




# “I have lost in every facet of my life”: the hidden burden of severe asthma

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**Severe asthma imposes long-term, debilitating burdens requiring additional support services for patients and carers** <http://ow.ly/grpE30db5FR>

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**ABSTRACT** People with severe asthma are thought to face a sizeable daily disease burden. This study aimed to explore the little-known life experiences of people living with severe asthma.

Adults with severe asthma were invited for telephone interview. Semistructured interviews were conducted until no new themes emerged. The 25 interviews were recorded, transcribed and analysed thematically.

Four themes emerged. 1) “The body as a hindrance”: severe asthma placed broad limits on life from daily chores to career, relationships and family life that left interviewees feeling emotionally distressed. 2) “Burden of treatment”: participants mostly accepted the need to take treatment, but were particularly concerned about side-effects of oral corticosteroids. 3) “Alone with asthma”: interviewees felt misunderstood and alone in their experience of breathlessness and frightening exacerbations; practical and emotional support needs were often lacking and the emotional distress of severe asthma was amplified in those with little support. 4) “Striving to adapt”: patients used both positive strategies (acquiring self-management skills) and less positive strategies (avoidance of physical exertion) in the process of adjustment to living with severe asthma.

Severe asthma imposes long-term, debilitating burdens and should be considered differently to milder disease. There is an urgent need to improve practical and emotional support services for patients and their carers.

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## Introduction

*I have lost in every facet of my life. You know, my earning capacity, my self-esteem, my sense of achievement, my relationships. You name it, it's been there. And my asthma has been this severe all of my life.* (Rhonda, female, 54 years)

Asthma is one of the most common chronic conditions worldwide. For most patients with asthma, symptoms can be well controlled and exacerbations prevented with inhaled therapy. However, an estimated 5–10% of patients have “severe asthma”, which is defined by the presence of persisting symptoms, airflow limitation and/or exacerbations despite high-dose conventional treatment, or that is only well controlled during high-dose treatment; it is thus often referred to as “severe refractory asthma” [1]. Specialist assessment is required for its diagnosis, since uncontrolled asthma can also be caused by problems such as misdiagnosis, incorrect inhaler technique and poor adherence [2, 3].

Severe asthma is heterogeneous in its characteristics and causes, but quantitative data indicate that people with severe asthma face a consistently heavy burden with daily symptoms such as cough and dyspnoea and frequent exacerbations often requiring hospitalisation compared with patients with milder disease [4–7]. Patients are usually prescribed high-dose inhaled corticosteroids, often with additional short- or long-term oral corticosteroids [7]. These treatments carry the risk of adverse effects that have varying impacts on patient quality of life and health status, including weight gain, sleep disturbance, depression and osteoporosis [8].

Little is known about the life experiences of people with severe asthma [9–12]; however, given the high symptom burden and the failure to adequately respond to conventional treatment, patients' experiences are likely to be different from those of patients with milder disease.

The aim of this study was to explore, in patients' own words, their personal experiences of life with severe asthma. Qualitative methodology is indicated for this type of research as it provides a level of contextualisation and immersion in the individual's life experience that facilitates understanding [13]. We aimed to describe the emotional and practical burdens of severe asthma, and to identify support needs to help health professionals and policy makers be aware of and respond to the needs of people with severe asthma.

## Material and methods

### Study design

This was a qualitative study of the experiences of adults with severe asthma, utilising in-depth, semistructured interviews.

### Recruitment and selection

Participants with severe asthma aged  $\geq 18$  years were identified *via* the AustralAsian Severe Asthma Research Registry (established by the AustralAsian Severe Asthma Network). For entry into the registry, participants are required to have satisfied guideline-based criteria for severe asthma [1]. As the Registry did not include patients from all areas of Australia, we also recruited participants *via* respiratory specialists involved in managing patients with severe asthma and provided them with a letter summarising the guideline-based criteria (supplementary material A1). Patients were excluded if they were participating in an intervention study, an observational study involving more than one study visit or had finished an intervention study <12 months ago. The treating physician provided the patient with written study information and a consent form; the patient contacted the study coordinator to indicate their interest. Patients who completed and returned the consent form provided basic demographic data by telephone to facilitate purposive sampling, which aimed to achieve diversity in terms of age, sex, socioeconomic status and geographic location (state).

### Data generation

The demographic data collected prior to the interview included currently prescribed respiratory medications, age at asthma diagnosis, number of asthma-related emergency department visits and hospital admissions in the last 12 months, smoking status (Do you smoke?/Have you smoked in the past?), living status (Who lives in your household with you?), age, sex, postcode (to establish location and estimate socioeconomic status) and symptom control by the Asthma Control Test [14].

All interviews were conducted by telephone by J.M.F. and were audio recorded. Participants were assured that the interview would be kept strictly confidential. Our interview guide (supplementary material A2) aimed to explore: 1) the impact of severe asthma on the quality of life of patients and their family/friends, 2) day-to-day management of severe asthma and its challenges, and 3) experience of exacerbations. Field notes were taken immediately after each interview to record emergent themes, the situational context

and/or new topics for follow-up in subsequent interviews. Using an iterative process, we revised the interview guide after the fourth interview to include two new items that had emerged as important: 1) childhood experiences of asthma and 2) a typical day with asthma (supplementary material A2). Interviews continued until no new themes emerged.

**Analysis**

Recordings were transcribed verbatim, and the transcripts were anonymised and entered into NVivo version 11 (QSR International, Doncaster, Australia) to aid data management and coding. We analysed the data thematically beginning with familiarisation (reading/re-reading transcripts, field notes) and analytic memoing [15]. J.M.F. performed initial descriptive coding, which later progressed to inductive pattern coding and synthesis of data into themes and subthemes [16]. Themes were repeatedly checked to ensure they represented the content of the interviews. The analysis was carried out iteratively, as each new interview was completed. Cross-case comparison and charting/mapping were applied to assist interpretation, and negative evidence and rival explanations investigated. To enhance the rigour of the analysis, an audit trail was constructed [17]; two co-authors (J.M.F. and H.K.R.) met regularly to discuss each step of the analysis and themes were discussed frequently with other clinical colleagues.

**Ethical considerations**

The University of Sydney’s Human Research Ethics Committee approved the study protocol (2014/486). All participants gave written informed consent.

**Results**

Participants (n=25) from a wide geographic distribution (age range 23–81 years; 68% female, 48% living in a socially disadvantaged location) were interviewed (table 1). Many reported experiencing debilitating symptoms including shortness of breath, chest tightness, cough and interrupted sleep, in a pattern of either daily symptoms or a combination of good and bad symptom days, together with sudden-onset attacks (supplementary material A3).

Four themes (summarised in tables 2–5 with additional detail in supplementary material A4) described the main results: “The body as a hindrance”, “Burden of treatment”, “Alone with asthma” and “Striving to adapt”. Illustrative quotes are presented with a pseudonym, sex and age of interviewee.

**Theme 1: “The body as a hindrance”**

Participants described hindrances that were “Personal” (predominantly impacting the self), “Interpersonal” (concerning interaction with others) and “Extrapersonal” (affecting the participant’s inclusion in wider society). The burden of these hindrances tended to mirror the pattern of the participant’s asthma symptoms, from persistent, daily limitations to symptom-free many days a year. See table 2 and supplementary material A4.

TABLE 1 Participant demographics

<b>Subjects</b>	25 <sup>#</sup>
<b>Age years</b>	54 (23–81)
<b>Female/male</b>	68/32
<b>Smoking status current/past/none</b>	0/64/36
<b>Living alone or with children/with partner or other adult</b>	20/80
<b>Living in a socially disadvantaged area<sup>¶</sup></b>	48
<b>Living in a regional location, outside a major city<sup>*</sup></b>	16
<b>Age asthma diagnosed years</b>	17 (1–50)
<b>Daily prescribed inhaled corticosteroid dose µg<sup>§</sup></b>	1600 (1200, 2400)
Also prescribed omalizumab	32
<b>Asthma Control Test score<sup>f</sup></b>	16 (12, 19)
<b>One or more hospital admissions in last 12 months</b>	36

Data are presented as n, median (range), % or median (upper, lower quartile). <sup>#</sup>: living in state: New South Wales/Australian Capital Territory 44%, Victoria 20%, Queensland 12%, South Australia 8%, Western Australia 8%, Tasmania 8% [32% AustralAsian Severe Asthma Network-referred]; <sup>¶</sup>: socioeconomic indices for area quintile ≤3 [26]; <sup>\*</sup>: only 10% of Australians live outside major cities [27]; <sup>§</sup>: beclomethasone dipropionate equivalent; <sup>f</sup>: Asthma Control Test scores reflect asthma symptom control over the previous 4 weeks, classified as: 5–15=very poorly controlled, 16–19=not well controlled and 20–25=well controlled [14] [the range of scores in this sample was 7–23; all participants satisfied the European Respiratory Society/American Thoracic Society Task Force criteria for severe refractory asthma [1]].

TABLE 2 Theme 1: “The body as a hindrance”

<b>Personal hindrances</b>	
Physical	“Most housework I can’t do. Can’t vacuum, I can’t do the bathroom or anything like that.” (Nancy, female, 51 years)
Spontaneity	“Running around the oval after my little boy. I have to stop, take some medication, give it 5 minutes, then chase him. I can’t just go ‘Let’s go now!’ you know.” (Stephanie, female, 38 years)
Independence	“[I’d like to] enjoy my day, being able to do the things I can’t do, and not having to depend on anybody.” (Katherine, female, 59 years)
<b>Interpersonal hindrances</b>	
Socialising	“People are offended if you say you can’t come to a dinner ... I guess it’s fair to say there’s some friends who won’t ask me to things [anymore].” (Paul, male, 62 years)
Relationships	“He loves camping but I can’t go where you can’t get phone reception. And the sex [is unattractive due to shortness of breath] ... And yeah that relationship, it’s gone to crap [sic].” (Casey, female, 48 years)
Parenting	“When my kids were young I really couldn’t play with them all that much.” (Larry, male, 54 years)
<b>Extrapersonal hindrances</b>	
Career choice	“I was knocked back [from nursing] due to my asthma. And that would probably have been the hardest thing because it was the only thing I had ever wanted to do.” (Nancy, female, 51 years)
Career discontinuation	“There comes a point where you can’t do the job anymore so you’ve got to get out of there and let someone else do the job.” (Larry, male, 54 years)
<b>Emotional distress</b>	
	“It’s frustrating, upsetting. There’s things I really wanted to do and I haven’t been able to do ... It does make you depressed, because people don’t see the sickness that has happened over my life.” (Brenda, female, 53 years)
	“On some occasions the mind’s there and wants to do it but the body can’t keep up ... and it sort of makes you feel worthless in a way.” (Neil, male, 60 years)

*Personal hindrances*

Participants described many physical limitations of severe asthma, such as the inability to perform even simple household chores, walk far or uphill, or engage in pleasurable activities that required exertion (e.g. sports). They also described loss of spontaneity or independence. Personal hindrances commonly had emotional consequences, with interviewees feeling worthlessness, hopelessness, frustration or self-directed anger.

*Interpersonal hindrances*

Asthma restricted the social lives of participants, with some friends or family taking offence and no longer inviting people with severe asthma socially. Intimate relationships suffered. Interviewees were unable to pursue normal activities, including sex, sometimes resulting in relationship breakdown:

*He loves camping but I can’t go where you can’t get phone reception. And the sex [is unattractive due to shortness of breath] ... And yeah that relationship, it’s gone to crap [sic].* (Casey, female, 48 years)

Participants who were mothers or fathers missed out on desired interactions with their child due to the inability to lift the child or run. Interpersonal hindrances left interviewees feeling loss, guilt, anger or resentment, and their support needs meant family, most often partners, were burdened by additional household and financial responsibilities, at times requiring them to miss work.

*Extrapersonal hindrances*

Career was impacted including ineligibility for certain professions, poor work attendance due to illness or inability to perform certain tasks. Some had to change their occupation, usually reluctantly, to something more suitable for their asthma or give up work completely, resulting in a loss of cherished social interaction and/or support from colleagues.

TABLE 3 Theme 2: “Burden of treatment”

<b>Ambivalence about treatment-taking</b>	
Accepting it	“Well, you’d probably be better never taking anything but that doesn’t work. So if I need to take it I take it ... If you don’t you’ll end up being quite sick and you’ll end up in hospital so you don’t really have much choice.” (Linda, female, 65 years)
Disliking reliance on it	“I mean having to be reliant to take the medication [is something I’d like to change]. I mean number one it’s reasonably expensive ... I suppose the fact is I’ve just accepted that it’s one of those things, but it would be nice not to have to take anything ... it’s a lack of freedom I suppose.” (Cynthia, female, 51 years)
Time-consuming	“Well I know they work but really, it takes so much time to take it all. You just wish that [medicines] were combined ((laughs)). You know, if, even just two of the sprays, if they could just combine those and then the other two combined as well ... I don’t know, I’d just be a freer agent I guess.” (Jacinta, female, 63 years)
<b>Oral corticosteroid adverse effects</b>	
Concern about future severe side-effects	“I’m thinking I’m probably going to get side-effects from the cortisone. The worst thing is you know, you get osteoporosis and I can just fall over or something and break a hip.” (Pamela, female, 60 years)
Concern about very severe side-effects	“I’ve just been diagnosed with Addison’s disease recently which is my adrenal glands have shut down. So that’s from the use of steroids ... Addison’s disease is like, it’s all your hormones in your body and, like it can cause you to have inflamed joints. They did say that because of the Addison’s my appendix is flared up and I’ve just had [it] removed just 2 weeks ago. So you don’t have that ability to fight things, infections. If I cut myself, wound healing takes a lot longer ... I get quite fatigued and all that sort of thing.” (Brenda, female, 53 years)
Concern about changes to physical appearance	“I just came off the prednisone and the pictures are not flattering. I’m embarrassed [about the weight gain] ‘cos I can see that I’m so puffy.” (Rebecca, female, 45 years)

**Theme 2: “Burden of treatment”**

The subthemes “Ambivalence about treatment-taking” and “Oral corticosteroid adverse effects” represented treatment burden. See table 3 and supplementary material A4.

*Ambivalence about treatment-taking*

Interviewees mostly accepted the necessity to take inhaled reliever and preventer therapy, but they disliked the feeling of reliance on it. Some felt inconvenienced by attending regular appointments for injectable biologicals, and the time-consuming and restrictive nature of daily treatment-taking meant that others felt like treatment took over their lives:

*You’re a slave to this regimented ordeal you’ve got to go through every day.* (Larry, male, 54 years)

*Oral corticosteroid adverse effects*

Many were concerned about current and future severe side-effects of oral corticosteroids (e.g. cataracts and osteoporosis) and some experienced serious severe effects such as avascular necrosis or Addison’s disease. Female interviewees particularly expressed embarrassment or unhappiness about side-effects that changed their physical appearance:

*I’m embarrassed [about the weight gain] ‘cos I can see that I’m so puffy.* (Rebecca, female, 45 years)

**Theme 3: “Alone with asthma”**

The subthemes “Being misunderstood”, “Stigma and disclosure”, “Disrupted identity or self-concept” and “Alone with exacerbations” embodied a feeling of misunderstanding and aloneness with severe asthma. See table 4 and supplementary material A4.

TABLE 4 Theme 3: “Alone with asthma”

<b>Being misunderstood</b>	
Confusing severe asthma with fixable milder asthma	“You have all these ads on telly with wonderful Australian cricketers that play world class cricket, and they take their puffer. ‘We have asthma but we can do anything’ ... [People think] ‘So why can’t you do that?’.” (Pamela, female, 60 years)
Resentful partners	“He’s resentful of it. Sometimes I wonder if he really thinks I’m that sick at all, and I know he doesn’t understand.” (Stephanie, female, 38 years)
Emotional distress	“I have struggled with [depression] personally when I have been so, so sick, and I probably struggle with it every day now that I live alone. It’s harder [(becomes emotional)].” (Rhonda, female, 54 years)
General public education to address misconceptions	“I think it needs a bit more publicity. Because when you say to people ‘I’ve got severe asthma’ I think 90% of the population goes ‘Oh yeah, asthma. Every second person has that.’ I don’t think there’s a comprehension there. And you don’t want it as a sob story, but there needs to be that acknowledgement that people with severe asthma are [not mild] asthmatics.” (Stephanie, female, 38 years)
<b>Stigma and disclosure</b>	
Insensitive comments	“I went to a musical with a friend ... she turned to me and said ‘How on earth did you hear any of that? You were wheezing louder than the choir’ ... I felt ‘Gee, well, where do I fit in? Where is my place? Where am I supposed to be?’.” (Rhonda, female, 54 years)
Concealing asthma	“I don’t want to be specialised at all in their eyes, or treated in any different way because I’ve got asthma.” (Steven, male, 71 years)
<b>Disrupted identity or self-concept</b>	
Dissociative thoughts	“[Asthma] isolates you because inside there’s an emptiness or a difficulty with trying to balance with who you really are and what you need to be ... It’s like trying to avoid yourself while maintaining some sense of self.” (Rhonda, female, 54 years)
<b>Alone with exacerbations</b>	
Panic, fear and anticipation of death	“Suffocation. Can’t breathe. Dying. No other way to put it ... Trying to control my breathing, panicking at the same time because I can’t breathe and [thinking] am I going to see the night through?” (Neil, male, 60 years)
Use of cognitive breathing/relaxation strategies	“Even if I have to lay on the bed and just settle, relax, try and breathe, and get it out of my head that it’s my last breath because that’s what panics you.” (Joan, female, 52 years)
Habituation/poor perception of symptoms	“I can cope quite well with very little output if you know what I mean. So you adjust to that level. And you don’t really realise how bad [your asthma] is until someone points it out to you.” (Stephanie, female, 38 years)
Family member’s trauma	“I think it has changed the way [my son] has turned out because he’s sort of a bit of an anxious character now because he saw some terrible things happening to me and he panicked and thought you know, ‘I’m going to lose my mum’.” (Jacinta, female, 63 years)

*Being misunderstood*

Participants felt they were the only ones who could understand what it was like to have asthma. They believed people without asthma thought they were exaggerating their symptoms or hospitalisations, perhaps because asthma was “invisible” or because it was difficult for people without asthma to relate to symptoms such as extreme breathlessness. The general public confused severe asthma with milder asthma that should be easily controlled with conventional inhaled treatment; interviewees considered general public education necessary to address such misconceptions.

While many participants had supportive people in their lives, some described partners who lacked empathy or had become resentful of the long-term debilitations of asthma and the burden of providing support. Inadequate emotional support resulted in substantial emotional distress (e.g. depression) that was

perceived to be poorly recognised by health professionals and especially affected participants living alone. Family education to better understand severe asthma was requested, so family could cope better with participants' asthma-related emotional distress. Some participants felt that provision of mental health support was lacking or poorly delivered but would be beneficial, while others felt it was beyond the role of medical health professionals or unnecessary.

#### *Stigma and disclosure*

Friends or members of the public often made insensitive comments to people with severe asthma. While some participants were comfortable disclosing their asthma, stigma made others feel embarrassed and led them to conceal it and/or their inhaler use in public, in order to appear healthy or avoid being treated differently.

#### *Disrupted identity or self-concept*

Participants described discomfort with repeatedly “being false”, in hiding asthma from friends; they also reported that asthma led them to withdraw socially:

*[Asthma] does make you introverted.* (Jacinta, female, 63 years)

For Rhonda (female, 54 years), the need to constantly fight against the hindrances of asthma had resulted in dissociative thoughts.

#### *Alone with exacerbations*

Most participants had experienced frightening exacerbation symptoms including a feeling of drowning or suffocation; the inability to talk or move during exacerbations delayed calling for assistance. They described extreme panic, fear and anticipation of death. In contrast, some individuals reported stoicism in response to exacerbations with the help of cognitive strategies, such as telling themselves “You can make it” or relaxation and/or breathing techniques. For others, stoicism was driven by a concerning combination of habituation to daily symptoms and poor perception of worsening symptoms.

Some participants coped with the reality of unpredictable exacerbations by forward planning (e.g. keeping medications close by for easy access). Others avoided or delayed seeking help for exacerbations to evade the disruption hospitalisation would bring to their lives or overused their reliever inhaler believing, incorrectly, that this could prevent future attacks.

In the aftermath of exacerbations interviewees reported shock at the proximity to death, relief at being alive, concern about the unpredictability of future exacerbations or emotional disorder:

*I felt sorry for myself for well over a month.* (Cheryl, female, 53 years)

All participants described the need for exacerbation-related support. During exacerbation, this ranged from fetching medications, prompting to go to the emergency department, transport to hospital, calling for emergency assistance to emotional support for their children. During recovery, support needs included household chores, child care, house calls to check on the interviewee, providing the interviewee opportunity to emotionally break down and encouragement that “it will get better”.

Participants felt their family members, including children, experienced stress, fear or even trauma as a result of going through an exacerbation with them, and family often showed concern and feelings of protectiveness of the interviewee in the aftermath. At the same time some family/friends perceived that the interviewee could have done more to prevent their exacerbation.

#### **Theme 4: “Striving to adapt”**

The subthemes “Adjustment to life with severe asthma” and “Concerns for the future” represented the theme “Striving to adapt”. See table 5 and supplementary material A4.

#### *Adjustment to life with severe asthma*

As seen in other chronic diseases [18, 19], our participants strove to adjust to their diagnosis over time and reported going through different stages, in unique ways with different degrees of success. A small number had adapted well, but the majority were struggling to deal with the daily burden:

*[It's] crap [sic] ... [asthma] affects every hour of every day of every week of every month of every year of my life.* (Stephanie, female, 38 years)



TABLE 5 Theme 4: “Striving to adapt”

<b>Adjustment to life with severe asthma</b>	
Good adjustment	“Asthma doesn’t dominate my lifestyle. It’s part of who I am.” (Paul, male, 62 years)
Poor adjustment	“[It’s] crap [ <i>sic</i> ] ... [asthma] affects every hour of every day of every week of every month of every year of my life.” (Stephanie, female, 38 years)
<b>Positive coping strategies</b>	
Acquiring self-management skills	“It wasn’t really until I had a full asthma plan working closely with a specialist, which is now many years ago, that I was actually able to get all those things under control.” (Paul, male, 62 years)
Managing emotional problems	“Stop wallowing in self-pity basically ... Try and camouflage it with something else ... Like I might go out. Get out and walk the streets, and look in shop windows.” (Larry, male, 54 years)
Switching to doable activities	“I do exercise with people who know my limitations and they don’t care if I stop or whatever ... Yeah, I don’t make myself do [things] that make me really wheezy ... I just don’t put myself with those people that run their 42 km marathon because I know I couldn’t do something like that.” (Cheryl, female, 53 years)
<b>Negative coping strategies</b>	
Pushing through	“Being in a state where I probably should’ve been in hospital because my lung function was that bad ... having to get it done [at work] because the guy standing next to you is perfectly healthy ... and you’ve got to keep up with him.” (Larry, male, 54 years)
Risk aversion/exertion restriction	“Like this morning I had to go to the eye specialist ... which is not far, over the road actually. I thought ‘Will I walk? No I’ll drive because I might get out of breath’.” (Gloria, female, 81 years)
Vigilant monitoring of symptoms	“I am so in control of my asthma now. I do not let myself have an attack. If I get the slightest inkling that something’s happening, I am onto that nebuliser like you wouldn’t believe!” (Jacinta, female, 63 years)
<b>Childhood experiences</b>	“I avoid doctors like the plague. Because I’ve seen so many of them I guess. When I was a kid, every time I saw a doctor they’d whack me in hospital. So maybe that’s got something to do with it.” (Jacinta, female, 63 years)

There was evidence of incomplete adaptation to severe asthma; while most interviewees accepted they had “asthma”, one denied having asthma and few accepted that they had “severe asthma”. In their process of adjustment, our interviewees had used positive and/or negative coping strategies (table 5). Childhood experiences had influenced some adult behaviours; for example, Jacinta (female, 63 years) described terrifying childhood hospitalisations that contributed to her decisions to delay or avoid emergency care as an adult.

*Concerns for the future*

People with severe asthma hoped their asthma severity would stay the same as it was now or perhaps improve if they continued to carry out self-management activities. Interviewees were concerned that new comorbidities could emerge, possibly related to asthma medication side-effects, that their asthma could become worse or that they could die earlier than peers without asthma. Some described new therapies, including biologicals, as offering hope for preventing their asthma worsening in old age. Others were worried that asthma-related health costs could become unmanageable due to limitations on their ability to work.

**Discussion**

This study describes, in patients’ own words, the significant daily symptoms, limitations and emotional consequences of severe refractory asthma and of its treatment, particularly oral corticosteroids. It identifies important practical and emotional support needs that are not currently met, to the detriment of people with severe asthma and their family members, and highlights the isolation that they feel from others in the community.



Interviewees described ongoing emotional distress in response to the limits their asthma imposed, yet they rarely, if ever, discussed their feelings. The ability to discuss disease-related concerns is important for adaptation to chronic illness and prevention of more serious emotional disturbance [20, 21]. There was evidence of incomplete adaptation to severe asthma by our interviewees, such as denial of asthma or not accepting “severe asthma”. The need for access to emotional support is self-evident from our findings, but the time-pressured nature of primary and secondary care may mean that additional support services need to be developed as specialised add-ons to existing services, including through the use of multidisciplinary teams [22, 23].

**Support needs**

People with severe asthma expressed the need for “empathy and understanding”, “reasons to stay positive” and “encouragement”. These are similar to the types of emotional support described as helpful by rheumatoid arthritis patients [24]. Interviewees reported a lack of understanding of their experience of severe asthma by individuals in their lives. They particularly wanted their partner/spouse to understand, but some spouses were critical or resentful. Interviewees suggested support services for partners/family, including seminars on “the experience of breathlessness” and “living with someone with severe asthma”, and providing families with emotional support (e.g. after witnessing a frightening exacerbation). Partner criticism has been described in rheumatoid arthritis where it was associated with poorer psychological adjustment by patients [25]. A study of partner criticism in severe asthma, its impact and potential interventions should be investigated in more detail.

Interviewees suggested the development of a “life planning” support service for people with severe asthma that would provide someone to talk to about parenting, finances, career, ill-health retirement, and discussing feelings and intimate relationships. Such services could also improve access to the regular medical care needed for severe asthma by assisting with barriers such as child care and could circumvent risky adherence behaviours through discussion about medication concerns.

Public messaging such as “You can control your asthma” is largely aimed at patients whose asthma can be effectively managed by adherence to conventional treatment, but this strongly contrasts with the reality for people with severe asthma. Interviewees identified this as an important issue and suggested public messages to distinguish severe from milder asthma (table 6). Effective public messaging could help to diminish the stigma and misunderstanding experienced by patients with severe asthma.

Our findings go beyond those of four previous qualitative studies that describe how severe asthma affects physical health, impacts relationships, work and leisure, and detail the debilitating side-effects of oral corticosteroid treatment [9–12]. These studies were narrower in scope (e.g. focusing on a specific theme such as communication or corticosteroid therapy) and unlike the present study do not explore in depth the physical symptoms or emotional burdens faced by people with severe asthma, nor the specific support services that they need.

Strengths of the study include the broad range of participants interviewed, and the rich data obtained on physical, emotional and family burdens and support needs. For example, the range of asthma symptom control in this sample (as indicated by Asthma Control Test scores) allowed us to explore the varied impact of severe asthma, with some participants continuing to experience debilitating

TABLE 6 Public messaging content on severe asthma suggested by interviewees

**Messages for first responders**

Inform about quick deterioration in severe asthma

Advise about first aid, e.g. sit calmly with the patient for a bit, help them with what they need (e.g. assist with their inhaler), call an ambulance (check first with patient if possible)

People with severe asthma may need help to decide when to go to hospital

**Messages for people with severe asthma**

It’s not normal to be symptomatic – see your GP

You should have a plan from your doctor of what to do when symptoms worsen

Never ignore your symptoms – accept them and know you can take steps to make it okay

**Messages for the general public**

Bring people’s attention to how debilitating severe asthma is

Severe asthma is not fixed with a blue puffer

Severe asthma has long-term consequences and its treatment can have added complications (e.g. heart irregularity/hip problems)

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Sources suggested by participants included social media, television and print media.

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symptoms such as shortness of breath and cough every day, and others having a combination of good and bad symptom days, together with sudden-onset attacks, all of which placed important limits on people's lives. Limitations of this work include the small number of participants living outside a major city, which prevented us from fully exploring the impact of geographic isolation on living with severe asthma.

### Conclusions

While the focus of much research on severe refractory asthma is the identification of new targeted therapies [26], this study pinpointed substantial, overlooked patient needs. Patients experience significant emotional distress due to the long-term symptoms, treatment and limitations imposed by severe asthma. They described the urgent need for practical and emotional services to support them and their families in managing the burden of their disease. Health organisations and health professionals need to increase their awareness of these burdens so that healthcare services can be developed to assist severe asthma patients in their adjustment to chronic illness, and optimal access to appropriate care.

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