

“...I’ve said I wish I was dead, you’d be better off without me”: a systematic review of people’s experiences of living with severe asthma

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“ ...I’ve said I wish I was dead, you’d be better off without me”: A systematic review of people’s experiences of living with severe asthma

Daniela Eassey ^a, Helen K. Reddel ^b, Juliet M. Foster^b, Susan Kirkpatrick ^c, Louise Locock ^d, Kath Ryan ^e, and Lorraine Smith ^a

^a Faculty of Pharmacy, University of Sydney, Sydney, NSW, Australia; ^b Woolcock Institute of Medical Research, University of Sydney, Sydney, NSW, Australia; ^c Nuffield Department of Primary Care Health Science, University of Oxford, Oxford, UK; ^d Health Services Research Unit, University of Aberdeen, UK; ^e School of Pharmacy, University of Reading, UK

Abstract

Objective:

Our aim was to conduct a systematic review and synthesis of qualitative evidence exploring the lived experience of adults with severe asthma.

Data sources:

We searched MEDLINE via OvidSP, PsycINFO via OvidSP, PubMed, CINAHL, EMBASE, Sociological Abstracts, Google Scholar, the journals Qualitative Health Research and Qualitative Research, and a study of experiences of living with asthma by the Health Experiences Research group.

Study selections:

Studies were included if they used qualitative methods and explored the subjective experiences of adults (≥ 18 years) with a clear diagnosis of severe asthma.

Results:

From 575 identified studies, five met the inclusion criteria. Synthesis revealed an overarching theme of efforts that people living with severe asthma engage in to achieve personal control over their condition. Individuals ‘strive for autonomy’ through dealing with symptoms and treatment, acquiring knowledge, making decisions and reclaiming identity.

Conclusion:

This systematic review found a paucity of qualitative studies reporting on people's perspectives of living with severe asthma, and a focus on clinical rather than personal issues. Our synthesis reveals that severe asthma was disempowering, and a threat to identity and life roles. What was important to people living with severe asthma was striving to achieve a greater level of personal control over their condition, but these efforts received little support from their healthcare providers. Thus, more attention should be paid to understanding the self-management strategies and personal goals of people living with severe asthma. This may assist in designing interventions to better support patient self-management and improve health outcomes.

Introduction

Asthma is a heterogeneous condition, usually characterised by chronic airway inflammation, that affects people of all ages (1). It is estimated that over 300 million individuals in the world have asthma and this will increase to more than 400 million by 2020 (1-3). Asthma severity, which can range from mild to severe, is based on the level of treatment required to control symptoms and prevent exacerbations. In the last 15 years, the term 'severe asthma' has evolved, with clinical guidelines published in 2014 (4) formalising the definition as asthma for which good control is achieved only with high-dose inhaled corticosteroids and a second controller medication and/or oral corticosteroids (OCS), or when asthma remains uncontrolled despite this therapy (4). Making the diagnosis of severe asthma includes treating comorbidities and excluding modifiable contributors to uncontrolled asthma such as poor adherence and incorrect inhaler technique(5). It is estimated that 3-10% of the asthma population have severe asthma(4, 6); these patients have higher morbidity rates, and require more healthcare resources than patients with mild to moderate asthma (7-10).

To date, the vast majority of studies on severe asthma have focused on its definition (4), pathophysiology (11), and treatment options (5, 12). While this clinical research into severe asthma indicates that patients commonly have frequent symptoms and exacerbations, have comorbidities such as obesity or rhinosinusitis, and experience side-effects of treatment - particularly with oral corticosteroids (13, 14), there is little understanding of *how* these factors affect people with severe asthma, and *what* can be done to help improve their quality of life. Our aim therefore was to conduct a systematic review using qualitative evidence to answer the research question "What is the lived experience of adults with severe asthma?" We aimed to synthesise qualitative research studies to generate new insights and understandings of the existent empirical work (15).

Methods

The review protocol and study extraction are reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

Search Strategy

A systematic literature search was conducted from inception to July 2017 in the electronic databases MEDLINE via OvidSP, PsycINFO via OvidSP, PubMed, CINAHL, EMBASE and Sociological Abstracts. We also searched Google Scholar, the journals *Qualitative Health Research* and *Qualitative Research*, and a study of experiences of living with asthma by the Health Experiences Research group (16), and screened reference lists of relevant studies. The search strategy is provided in Appendix A.

Selection Criteria

Studies were included if they used qualitative methods and explored the subjective experiences of adults (≥ 18 years) with a clear diagnosis of severe asthma; for the purpose of this review, we defined severe asthma according to international guidelines published in 2014 (4). Articles were excluded if they: 1) were not in the English language, due to the absence of resources for translation; 2) did not address the personal experiences of living with severe asthma; 3) were observational, epidemiological or non-primary research articles (such as reviews and commentaries); and/or 4) involved study participants pre-selected through enrolment in another study with more specific inclusion criteria.

Two reviewers independently screened titles and abstracts of all identified references. Potential relevant studies underwent full text analysis. Disagreements were resolved by discussions with two other independent reviewers (LS and HKR).

Data extraction and synthesis

A systematic and iterative process was used to derive main concepts across the included studies from the initial coding stage through to the final synthesis of overarching themes. Patient quotes and the original authors' analytic interpretation of the qualitative findings were extracted verbatim, and became the raw data for the synthesis. Codes were initially generated from the text inductively to capture the meaning of the participants' perspectives and the authors' interpretations.

Analysis and synthesis of the data were conducted by drawing on elements of the meta-ethnographic method (17) and using a comparative thematic analysis approach(18). Meta-ethnography is a well-developed method increasingly used within healthcare research (Appendix B) (19).

Results

The initial search identified 575 studies. Thirty-one had investigated people's experiences of living with asthma, but 26 of these were not in severe asthma and are the subject of a separate review(20). Five studies therefore were included in the qualitative synthesis (Figure 1). Table 1 provides a summary of the included studies. Three studies were published in the last decade(21-24), four in the UK (22-25) and one in Canada (21). They included between 2-23 participants with severe asthma. All studies had a considerably higher proportion of female than male participants, consistent with the community prevalence of asthma and severe asthma amongst adults(8). The included studies reported experiences on the burden of disease (n=2)(22, 24), burden of treatment (n =3) (22-24), relationships with healthcare providers (HCPs) (n=2) (24, 25) and self-management (n=1) (21).

Synthesis of findings: Individuals with severe asthma are striving for autonomy

Our synthesis of the qualitative literature showed that, in the context of the substantial challenges of living with severe asthma, patients endeavour to obtain 'power' over their condition. Living with severe asthma has the potential to strip away an individual's self-worth,

confidence, and sense of autonomy and it was apparent that patients were '*striving for autonomy*' by their attempts to regain self-control and self-worth through seeking ways to understand and manage their condition.

Our analysis revealed four inter-related subthemes (Figure 2) which described people with severe asthma as 'Striving for autonomy' through 1) 'Dealing with symptoms and treatment' 2) 'Acquiring knowledge' 3) 'Making decisions' and 4) 'Reclaiming identity'. Italicized text between quotation marks below show extracts of participants' quotes from studies included in the synthesis (additional quotes are available in Appendix C).

Striving for autonomy through dealing with symptoms and treatment

This sub theme describes how participants '*cope*' (23-25) with and '*adapt*' (21) to severe asthma and severe asthma treatments "*to gain control and power over their condition*" (23). Participants sought to combat the sense of loss of control that resulted from having severe asthma, through learning how to manage their condition. One participant reported: "*for me, asthma is a huge part of my life it impacts on everything...you learn to deal with the condition when it does kick off...*"(26). Participants reported emotional distress associated with the side effects of oral corticosteroids; adapting their routines to accomplish daily activities; coping with debilitating symptoms; and managing their triggers.

Emotional burden associated with side effects of treatment

The authors of included papers reported that most interviewees were taking daily inhaled corticosteroids plus short courses of oral corticosteroids when their asthma became worse (21, 23, 27), with some interviewees taking oral corticosteroids every day (22, 25, 26). The burden of oral corticosteroids was mentioned in all studies and appeared to be one of the most challenging aspects of living with severe asthma (21-25). Interviewees described troublesome side-effects of oral corticosteroids including *weight gain*, '*puffy face*', '*blood pressure drops*', and

feeling *'hyper'*, as well as serious adverse effects such as osteoporosis and cataract. They reported particular difficulty coping with the psychological effects of oral corticosteroids such as anxiety, irritability and depression (22, 23) which are well-recognised in the medical literature.

Adapting to taking medications

Participants reported that to accomplish taking their medications, they would plan their day and/or establish routines. For one this meant: *"...keep[ing] them in the kitchen, beside the coffee, basically that's where it works best for me..."*(23). Another participant reported that having a routine meant *"having more of a life"* which helped her *"become more normal"* (26). Some had not fully adapted to medication-taking, for example, one participant reported: *"I think it's an awful kind of weakness on somebody if they need an inhaler"*(23).

Coping with symptoms

Participants often linked coping with symptoms and achieving control over severe asthma with being able to accomplish desired activities. For example one participant reported that: *"asthma control means to me that I would be able to complete activities, any kind of activities without having a bout of asthma...of shortness of breath"* (21). Interestingly, few participant quotes (or comments from study authors) were found about specific physical symptoms of asthma; one example was *"...I get puffed and short of breath and then I go blue..."*(26).

Hyland *et al.*,(22) highlighted that participants felt *'panic'* and *'fear'* in response to the unpredictable nature of their asthma, with some participants reporting avoiding any activities or situations that might trigger asthma symptoms.

Managing triggers

Interviewees reported learning what their triggers were, and that they viewed asthma management as not only taking medications, but also avoiding triggers(21). Triggers mentioned

were: household pets, cleaning products(26), *“stress...[and] anxiety”*(26), and, for one woman, worsening asthma during menstruation(27). Participants reported avoiding triggers, for example, by not visiting family, by removing or reducing the pets in their home (21), or by controlling the home environment to be able to keep their pets *“...I told her we are not getting rid of the dogs...so we bought three air purifiers...”* (21).

Striving for autonomy through acquiring knowledge

Participants described seeking knowledge to control and not be controlled by their condition, for example : *“Knowledge is power and I like to know what’s going on rather than just take the medicine and be quiet”* (23). They highlighted the key role HCPs played in their journey to acquire this knowledge and for some, the time spent with their HCPs was considered vital to acquiring knowledge. Others expressed desire for more information. Gaining knowledge was thought to be an enabling process in the participants’ efforts to regain ‘control’ over severe asthma.

Desire for more information

The process of acquiring knowledge gave participants a sense of control and empowerment over their illness. Describing their journey to seek knowledge, participants reported ways in which they would find information and the role HCPs played in this. One author reported: *“It seemed that the ability to access, communicate and gain the information and attention needed to regain asthma control was important to patients.”* (25). However another author reported that during some consultations, participants *“received little information about asthma from their GP”* (21). Particularly, when professional information was not provided, participants often sought it from a variety of sources such as medical journals, books, websites, friends and family, television and pamphlets (21, 23, 27). One participant reported that she initially wasn’t getting enough information from her doctor, so she looked up her symptoms on the internet to try to

find out more about them (27). For others, however, the information provided by HCPs either didn't seem to relate to their own condition, or was couched in medical terminology.

Time with HCPs

Lack of HCP time was considered a barrier to participants acquiring asthma knowledge. As one author reported: *"Doctors (GPs or specialist) were perceived to have limited time for questions or lengthy discussion"* (21). For most interviewees, primary health physicians were their first point of call (21, 25), and their main source of knowledge, so having sufficient time with them was valued. However, many interviewees reported feeling rushed during their consultations, as illustrated by this quote: *"he (physician) says 'Right, what's been going on, how's your asthma?' and he is just wanting you out of there, he just wants on to the next one [sic]"* (25). In contrast, it was reported that nurses provided more time and information.

Striving for autonomy through making decisions

The types of decisions participants reported making included weighing up the costs and benefits of severe asthma treatment; deciding on what treatment they wanted, how and when to take their medication. The extent of decision making often depended on the extent to which they relied on GP advice. According to Gamble et al., (23) interviewees who perceived that their general practitioner knew less about their disease than they did felt compelled to *"undertake disease management decisions themselves at times, rather than consult their general practitioners"*. Making decisions could thus be an unwelcome necessity or a free choice which led to feelings of empowerment over severe asthma.

Weighing up the costs and benefits

In the process of making health related decisions, participants reported weighing up the costs and benefits of striving for a normal life. According to Ross et al., (21) *"[benefits are]... related to the extent to which they can engage in normal everyday activities that are aligned with their*

personal values and beliefs...[and costs are] related to having asthma, its symptoms, and its recommended treatment." Participants themselves reported that to keep this balance, it would often require *'trial and error'* (21) and *'push[ing] the limits'* (21). For some, weighing up the severity of their symptoms with the extent to which they could engage in normal activities, impacted on their decisions to go to the emergency department (21).

Study participants reported making independent decisions about how and when to take oral corticosteroids. For some, taking them meant better quality of life: *"...when I've had to take steroids...I just feel at the end of the day, it's all about quality of life and I need to be able to keep a balance"* (23). For others, the thought of taking oral corticosteroids and their side effects would either *"make them stop or cut down on their steroids dose"*(23). Another participant reported side-effects themselves impacted on their ability to engage in daily activities: *"...The pros are that I am alive and able to do things. The cons are the side effects though."* (21). According to Hyland *et al.*, *"some patients reported delaying the start of OCS and delaying visiting the clinic when they knew they were deteriorating"* (22). Another participant reported that *"I would be on my knees rather than take them..."* (23).

Communication and relationships with HCPs

Interviewees reported wanting an equal relationship (23, 25) and *"two-way conversations"* (21) with their HCPs when making decisions related to their condition. Participants, however, felt disempowered when they perceived their HCPs as *"authoritarian...or paternalistic"* (25). One participant reported: *"... they (GPs) just wrap you up in cotton wool. It's just not what I want"* (25), while another reported rejecting GP advice due to not being heard, as illustrated by this quote: *"...I didn't follow it [action plan] because I never got to express my opinion... they [physicians] have stronger opinions..."*(21).

Some participants were reluctant to discuss their asthma with their HCP, perceiving HCPs as having preconceived ideas, for example: *"...they always blame your weight"* (25). Some reported

being selective when sharing information about emotional issues (e.g. stress exacerbating asthma) to avoid giving “*him [the GP] all my troubles*” (25).

Level of trust in HCPs

Some study participants believed that their decision making also depended on the level of ‘trust’ they had in their HCPs. This ‘trust’ was earned “*if the physician appeared to be knowledgeable*” (21) and if participants felt like they were involved in health related decisions. However, one participant reported that he didn’t trust his doctor because “*...they just give you medication just to say yeah whatever here you go get out of my site [sic]...*” (21), and for him, trusting his doctors meant they had a good “*connection*”. If there was no “*connection*”, then participants would make their own decisions.

Striving for autonomy through reclaiming identity

Most participants viewed their severe asthma as a condition which reduced their quality of life and disempowered them. Study authors described statements interviewees made about the impact of severe asthma on their identity, such as: “*loss of roles within personal relationships*” (23) loss of work (21, 22, 26, 27), “*not being themselves*” (22, 23) or “*being perceived as different by friends and family*” (23). For some interviewees, the side-effects of oral corticosteroids challenged their identity to the point where it posed an existential threat, as illustrated by the following quote about oral corticosteroid-induced irritability: “*...I’ve cried, I’ve said I wish I was dead, you’d be better off without me*” (22). Another participant reported that their identity shouldn’t be defined by their condition, as illustrated by the following quote: “*...I’m a person with asthma, I’m not the asthma first*” (26).

Challenges to life roles

Participants reported feeling isolated from friends and family when on oral corticosteroids. For others taking oral corticosteroids meant being “*unable to fulfil their normal roles*”. One

participant reported that, she would remove herself from her family when on oral corticosteroids.

For some participants, multiple asthma-related hospitalisations (9, 17 and 20 times in a year for three participants) (22, 26) affected their career. One participant reported that the unpredictability of their condition disrupted their working life (22). For some, this “*loss of the ability to work or function*”(21) meant being “*...put on total disability [pension]*”(21) . Others did not let their life stop because of their condition. To reclaim power over their condition, and restore autonomy, participants would learn how to “*adjust their lifestyle*” and shift their perspective to “*accommodate their asthma*”(21).

Discussion

To our knowledge, this is the first systematic review of qualitative studies exploring people’s experiences of living with severe asthma. The paucity of qualitative studies identified emphasises that, despite increasing research interest in severe asthma, the voice of people with severe asthma is rarely heard. The key theme emerging from our analysis is that individuals with severe asthma strive for autonomy in their efforts to reclaim ‘power’ over their asthma. This resonates with the wider literature on living with chronic illness. People seek personal autonomy (28, 29) through attempts to exert control over their condition to prevent disruption to their everyday life. Individuals feel empowered by attempts to gain a sense of ‘control’ or ‘mastery’ over an otherwise unpredictable chronic condition (28, 30).

This review adds considerable depth to the features and impacts of severe asthma highlighted in quantitative studies. Our findings illustrate how individuals with severe asthma encounter challenges to their personal identity through the disruption of personal roles, body image, emotional and cognitive processes, and social relationships. While similar findings have been reported for adults living with other chronic illnesses (31, 32), severe asthma has some important differences. For example, severe asthma is an ‘invisible’ condition not readily

observable to others (33). Asthma flare ups can be fatal; they sometimes develop within minutes, failing to respond to reliever inhalers. This unpredictability means some people with severe asthma live with fear. Severe asthma can also threaten social ties and relationships. A European survey reported that 27% of participants with severe asthma said their symptoms prevented them from seeing friends and family (34). In addition, many patients with severe asthma had to change a job role, leave a job or were unable to work at all (35), and up to two thirds of people with severe asthma were unable to hold a full time job due to their condition (14).

According to Charmaz, loss of control over normal day-to-day activities is a threat to self-identity (36). Some researchers have chosen to explore these concepts through viewing 'chronic illness as biographical disruption', where living with a chronic condition can significantly disrupt expectations of a normal life trajectory (37) (38). However like Williams (39), we also see evidence of the concept of chronic illness as 'biographical continuity'. As highlighted in our findings, people living with severe asthma described their efforts to adapt to altered expectations of their life trajectory, and indicated that their self-identity was an ongoing and adaptive process (39, 40).

Quantitative data highlight the physical symptoms of asthma, with many patients having day-to-day symptoms and/or acute asthma flare ups, including severe breathlessness and chest tightness. A 2007 severe asthma survey reported that one in five patients lived in fear that their next attack would be their last (41). In our review of the *qualitative* literature, however, we identified little evidence of participants' descriptions of the physical symptoms of asthma. It is unclear whether or not researchers in the reviewed studies asked directly about physical symptoms. Perhaps physical symptoms were considered too obvious for participants or authors to mention, or perhaps they were considered less important or less noticeable by participants in comparison to other aspects of living with this condition. Further research is needed to understand this finding.

Our synthesis highlights the patient-HCP's relationship as vital to overall health experiences. Although participants valued learning how to manage their condition to facilitate engagement in day-to-day activities, this was not always acknowledged during consultations. Interviewees described challenges to their autonomy during medical consultations, such as feeling their opinion or concerns went unheard. In response, participants sought to regain personal control, sometimes by deciding not to follow recommendations made by their HCPs. Other studies support that patients' perceptions about their HCPs (e.g. HCPs ability to listen and the extent to which patients feel they are treated as equals), can impact on their decision to follow medical recommendations (42, 43), and medication adherence (44-46). Our review also revealed discordance between the priorities of patients and those of their HCPs. HCPs tended to focus on symptoms and medications, whereas people with severe asthma were concerned with day-to-day issues such as going to work and maintaining social relationships (4, 47). For the person living with the persisting disability of severe asthma, this creates a tension between personal disruptions to daily life, and a disease management-based treatment paradigm (48). The difficulty of navigating the healthcare system and HCP relationships, which was also reported in a recent review by Pickles *et al.* of qualitative research in the broader asthma population (20), can become a threat to autonomy.

This synthesis identified a paucity of literature reporting patients' experiences of add-on biologic treatments such as omalizumab, mepolizumab, reslizumab and benralizumab for severe asthma. Their greatest clinical benefit is in reducing severe exacerbations, with more modest effects on day-to-day symptoms and quality of life(4). This divergence points to the need for future qualitative research to explore the impact of these treatments on the *overall* lived experience of patients with severe asthma.

Strengths and Limitations

Strengths of this review included its comprehensive search approach and the use of a methodologically robust qualitative synthesis, which is an emerging type of enquiry in the

health research field (49). This has enabled a rigorous and systematic interpretation of the unique patient experiences of living with severe asthma. This approach has revealed challenges to a range of significant psychological and social elements of daily life, such as self-worth, confidence and autonomy. We hope this will engender on-going research and debate on this debilitating and life-threatening condition.

The number of studies was small, reflecting the paucity of qualitative research in a rapidly-evolving clinical area. It is possible that some individual patients fitting the now-accepted definition of severe asthma (4, 50) were included in other, earlier, studies, as the term “severe asthma” was often previously used more generally for uncontrolled asthma (51). We excluded studies that, although using qualitative methodology, focused on specific medical research questions such as patient usage of action plans, which could therefore provide only limited insight on the lived experience of severe asthma from the patient’s perspective. However, the studies we included in our review still appeared to focus on rather specific and mostly clinically-derived issues such as experiences with oral corticosteroids or treatment adherence, which likely limited the information available about the full diversity of patients’ experiences.

Other limitations include that the identified studies were mostly conducted in white, inner city, populations, whose experiences may not be representative of those from different geographical locations, sociodemographic status and cultural backgrounds.

Conclusion

In this first systematic review and synthesis of the qualitative literature on people’s experiences of living with severe asthma, we propose that people endeavour to obtain power over their condition through striving for personal autonomy. To gain power, participants deal with managing symptoms and treatment, acquiring knowledge, making decisions and re-claiming their identity. Our synthesis has highlighted several areas which require attention by policy makers and HCPs, as in their quest to learn about and

self-manage severe asthma, patients often receive insufficient support from HCPs. Given the level of disability experienced by people living with severe asthma this is an important aspect of clinical care that must be addressed, rather than only focusing on pharmacological interventions. For this reason, it is imperative that more attention be paid to supporting self-management strategies and acknowledging the goals that are important to people living with severe asthma.

Conflict of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Author contributions

DE drafted the first and subsequent versions of the manuscript, with feedback from LS, HKR, KR and JMF. DE independently conducted the searches. Data extraction was conducted by DE and checked by experienced reviewers (LS and HKR). The process of coding was conducted by DE, LS, HKR and JMF. Data analysis and interpretation involved all authors. All authors read and approved the final version of the manuscript.

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Appendices

Appendix A- Search Strategy

ti=title, tw=text word

- 1 exp Asthma/
- 2 Asthma\$.ti. or wheez\$.ti,ab.
- 3 (asthmatic? or (asthma\$ adj2 (chronic\$ or patient?))).ab.
- 4 (lung disease or lung diseases).tw.
- 5 severe asthma.tw.
- 6 difficult asthma.tw.
- 7 or/1-6
- 8 exp adult/ or exp aged/ or middle aged/ or young adult/
- 9 (patient* or inpatient*).tw.
- 10 or/8-9
- 11 Qualitative Research/
- 12 ethnog*.tw.
- 13 phenomenolog*.tw.
- 14 participant observ*.tw.
- 15 constant compar*.tw.
- 16 focus group*.tw.
- 17 action research.tw.
- 18 qualitative stud*.tw.
- 19 (focus group* or interview*).tw.
- 20 (grounded adj (theor* or study or studies or research)).tw.
- 21 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20
- 22 patient experience*.tw.
- 23 lived experience*.tw.
- 24 life experience*.tw.
- 25 patient perspective*.tw.
- 26 experience*.tw.
- 27 health experience*.tw.
- 28 living with asthma.tw.
- 29 personal experience*.tw.
- 30 illness experience*.tw.
- 31 quality of life*.tw.
- 32 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31
- 33 7 and 10 and 21 and 32
- 34 limit 33 to (english language and humans)

The search, using the above terms, was conducted in: MEDLINE via OvidSP, PsycINFO via OvidSP, PubMed, CINAHL, EMBASE and Sociological Abstracts. We also searched Google Scholar, the journals Qualitative Health Research and Qualitative Research, and a study of experiences of living with asthma by the Health Experiences Research group, published on the healthtalk.org website, and we screened reference lists of relevant studies.

Appendix B- Further information on methods

The present authors followed the seven main phases of synthesis used in meta-ethnography (17). In the first three phases we chose the topic focus, selected studies to synthesise, and initially read the studies separately for concepts and themes. In the next two phases we translated and synthesized how these concepts related to each other leading to the development of overarching themes (17). This allowed the reviewers (DE, LS, HKR and JMF) to analyse the individual studies in depth and explain any similarities or contradictions between them. Finally, in the 7th phase, we utilized the 'Line of argument' synthesis to build each concept into a 'whole picture'.

Appendix C- Tables

Table1- Theme 1: People living with severe asthma strive for autonomy through dealing with symptoms and treatment

Categories	Quotes
Emotional burden associated with the side effects of treatment	<p><i>"I didn't realise until I started taking them just the effect they could have on you mentally. I would say I suffer from depression. The psychiatrist reckoned that I have a steroid induced psychosis. I battle with myself every time I feel the asthma getting worse. I probably think I should have them upped at the minute...but I keep thinking to myself maybe it'll go away. It's like a bomb waiting to explode."</i> (23)</p> <p><i>"I know I was never depressed before I started on steroids"</i> (22)</p> <p><i>"I can't tell you how much I hate being on them because of the depression"</i>(22)</p> <p><i>"Patients reported that their increased weight was embarrassing"</i>(22)</p>
Adapting to taking medications	<p>Taking puffers at work- <i>"I wouldn't take them in work; I'd wait till I'm on my own. Sometimes I would have climbed the stairs and went in and everybody was sitting and I would have thought 'Oh God I need my inhaler', but I would have held off."</i> (23)</p> <p>Routine- <i>"...I prefer to get up and sort myself out in the mornings and take the steroids after I've had a cup of coffee."</i>(23)</p> <p><i>"But things like my nebuliser, I have to buy myself. I've got two, I've got a portable one that I can carry around in my handbag and I've got my big one, compressor one upstairs, that I use at home."</i> (26)</p> <p><i>"The nebuliser takes up quite a lot of time in the mornings when you are getting ready with the kids and things like that for school."</i>(23)</p> <p><i>"...if someone says to me, 'Oh, we're going out, oh, do you want to stay over?' I can't, I, because the med, the type of medication I take, I can't miss a day. I mean, yeah, I do get sick of taking it, you know, after breakfast, ah, I'll just take my medicine, I jokingly say it's my second breakfast, you know, all the pills, takes, takes one and a half mugs of tea to take all my pills [laughs] in the mornings, you know."</i> (26)</p>
Coping with symptoms	<p><i>"...I have to be very careful that I don't get over-tired; it's getting over-tired makes me, can make me wheeze..."</i>(26)</p> <p>Avoiding symptoms- <i>"[going to his] brother's house...or anywhere...[so they would]...meet up in town or...[at their place since he knows]...it's a safe clean environment"</i> (26)</p>
Managing triggers	<p>Stress and anxiety- <i>"...getting anxious about it, it just spirals, and I now know that anxiety and stress are one of my big triggers, psychological thing. You know, if I think I'm going to get ill, then I can, I can almost make it, make it happen, almost self-fulfilling because you think, 'Oh, I've sneezed, I've got a cold I'm going to be ill'"</i> (26)</p> <p><i>"...I can't go to my brother's house, brother and his wife and my niece because they've got a cat, but they had the cat before or my sister-in-law had the cat before she married my brother. So, you know, we can't really ask her to get rid of the cat, but my aunt has always had cats as well..."</i> (26)</p> <p>Cleaning products- <i>"...I mean other triggers for me include things like, cleaning products, bleach I mean, I went to my grandmother's house a few weeks ago and her cleaner had been in and left, left bleach in one of the loos"</i></p>

	<i>which, you know, is perfectly normal, it's what people do, but I'd have only been in the house five, ten minutes and I knew that there was bleach somewhere; I couldn't smell it but I could feel it."</i> (26)
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Table 2- Theme 2: People living with severe asthma strive for autonomy through acquiring knowledge

Categories	Quotes
Desire for more information	<p><i>I'd like to know exactly what they do to you - and they don't tell you that! It took me a few years to realise you should always request information, you're never told these things, you have to find out for yourself"</i> (23)</p> <p><i>"It was also encouraging to find that most participants wanted more accurate information and more education from health professionals. "</i> (23)</p> <p>Finding information on the internet- <i>"...I was doing research on the internet...and I went to the doctor and they all agreed it was something it was called catamenia [sic] asthma..."</i> (27).</p> <p>Information not related to their condition- <i>"...everything was geared towards a moderate type asthmatic and it made me feel like I was doing something wrong, or I wasn't controlling things well enough..."</i>(21)</p> <p>Medical terminology used- <i>"Yes, sometimes the information is written at...the doctor level and not at a patient's level. So sometimes the information can be overwhelming if it is not at a level that I can understand"</i> (21)</p> <p><i>"Written or oral information was not always given in language appropriate for the lay or even for health care professionals unfamiliar with the jargon of the specialty."</i> (21)</p> <p>Use of analogies stood out as particularly useful for clarifying meaning: <i>"...you can picture it better. Like she used this thing where your asthma symptoms are the top of an iceberg and 7/8 of it is what is going on in your lungs, you can't see that and the symptoms are only a little chunk. So it's like if you are having symptoms, it is like eight times worse inside your lungs. So, . . .it's very, very, good. It's down to earth."</i>(21)</p>
Communication and relationships with HCPs	<p><i>"...and so their [physicians] opinion of the drugs that they see work is not necessarily the drug that will work on everybody. So that open-mindedness and the listening to the patient as opposed to a closed conversation versus an open conversation"</i>(21)</p> <p><i>"...he was a great Doctor... slightly arrogant, but, you know, who was so focused on my allergies and minimising my allergy exposure and yeah, and sort of cleaning my life up so I wasn't exposed, didn't, he didn't actually look at me and how I was living and he didn't actually look at my asthma which I know sounds really odd..."</i> (26)</p> <p>Disclosure of adherence: <i>"Similarly, two other participants stated that they would only admit to not taking their inhaled steroid if asked directly by their GP. ."</i> (25)</p> <p><i>"Patients do not discuss non-medical matters in the consultation and perceive that they should cope with these broader, non-medical issues themselves"</i> (25)</p> <p><i>"Recently I've seen them [GPs] quite a bit. . . the last few months. Just cause I've had colds. and they threatened me with the asthma clinic."</i>(25)</p>
Time with HCPs	<p>Nurse- <i>"Uhm, well sometimes she (nurse practitioner) points out things but just talking. We spend a longer time talking. She will catch a few things, stuff like that and then I can ask her questions (allied health professional) . . . Dr. (asthma specialist) does not have time for all of these questions."</i>(21)</p>

	<i>"What is it, a five-minute interview with the doctor? ... (with the practice nurse) you've got time..." (25).</i>
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Table 3- Theme3: People living with severe asthma strive for autonomy through making decisions

Categories	Quotes
Weighing up the costs and benefits	<i>"Participants stated that they often took management decisions themselves. It was evident that these decisions seemed to involve weighing up costs and benefits. This sub-conscious analysis was expressed in various ways" (23)</i>
Decisions about taking oral corticosteroids	<i>"I would have started them (corticosteroids) myself, because I thought this the only thing that helps me. The doctor used to say to me 'You know - you diagnose yourself!'" (23)</i> <i>"I will cut them down and maybe the consultant has said stay on two tablets until I see you in four weeks, but if I feel okay I won't stay on those two, I mean I probably will cut them down again, maybe I shouldn't but..."(23)</i> <i>"It's the lesser of two evils - it depends on how badly I'm suffering and if it gets really bad and affects my life-style and my work, then I do take them."(23)</i>

Table 4-Theme 4: People living with severe asthma strive for autonomy through reclaiming identity

Categories	Quotes
Challenges to life roles	<i>Feeling isolated from friends and family when on oral corticosteroids-"I'm good craic [meaning good company] and talk away usually, but when I'm on them [oral steroids], if I phone my friends, they say you 'Are back on those tablets?', because I don't want to listen."(23)</i> <i>Work- "What it meant then was loss of my occupation uhmm loss of the ability to work or function . . . Uhmm and put on total disability and what it now means is [pause] managing it with my life. So my life does not stop as a result of the asthma. I just adapt...I have had to adjust my lifestyle."(21)</i> <i>"I lost my job, I was medically discharged because I was in and out of hospital" (22).</i> <i>"I went through a period of several years, where I was in the hospital a lot and asthma was disrupting my whole family's life and I wanted to shut it out and I am in my 'rebellious, I am not going to deal with it' stage"(21)</i> <i>Being unable to fulfil normal roles-" Oh even the children know now when I'm on them, they say 'Mummy's back on her drugs'. I am really bad tempered and wicked, just really, it's like if I'm pre-menstrual, its even worse, I just go upstairs and sit in a room to get away from them all rather than say things that I'd regret!"(23) .</i>

Table 1- Details of included studies: aims, definitions of severe asthma, sample characteristics and methods

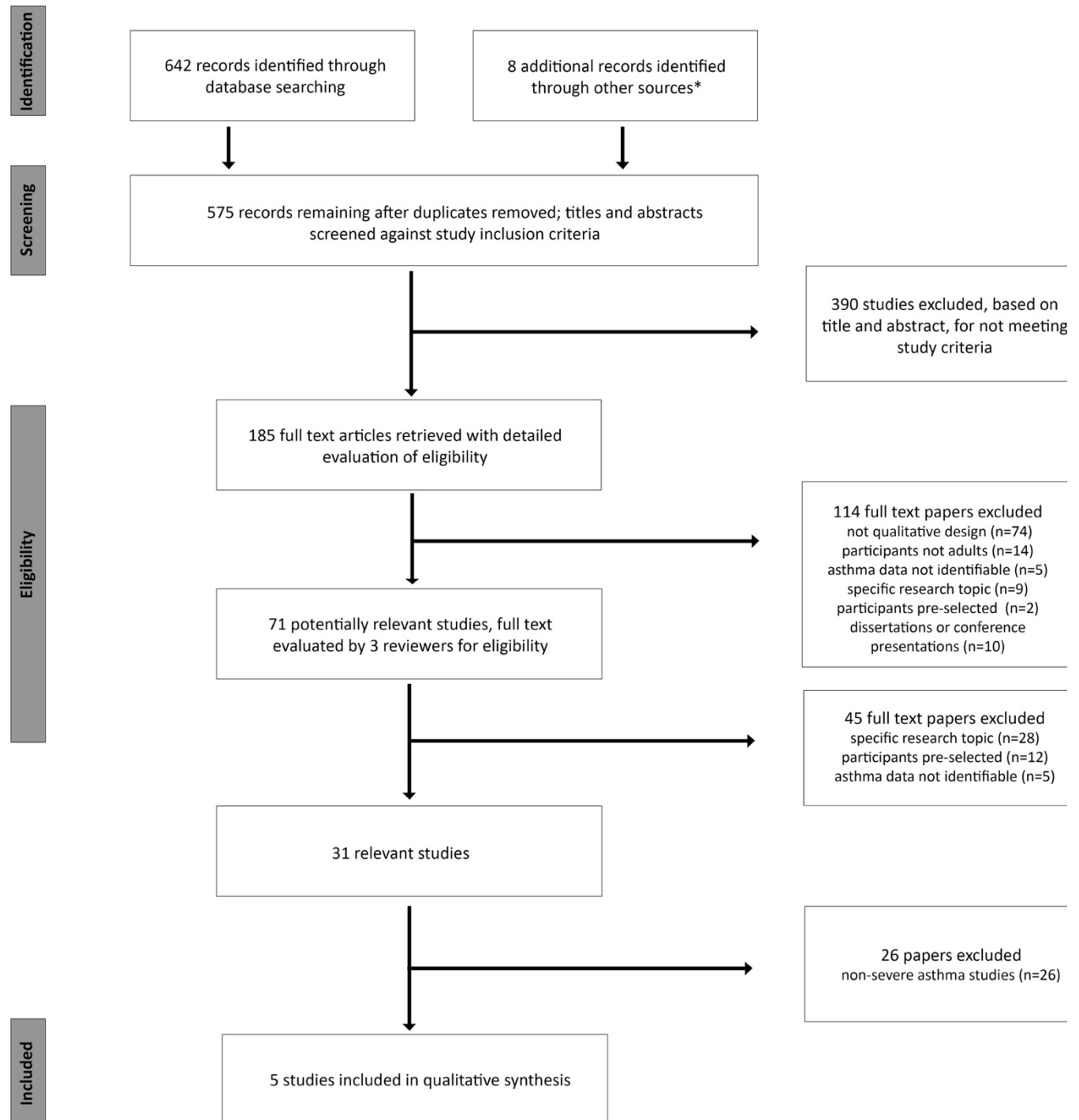
Study Details (Author, Year)	Sample characteristics			Aims	Definition of severe asthma	Design Framework/Method
	Diagnosed with severe asthma (total sample size)*	Age range	Female, number of those with severe asthma			
Moffat <i>et al.</i> , 2006 (25)*	3 (14)	Not given	Not stated (8/14 of whole sample)	Experiences during primary care asthma consultations.	Considered by GP to have severe and/or difficult asthma, and taking Step 4 or above of the British Thoracic Society/Scottish Intercollegiate Guidelines Network treatment guidelines	Grounded theory approach/ semi-structured interviews (audio recorded)
Gamble <i>et al.</i> , 2007 (23)	10 (10)	25-58	7/10	Practices associated with taking corticosteroids, decision-making processes, and adherence.	Asthma remained difficult to control with prominent breakthrough symptoms and frequent exacerbations, despite treatment with high dose maintenance inhaled therapy; at least one exacerbation requiring oral corticosteroids in the previous 12 months	Phenomenological/non-structured interviews (audio recorded)
Ross <i>et al.</i> , 2010 (21)	8 (8)	23-53	6/8	Perceptions about self-management.	Severity classification by an asthma specialist based on American Thoracic	Semi-structured interviews (audio recorded)

					Society/European Respiratory Society Task Force; all participants had received intense subspecialist assessment and optimization within the context of an asthma clinic for a minimum of 6 months, and had received asthma education from a certified asthma educator or an asthma specialist	
Hyland <i>et al.</i> , 2015 (22)	23 (23)	28-70	19/23	1) Burden of asthma and its treatment 2) Items in existing asthma scales and whether they provide a valid assessment of the patient experience	Definition not clearly stated, but participants were recruited from a specialist severe asthma clinic to which patients were referred if their asthma remained uncontrolled despite high levels of preventative (primarily inhaler) medication.	Open-ended interviews (audio recorded) and use of asthma assessment scales
Health Experience Research Group (2015) UK (24)*	2 (37)	16-73 (34 and 60)	2/2	Explore people's experiences of health, illness and healthcare.	Definition not provided in online resource; two participants Jenny (26) and Jane-Z (27) were identified by authors (HKR and DE) as having severe asthma, based on details about asthma symptoms, specialist assessment, and medications.	In-depth, semi-structured interviews (video recorded).

*Where materials published online reported data and quotes from a mixed severe and non-severe population, two authors (DE and HKR) identified the comments and quotes from participants who appeared to satisfy current guidelines criteria for severe asthma(4).

Figures

Figure 1. Flow of information through the different phases of the systematic review (based on PRISMA reporting flowchart)



* Healthtalk.org webpages for 2 patients with severe asthma included as one record

Figure 2. Conceptual diagram of the overarching theme and sub-themes synthesised in this review, from studies that explored patients' experiences of living with severe asthma

