotes are included below:

“Now, when I’m lying in bed and I’ve been out of breath, all of a sudden, it’s like your heartbeat, it goes quieter and quieter and you’re thinking, now that’s great, why do I have to keep panicking, fighting for me breath?” (Focus Group, P18)

“Like it’s just you’re talking and then you’re out of breath and you get up and go to do anything, it’s an effort, no. Just that it changes your life completely, put it that way” (Interview, P30)

By contrast, participants with asthma discussed the impact of shortness of breath with respect to the triggers of their exacerbations and their ability to undertake normal activities, including exercise; illustrative quotes are included below:

“And with me it’s like, shortness of breath on a day-to-day basis, but like the winter, during the winter, I have that sharp tightness in my chest and that wheeziness, so it’s first thing in the morning and at night. And I’ve got to get the kids off to school, that’s when the short of breath gets worse in the morning, and the school run.” (Focus Group, P11)

“And yeah, like trying to play football and I start wheezing. It’s impossible like, you just, you start and then you just have to, yeah, go nuts and then just try and get through it. Yeah, it’s pretty much the same thing, it’s just the shortness of breath, the coughing. You just can’t get as much like air into your lungs.” (Focus Group, P06)

Participants also discussed their coping strategies, which could be classified into two main themes: struggling to continue normal activities or avoidance of activities (Table S2).

Emotional Impact and Coping: Participants with Asthma or COPD

Beyond the physical impact of symptoms, the emotional impact of each condition was assessed (Table S2). Participants with asthma or

Table 3 Areas where participants reported an impact of their condition

Area affected, <i>n</i>	Focus groups		Individual interviews	
	Asthma (<i>n</i> = 18)	COPD (<i>n</i> = 15)	Asthma (<i>n</i> = 21)	COPD (<i>n</i> = 18)
Physical				
Exercise/activities/sport	16	12	15	10
Functioning (walking/stairs)	4	3	12	17
Housework/gardening	0	3	3	10
Work/study	2	3	4	3
Sleep	14	8	16	16
Emotional				
Sadness/depression/anxiety	4	5	3	6
Embarrassment/stigma/self-consciousness/identity	14	13	9	8
Fear/panic	8	9	8	0
Fear of the future	3	3	0	0
Social				
Social life	5	3	8	9
Inability to plan	0	1	3	0
Lifestyle	0	0	8	0
Other issues, e.g., pets/smoking	5	4	3	0

COPD chronic obstructive pulmonary disease

COPD reported a combination of embarrassment, anxiety, depression, fear, and sadness as a result of their condition (Table 3).

In the asthma focus groups, feelings of self-consciousness were reported in relation to not wanting to use an inhaler in front of others, embarrassment from symptoms, feeling stigmatized, feeling judged, and being singled out as different. Participants also reported feelings of fear or panic in relation to sensing that their inhaler was not working, symptom exacerbation, and thinking that they might die because of the experience of symptoms. In interviews, some participants mentioned feeling social isolation as they are stared at in public when they cough or breathe heavily. They reported simply wanting to feel like others. Patients reported that they felt vulnerable without having

inhalers at hand and that this may lead to psychological dependence.

The emotional impact of COPD included feelings of embarrassment (related to audible wheeze or uncontrollable coughing) and fear (panicking as symptoms worsen, which in turn could make symptoms worse and being frightened of the condition). Denial was another issue, relating to participants being embarrassed by the condition and wanting to feel normal. Four participants in the COPD focus group discussed having some psychological difficulties, related to fear, anxiety, or depression. The emotional impact of COPD discussed by participants during interviews included feeling sad or depressed because of not being able to do things, feeling embarrassed by symptoms such as coughing, feeling useless or hopeless at not

being able to do the same activities as other people in their age group, and nervous or apprehensive.

Treatment: Participants with Asthma or COPD

Sleep was rated as an important aspect of treatment by many individuals with asthma or COPD (Table 4). More individuals with asthma than COPD reported additional concerns about treatment, including “length of relief”, “speed of action”, and “ease of use” (Table 4; Table S4).

Adherence to prescribed treatment was frequently discussed in all of the focus groups. Reasons for adherence in both conditions included individuals not being able to manage without their medication, noticing deterioration if doses were missed, following their doctors’ recommendations, having a desire to

maintain their lifestyle, and fears of hospitalization or symptoms returning.

Reasons for non-adherence, which were discussed more widely by individuals with asthma than COPD in the focus groups, included wanting to feel in control and not having to depend on medication, reducing the cost of prescriptions, and the belief that they could miss doses without symptom recurrence (Table S4).

Participants generally preferred a treatment that would solve the symptoms and impacts mentioned above for each condition. Individuals with asthma or COPD most frequently reported “sleep”, “speed of action”, and “length of relief” as factors to consider for an ideal treatment (Fig. 2).

Individuals with asthma reported a strong preference for treatments that were easy to use; this was less of a concern for individuals with COPD (Fig. 2).

Table 4 Summary of participants’ preferences for treatment

Aspect of treatment, <i>n</i>	Focus groups		Individual interviews	
	Asthma (<i>n</i> = 18)	COPD (<i>n</i> = 15)	Asthma (<i>n</i> = 21)	COPD (<i>n</i> = 18)
Sleep	6	5	10	11
Length of time symptom-free	0	4	12	5
Effectiveness	0	2	0	0
Frequency of dosage	0	1	6	0
Side effects	0	1	1	7
Ease of use of inhaler	0	0	17	1
Speed of action	5	0	14	8
Reliability	2	0	0	0
Impact on children	2	0	0	0
Cost of treatment	1	0	0	0
Wanting to be “normal”	1	0	0	0
Ability to exercise	1	0	0	0
Reduced number of medications/frequency of renewing inhalers	0	0	2	0

COPD chronic obstructive pulmonary disease

Perspective of Clinical Experts on Impact of Asthma or COPD and Current vs. Ideal Treatment

The views of clinical experts with experience of treating asthma ($n = 2$) or COPD ($n = 2$) were also sought for comparison with those of the participants with each condition (Table S3). Clinical experts considered the most

debilitating symptom for patients with asthma or COPD to be breathlessness; the impact on sleep was noted to a similar extent as the impact on social life. Self-consciousness was anticipated to be a problem for patients with asthma but was not mentioned in relation to COPD. Overall, the clinical experts were aware that many areas of individuals' lives were affected by their condition; however, the impact of symptoms

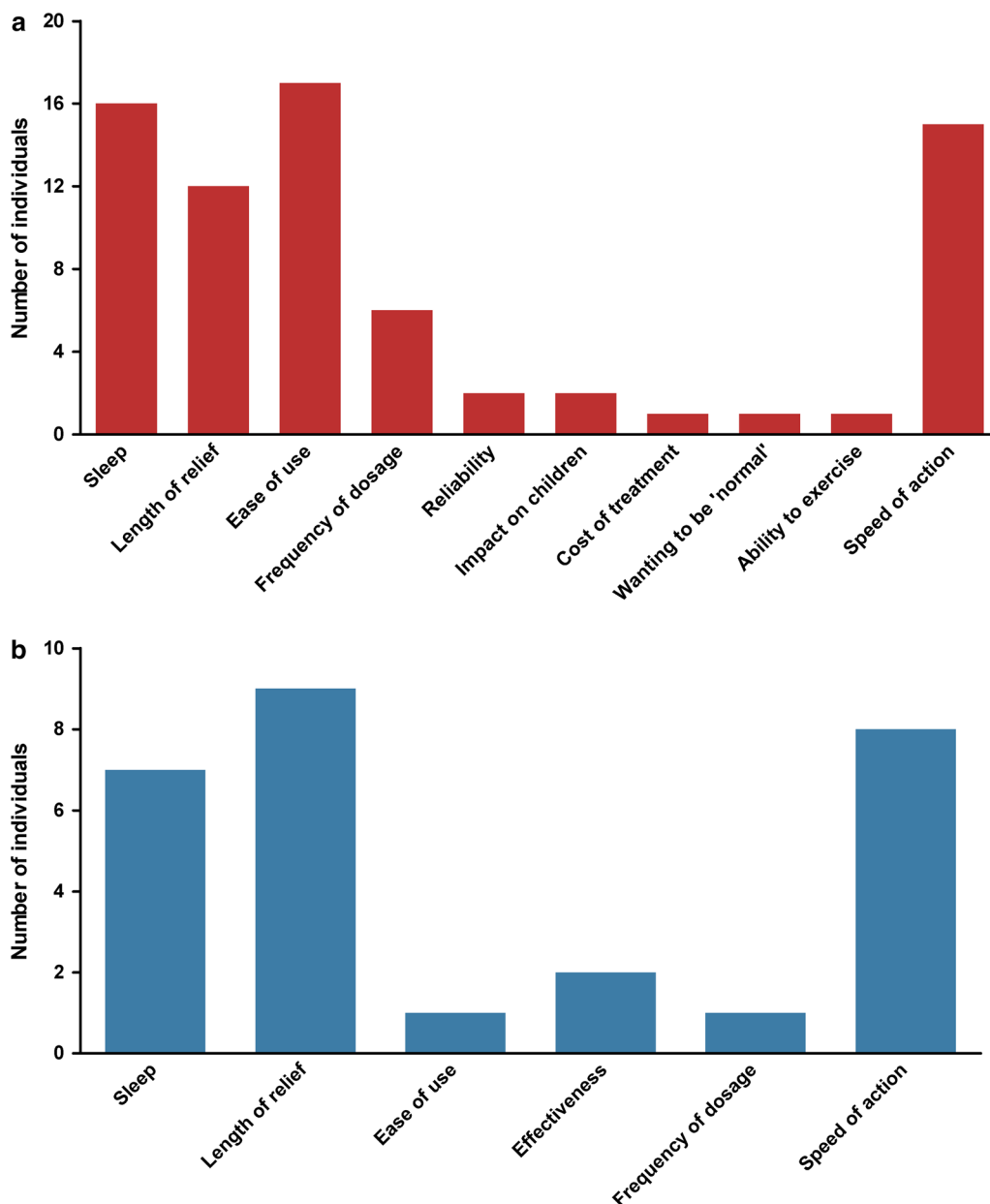


Fig. 2 Ideal factors of treatment for **a** asthma ($n = 33$) and **b** COPD ($n = 33$)

on individuals' physical abilities was not mentioned, or they were not discussed to the same degree.

Factors that clinical experts considered important in the treatment of asthma included a long duration of effect and reliability of symptom control, to ensure patient confidence. The ability to prevent lung function decline in COPD was of paramount importance to clinical experts, followed by the ability to control individuals' symptoms (Table S3).

DISCUSSION

Main Findings

Our series of interviews and focus groups confirmed that when discussing their condition individuals with asthma or COPD have a tendency to focus on life impact, rather than symptoms per se. In contrast, when clinical experts were asked about how the conditions affected patients, they tended to focus on symptoms, and not the impact of symptoms on patients' lives.

Interpretation of Findings in Relation to Previously Published Work

In our study, the most commonly reported symptoms in both asthma and COPD were shortness of breath, cough, chest tightness, and wheezing. Recent qualitative analyses report the same most frequently reported symptoms in asthma [29], and shortness of breath and cough in COPD [30]. In our study, breathing difficulties or breathlessness was most frequently reported as the worst aspect of asthma or COPD, as previously reported [29, 30]. These symptoms may, however, have diverse impacts on individuals' lives.

Physical activity and disturbed sleep were the physical areas most frequently impacted by both asthma and COPD in this study, similar to previous reports [29, 31]. The emotional impacts of each condition were represented by fear, depression, and embarrassment of their condition and/or of inhaler usage in public,

with several individuals feeling a stigma attached to the latter in particular.

Participants' perceptions of the burden and impact of asthma and COPD were broadly similar; however, there were some differences between the conditions. Asthma appeared to have a more decisive impact on lifestyle than COPD did; specifically, individuals with asthma expressed a greater degree of fear or panic and were more concerned about triggers, possibly because of the unpredictable nature of asthma exacerbations. Anxiety disorders are common in patients with asthma and are known to influence use of primary care health resources and perceptions of life impairment due to asthma [32]. Such concerns had an impact on participants' lifestyles: individuals with asthma often felt unable to carry out activities that they had done previously (leading to avoidance), while individuals with COPD were more likely to pace themselves (adjustment). Individuals with asthma expressed a stronger desire to lead a normal life than individuals with COPD, while slightly more participants with COPD than asthma reported emotional impacts, such as sadness or depression; this was expected as the prevalence of depression is known to be higher for individuals with COPD than the general population [33].

Most participants expressed confidence in their treatment, with high reported adherence to prescribed therapy (asthma: $n = 11$, 61%; COPD: $n = 12$, 80%), which differs to published rates (asthma: 22% to 63% adherence in a systematic analysis [34]; COPD: 23% to 43% adherence in a retrospective analysis of real-world medication use [21]). This discrepancy may reflect interviewer effects; however, self-reported adherence is frequently higher than actual adherence levels in pediatric asthma [35, 36] and a similar trend may also prevail in adult patients with asthma or COPD.

Individuals' treatment preferences tended to center on what they considered to be the most important impacts or limitations, and wanting a treatment that would address those issues. Specific treatment preferences for both conditions included improved "sleep", "speed of action", and "length of relief". "Ease of use" was particularly important in asthma to facilitate

use during an exacerbation, suggesting that this aspect should be prioritized in the design of novel treatments for asthma. Several participants mentioned concerns about effective use of their inhaler device, indicating that individual instruction is also needed and should be considered by clinical experts when prescribing.

The impacts of asthma and COPD that clinical experts generally perceived to be important were not necessarily reported by the participants with these conditions. As a result of the small number of clinical experts in this study their views must be considered as illustrative only; however, clinical expert assessments and patient-reported outcomes frequently fail to correlate [37], particularly in COPD [38]. In the present study, there were notable exceptions to the impacts that clinical experts mentioned, such as impacts on physical abilities in both conditions and feelings of self-consciousness in COPD. The experts interviewed may not have been fully aware of the reported impacts, as there is a well-known clinical bias towards focusing on symptoms as opposed to life impact (e.g., the impact of COPD symptoms at night on other areas of patients' lives, such as their ability to get up for work, may not always be appreciated [39, 40]).

An additional insight of our study was that symptoms were discussed less within the focus group setting than in the individual interviews (although symptoms were perceived as important in both contexts). The interview format should thus be considered when designing future research so that questions may be asked directly, and for participants to be able to respond to questions comfortably and openly.

Strengths and Limitations of This Study

The strengths of this study included the adoption of a patient-centric perspective, allowing for a deeper understanding of the lifestyle impact and restrictions these patients face, having a large sample size for the qualitative methodology, and the use of thematic analysis using MAXQDA [41], a rigorous and transparent qualitative analysis approach that is well suited to qualitative patient-reported outcomes

research [42]. Additionally, comparable to most studies assessing outcomes in clinical practice and outside a randomized controlled trial context [13], all participants in this study reported a physician diagnosis of asthma or COPD.

There are some limitations to our study. Firstly, a moderate limitation in assessing disease severity in this study was the requirement for ACT reporting after the asthma interviews and focus groups. Consequently, many questionnaires were returned several months after the interviews were conducted and there was a high proportion of incomplete responses. As a result, ACT scores may not have accurately reflected each individual's disease control at the time of interview; however, the themes, symptoms, and impact described seem fairly typical of asthma patients in general [29]. The ACT and CAT data were collected for descriptive purposes only. However, given the difference in proportion of completed ACT and CAT questionnaires it was not considered appropriate to stratify participants' responses according to severity of asthma or COPD.

Secondly, although it would be interesting to correlate individuals' assessments of their condition with actual disease severity, this was difficult to ascertain in our qualitative study. For example, there was a generally high level of severity recorded by ACT and CAT in our study population. The ACT and CAT used in this study are widely used tools, recommended for measurement of asthma and COPD severity [2, 4]. In our study, the mean ACT score was 16.95, indicating more poorly controlled asthma than in large cohorts from Australia and the USA (with mean ACT scores of 19.2 and 18.6, respectively) [43, 44]. Similarly, the mean CAT score in our study was 24.68, indicating a higher impact of COPD on participants' lives than in the recent UK Salford Lung Study COPD population (where the mean baseline CAT scores were 22.05 in the usual care group and 20.97 in the fluticasone furoate/vilanterol group) [45]. In future analyses it would be useful to validate our findings in a cohort of participants closely representative of the general population for asthma and COPD severity.

There was also an unusually high proportion of participants with COPD who did not report a

history of smoking, particularly in the focus groups (9/15 focus-group participants and 6/18 interview participants with COPD reported never smoking). As information on smoking history was self-reported, participants' responses may have been influenced by social desirability, such as a perceived stigma of smoking, and may not accurately reflect their smoking histories. Comparisons of self-reported smoking with serum cotinine levels have shown that although self-reported smoking statuses are typically accurate for individuals reporting never smoking or current smoking, former smokers are likely to under-report their smoking history (particularly for conditions where a causal link of smoking is well known; discrepancies have been reported for approximately 10% of former smokers with polycystic ovary syndrome [46] and over 50% of former smokers with lung cancer [47]). We do not consider that participants' reported experiences of COPD symptoms and impact in our study would have been affected by any under-reporting of their smoking histories.

From this qualitative sample it is difficult to generalize these results to a "typical" asthma or COPD population, yet the reported symptoms are fairly typical for asthma and COPD on the whole [29, 30], suggesting a balanced sample in this respect.

Implications for Future Research

The aim of this analysis was to identify themes that will be used to inform the design of a subsequent, larger study, powered to quantitatively capture representative responses of patients with asthma or COPD.

CONCLUSIONS

Individuals with asthma or COPD experience substantial limitations to their QoL, and tend to focus on these limitations rather than symptoms as such, which may have implications beyond the disease impact commonly appreciated by clinical experts. Therefore, it is important for clinicians to discuss the impact of asthma or COPD on individuals when

prescribing treatment. Individual preferences for treatment are also an important consideration for the most beneficial design of future therapies. The considerations identified in this first qualitative phase of the study will be applied to a subsequent detailed discrete choice experiment survey, which will be reported in a future manuscript.

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Compliance with Ethics Guidelines. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation

(institutional and national) and with the Helsinki Declaration of 1964, as revised in 2013. Informed consent was obtained from all patients for being included in the study.

Data Availability. Access to the datasets supporting the conclusions of this manuscript may be obtained via <https://www.clinicalstudydatarequest.com/>.

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