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# Exploring the experiences of older adults living with asthma in the United Kingdom: A co-produced qualitative study

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A R T I C L E I N F O	A B S T R A C T	
A R T I C L E I N F O Keywords: Aging Asthma Older adults Qualitative methods	<i>Background:</i> Older adults are the fastest growing population in the UK, but asthma is often underdiagnosed, undertreated and poorly self-managed in this population. It is necessary to explore the experiences of older adults with asthma to identify areas of research that could improve quality of life. This study aimed to explore the perceptions of older adults in the UK living with asthma and how it impacts their lives. <i>Methods:</i> Telephone interviews were conducted with 15 adults with General Practitioner diagnosed asthma, aged 60 years and over, from across the UK. Interviews were audio-recorded, transcribed verbatim and thematically analysed. This study was co-produced with an Asthma UK Centre for Applied Research (AUKCAR) Patient and Public Involvement Lead and guided by the National Institute for Health Research UK standards for Public Involvement in Research to ensure meaningful public involvement. <i>Results:</i> Themes clustered around impact of asthma, managing asthma, interaction with healthcare and understanding of asthma. Participants experienced increased physical, psychological and social impacts of asthma management as they aged which led to feelings of isolation. Competing multimorbidities and polypharmacy complicate treatment and self-management of asthma. Ageism and a lack of empathy from health care providers were mentioned by the majority participants. Quality of care varied widely across the UK, however all participants had seen a healthcare professional for an asthma review in the previous 12 months. <i>Conclusions:</i> Older adults experience increased challenges in managing their asthma due to increased multimorbidities, polypharmacy and ageism from healthcare providers.	

#### 1. Introduction

Asthma is a common respiratory condition which impacts around 339 million people globally [1]. In the United Kingdom (UK), 1 in 12 adults and 1 in 11 children are receiving asthma treatment [2]. Asthma care in the UK is estimated to cost over £1 billion per annum in primary care consultations, hospital care, and disability claims [3]. Every year, over 1,400 people die from asthma, with many of these deaths are preventable by medical and professional care and self-management [4].

The proportion of older adults in the UK is growing faster than other segment of the population. This group is estimated to increase by 8.6 million in the next five decades [5], and as life expectancy increases, the number of people living with long term conditions will also rise. The rising burden of disease from asthma in this age group highlights the

need for further exploration and understanding of the impact of living with asthma [6]. Older adults have been identified as a "*forgotten generation*" [7], as asthma is generally considered to be a disease of children and young people [8], despite evidence that it is prevalent in older populations [9]. Asthma deaths have been declining in children and young people and increasing in older adults [4], and the majority of asthma deaths occur in adults aged over 65 years [10].

Asthma prevalence in women increases by age [11], and menopause has been identified as a predictor for late onset asthma [12]. Older adults are more likely than younger adults to attend a healthcare professional for their asthma [13], and asthma-related hospitalisations are significantly higher in older adults [14]. Despite the reported prevalence of asthma in older adults, gaps have been identified in the clinical care they receive and it is often under- or misdiagnosed, undertreated and

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Abbreviations: Asthma UK Centre for Applied Research, AUKCAR; Chronic Obstructive Pulmonary Disorder, COPD; National Institute for Health Research, NIHR; National Health Service, NHS; Patient and Public Involvement, PPI; United Kingdom, UK; REgister for Asthma researCH database, REACH.

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poorly self-managed [15]. Older adults are more likely to be living with multiple conditions, which have competing symptoms, treatments and medications, making self-management complex and challenging [16]. Asthma symptoms, such as breathlessness, can be misinterpreted as normal physiological changes within the lung due to ageing or attributed to other lung conditions like Chronic Obstructive Pulmonary Disorder (COPD), as distinguishing between asthma and COPD symptoms can be difficult as the diseases overlap [17]. The prevalence of cigarette smoking in older adults can contribute to further diagnostic uncertainty due to potential damage to the respiratory system [18].

Self-management of multimorbidities often involves complex medication regimens and polypharmacy issues such as drug interactions and non-adherence are prevalent [19]. Many older adults are reluctant to take multiple medications, resulting in the prioritisation of certain diseases (and treatments) above others and medication doses being spaced out or omitted completely [20,21]. However, not all non-adherence is intentional [22]. Reduced physical capacity due to arthritis in the hands can impact the ability to administer inhalers, cognitive issues can interfere with understanding, learning and actioning self-management techniques and visual impairments can impede ability to read prescriptions, written medication instructions and asthma action plans [23]. Administration of medication can also create issues with older adults incorrectly perceiving their inhaler technique more highly than reported by their clinicians [24], and poor inhaler technique is associated with an increased risk of asthma related hospital admission [25].

Older adults are often under-represented in research due to: accessibility issues; physical limitations; ageism, and strict clinical trial inclusion criteria which excludes individuals with multimorbidities and history of smoking [26]. Excluding older adults from drug trials results in treatments being trialled on a younger population who are at lower risk of adverse side-effects from medication [27]. Side effects from inhaled corticosteroids include thinning skin and oral thrush, are underestimated by healthcare professionals [28].

The majority of older adults' asthma research is conducted in Australia or North America, where healthcare systems are very different to the UK's National Health Service (NHS) [29]. We report here a qualitative study undertaken to address this knowledge gap and explore the perspectives of older adults living with asthma in the UK, how they manage their condition; how it impacts their lives and progression of asthma symptoms over the years.

#### 2. Methods

#### 2.1. Study design

A qualitative study was undertaken as we aimed to explore the perceptions of older adults living with asthma in the UK. Ethical approval was granted by the Social Research Ethics Group, University of Edinburgh. The 32-item COREQ checklist [30] was used to guide reporting the research.

#### 2.2. Patient and Public Involvement

Patient and Public Involvement (PPI) is defined by the National Institute for Health Research (NIHR) as research carried out 'with' or 'by' members of the public, rather than 'on' or 'to' them [31]. This study was co-produced with an Asthma UK Centre for Applied Research (AUKCAR) PPI Patient Lead (EE) following the AUKCAR PPI strategy and guided by the NIHR UK standards for Public Involvement in Research [32] to ensure meaningful public involvement. PPI members were involved throughout the study. EE approached TJ with the idea for the project and TJ suggested the methods; EE provided a lay perspective on the experience of being an older adult and living with asthma; PPI members participated in pilot interviews and provided feedback on interview style and questions; EE was involved in reviewing, defining and finalising the themes, and is also a co-author.

#### 2.3. Participants and recruitment

Participants were identified through the register for Asthma researCH database [33], the AUKCAR Patient Advisory Group and snowball sampling. Inclusion criteria was UK based adults, aged 60 years and over with a diagnosis of "active asthma". Sixty years was chosen as this is the age in which prescriptions become free in England. "Active" asthma is defined as a diagnosis of asthma and a prescription for an asthma-related drug in the preceding 12 months [34]. Eligible participants were emailed a participant information sheet and consent form, produced in collaboration with AUKCAR PPI members to ensure they were accessible to a lay audience. Gender, age and location were asked and we initially sampled 16 participants for interviews. One eligible participant withdrew from the study due to health reasons and all authors agreed data saturation [35] had been achieved after 15 interviews so no further recruitment was undertaken. All participants were previously unknown to the interviewers (FF, LR), however the participants were informed prior to the interview that they were students with an interest in asthma in older adults. Participants did not receive any incentives for taking part. Informed written consent was obtained from all participants prior to taking part and reconfirmed verbally at the start of their interview.

#### 2.4. Data collection

The topic guide was produced in collaboration with a PPI member (EE), discussed within the multi-disciplinary research team and piloted with four additional PPI members (Supplementary File 1). Fifteen semistructured telephone interviews were undertaken between February and March 2020. Telephone interviews reduced potential participation barriers such as travel costs and restricted mobility and allowed UKwide recruitment. Interviews were conducted by a male final year Medical Sciences student (LR) and a female intercalating Medical student (FF), both with an interest in asthma, and a trained qualitative researcher (TJ) was present for all interviews. There were no follow up interviews, however all participants were provided the opportunity to review their interview transcript and provide feedback after the interview. Three accepted the invitation to review their transcript and two provide amendments (name of medication).

Field notes were made during the interviews and they were audiorecorded and transcribed verbatim. Thematic analysis was undertaken [36] and transcripts coded by NVivo 12 software. Two researchers (FF, LR) familiarised themselves with the data by carrying out the transcripts and immersing themselves in the data by reading the transcripts multiple times to generate initial codes. All transcripts were double coded independently. Analysis was iterative with continual reviewing, reflection and synthesis of the data (FF, LR, TJ). Themes were derived from the initial codes and a coding manual produced with all codes and themes described and example quotations provided (FF, LR, TJ). All codes and themes were reviewed, defined and finalised in discussion with the multi-disciplinary research team to ensure valuable perspectives were included (FF, LR, TJ, MF, EE). Participants were invited to an online seminar presenting the results and offered the opportunity to comment at the meeting or afterwards by email. Feedback from participants was positive and no changes were made to the final results.

#### 3. Results

Sixteen participants were recruited from across the UK. However, one participant withdrew prior to the interview due to an asthmarelated hospitalisation. Fifteen participants each completed one individual, semi-structured telephone interview. Interviews lasted 19-41 minutes, no participants withdrew during or after the interviews, and no follow-up interviews were undertaken.

Participant characteristics are shown in Table 1. Participants were from across the UK (England = 7; Scotland = 7; Northern Ireland = 1)

#### Table 1

Participant characteristics.

Variable	Count	Percentage
Age	63-93 years	
Range	70.6 years	
Mean		
Gender n (%)	96	60
Female		40
Male		
Asthma diagnosis n (%)	1	6.7
Childhood onset	14	93.3
Adult Onset		
Duration of asthma n (%)	1	6.7
0-10 years	2	13.3
11-20 years	5	33.3
21-30 years	4	26.7
31-40 years	3	20
41 + years		
	6	40
Multimorbidities n (%)	4	26.7
Osteoarthritis	3	20
Allergies (inc. hay fever)	3	20
Visual impairments	3	20
High blood pressure	2	13.3
Osteoporosis	2	13.3
Cardiovascular disease	2	13.3
Diabetes (Type 2)		
Gastro-oesophageal reflux		
Number of multimorbidities (%)	1	6.7
0 conditions	2	13.3
1 condition	3	20
2 conditions	3	20
3 conditions	3	20
4 conditions	2	13.3
5 conditions	1	6.7
6 conditions		

and there were slightly more female participants (n=9) than male (n=6). Participants ranged in age from 62-93 years (mean 70.6 years) however there were no participants in their eighties. Participants reported having between zero and six additional long term conditions, with the majority living with at least one additional condition (n=14) and osteoarthritis being the most common (n=6). Only conditions reported by 2 or more participants have been recorded in Table 1.

Thematic analysis identified 5 main themes: (1) Impact of asthma on daily living; (2) managing asthma; (3) asthma and multimorbidities; (4) interaction with healthcare; (5) understanding of asthma. The findings are presented under these headings and a minor theme heading of COVID-19.

#### 3.1. Theme 1 - Impact of asthma on daily living

Many participants mentioned the physical restrictions that asthma place on their life, interfering with their day to day life, forcing them to introduce adaptations and preventing them from engaging in previously enjoyable activities. Asthma was described as "*tiring*" and participants noticed this fatigue had increased as they grew older, in part due to the natural progression of age but also due to living with a chronic condition. Avoiding triggers was important to participants, and this was achieved by avoiding places with high levels of pollution or pollen, wearing a face covering or administering additional does of their inhaler beforehand.

"Certain things like dusting or using the hoover; doing that for very long, it gets very hard so you have to sit down for a while"

"there are some things that I now can't do...not just...because of my age but because the asthma is interfering...We have got a large dog who absolutely adored running. Well I just can't run with him."

"I have to be careful...it [asthma] really does impact where I can go."

Restrictions placed on participants due to living with asthma had an impact on their social connections. Some felt embarrassment at the symptoms of their condition and how this hampered their abilities to participate in leisure activities. One participant felt asthma had placed a strain on friendships due to lack of people's understanding of asthma, the seriousness of the condition and the devastating effect it can have.

"It [asthma] restricts me, as I say, as far as walking is concerned with a group of similar age [people]...it would be embarrassing and awkward and all the rest of it to be dropping behind them on hills."

"I have a friend who...even when I've been taken into casualty, she doesn't seem to get the seriousness of it [asthma], she just, 'oh are you over your little asthma attack now'."

Living with asthma meant many participants experienced a persistent fear about their asthma and the possibility of an exacerbation. Day to day lives were impacted by a continuous underlying anxiety about potential exacerbations and need to know if they were able to access medication quickly. However, one participant felt that their years of experience living with asthma provided them confidence in their ability to effectively manage their symptoms.

"you get very worried about [asthma attacks]. You get worried about what is going to happen."

it's fear in my case, because if I don't take a dose...I do start to feel very unwell, and that kind of underlying anxiety...keeps me on top of things"

"When I was first diagnosed, I think I felt rather anxious...Whereas now, I can judge it more."

Side effects of long-term use of asthma medication such as thrush, hoarse voice and thinning of the skin caused discomfort and disruption to participants' lives. However, several participants advised they were unclear which symptoms were a result of living with asthma or merely signs of getting older.

"My skin just sort of shreds...I would have to be covered up in the summer which meant I was hot. I had to protect my legs because I kept damaging my legs on the bicycle"

"it can be difficult to distinguish between the side effects of the drugs and other changes that are going on as I get older."

#### 3.2. Theme 2 – Managing asthma

The importance of routine in effectively managing their asthma was a prominent topic discussed by the majority of participants. By integrating asthma self-management into their routine, it was easier to adhere to medication and recognise changes in symptoms. However, large lifestyle changes such as retirement were disruptive, interfered with long-standing routines which necessitated lifestyle adaptations.

"it's been so many years, it's now just part of my routine."

"When I was working it was easy... I would take it with my tea break in the afternoon...But now that I am retired I have had to actually put an alarm on my phone"

Taking medication became so integrated into daily routine that it became a task performed instinctively, leading to issues remembering whether it had been taken and increasing the risk for double-dosing and associated side effects. Cues such as keeping inhalers in the same place, or leaving it somewhere specific after use acted as reminders for taking medication.

"I do take the medication automatically... I may sometimes think...I can't actually remember having done that."

"the only way I do it, is by having a kind of visual symbol...I have to put [inhalers] in a particular spot in the morning."

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Mobile phone alarms were used as a reminder to take medication, apps were seen as a useful tool to support asthma self-management and the internet was a good educational resource to learn more about asthma. All of our participants were recruited through email, therefore had technological knowledge. However, they acknowledged that technology might not be suitable for all older adults and some older adults may need alternative types of resources that were accessible specifically for this population.

"One of the things that's come up now and again...was the development of apps...for everyone to use regarding their condition, but...there's an awful lot of my age group that have no idea what an app is."

"You'd be amazed at the number of [older] people that don't use computers, so they can't go on and check it...if you go to the GP today, there definitely won't be leaflets on asthma, definitely not..."

Living with someone else also provided a reminder to take medication or check symptoms. One participant stated that his wife often noticed his asthma deteriorating before he did which allowed him to avoid exacerbations. Additionally, cohabiting meant that during exacerbations, there was someone else present to support with asthma selfmanagement.

"It will tend to be my wife actually that will tell me 'you're coughing a bit more than normal' or 'you're panting"

"I'm quite fortunate in that I live with my husband...he is very fit...So, when I am unwell, then he is always there to look after me and make sure I've got all my medications."

"I think the younger ones would tend to be more controlled because of the fact that they've got parents looking after them... Whereas, with an older person, I think you're just left to swim along."

#### 3.3. Theme 3 – Asthma and multimorbidities

All but one of the participants were living with multiple conditions (Table 1) and had to negotiate competing treatments, medications and symptoms. Asthma was considered a management priority due to the necessity to breathe and life-threatening nature of exacerbations. However, other conditions were often more limiting, such as arthritis, and their symptoms impacted asthma self-management. Using a spacer when taking an inhaler was preferred as it compensated for dexterity issues result from musculoskeletal conditions.

"Breathing is very basic...you need to look after your breathing before anything else"

"I've got arthritic fingers, and if you're trying to take a deep breathe...and to depress the inhaler at the same time, with your rather cranky fingers, it's actually quite hard...having a volumizer [spacer] it's easier...I can breathe it at leisure."

Living with multiple conditions meant participants had to navigate complex management regimens and polypharmacy. A common problem discussed was the experience of being denied optimum treatment for another conditions because it was contraindicated for use in patients with asthma. The higher treatment burden contributed to difficulty remembering to take multiple medications; pill boxes were a popular aid in managing polypharmacy.

"The doctor has wanted to give me something, a medication, and they have had to say: 'oh no, you can't have that because you're asthmatic'."

"I'm struggling to remember to take them...for elderly people it is [a problem]. I have a lot of pills to take...it is a problem, increasingly, I think, for people to remember to take all these things in the right order."

#### 3.4. Theme 4 – Interaction with healthcare

The clinician-patient relationship was mostly negative with participants feeling that staff lacked an understanding of asthma and the complexities of managing multimorbidities. Health care professionals were perceived as being dismissive and disinterested in participants which resulted in participants being reluctant to share concerns or issues with their medical team. Older adults reported feeling like they were a burden to the healthcare system as they required additional support due to age and living with multimorbidities.

"I've found that my primary care team...they tend to be very dismissive of [the side effects]. Just say, 'oh well, that's something you've got to live with'."

"You don't bother to say, 'actually my fingers are cranky and this and that and the other', 'cause you think 'this person's not interested'."

"People like me who have a number of conditions are expensive to the health service...there is certainly a feeling about 'oh not you again'. It's not given off by any individual, but you get that feeling around the service."

Ageism was experienced by all participants and manifested in a number of ways. Age was often used by healthcare professional to explain participants' symptoms or concerns, several participants felt their concerns were not taken seriously by healthcare staff who informed them some symptoms were inevitable because of age and therefore not worth taking time to address. One participant recalled a recurring situation where her assumptions about her cognitive capacities are based on her appearance.

"They say that as you get older, your airways are maybe not as fit, and they blame it on all these different things. Age is a great thing to blame, isn't it?"

"[medical staff] tend to look at my [white] hair and think I'm much older than I am. So, they think that they need to speak loudly to me... 'Have you really understood what I have said to you?'...I'm always asked about my memory...And it's like: 'Okay, why not see the person, not the head?'."

There were few positive experiences reported and they mainly came from interactions with healthcare professionals who were living with asthma themselves. These professionals were perceived as having greater empathy, knowledge and understanding of the challenges of managing asthma as they had personal lived experience.

"I've got a good asthma nurse, because she has asthma herself, so she tends to say, 'you're not doing that correctly'... and she'll show you"

"She understood, she didn't trivialise the problem...: 'I understand completely why these things might be difficult'. And that was a real help."

Accessibility of care varied between the participants. Inability to obtain a timely appointment with primary care was a common barrier to accessing care and those who were able to secure this felt they were in a privileged position. Despite this, all participants had attended an annual asthma review in the previous 12 months, with one participant attributing the attentive medical care they received to their advanced age.

"It's silly little things [that make healthcare worse], like trying to get appointment times with doctors...you are booking six weeks in advance... No use if you need it for the day"

"We are very lucky in that we don't have the normal system of having to ring up and wait for an appointment for several weeks...we can get appointments fairly quickly."

"They keep an eye on me more I suppose [now I'm older], making sure I have my medication and that I am using it properly"

Only two participants were in receipt of a personalised asthma action plan and were positive of the benefits for asthma self-management. Three participants mentioned not having a plan but only one participant had explicitly requested one from multiple medical teams and, despite asthma action plans being considered best practice, she had not been provided one.

"I've been given an asthma plan. It does help and did help when I first started"

"I've been with four different practices since I was diagnosed...in none of those practices have I had a written asthma plan. I have even mentioned it...and it hasn't been forthcoming."

#### 3.5. Theme 5 – understanding of asthma

The majority of participants were experienced patients who had been living with asthma for a long time. They had an in-depth individual knowledge of what living with asthma looked like for them, and reported an increase in asthma control due to their extensive lived experience of managing asthma. They desired more opportunities to engage in shared decision making with healthcare professionals, but felt the power balance was currently more paternalistic and their lived experence dismissed.

"I don't usually get to the point where I am sort of struggling to breathe anymore. I can manage to regulate it so that I don't really get to that stage"

"They assume they know about my condition and they don't because I've been living with it for 69 years and I know what I'm doing. And the way they speak to you, frankly is, it's patronising."

Participants described a lack of awareness and understanding of asthma in older adults from medical and research staff and the wider public who viewed asthma as a disease of childhood. Many believed that the needs and experiences of older adults with asthma were overlooked in favour of reporting on children and young people living with asthma.

"there is more emphasis on childhood asthma, in general, in the press and places like that and the general public domain"

"at my age people tend to start forgetting about you and your problems to look after the little ones"

Participants were positive about more research into asthma in older adults and prioritised simpler treatments and furthering the understanding of the pathophysiology of the asthma with the hope of identifying a cure. Simpler treatment regimens would make it less time consuming, which was important for those managing multiple conditions and the accompanying polypharmacy. Participants with dexterity issues due to arthritis were supportive of developing an easier to use device to enable effective delivery of inhaled medication.

"Is it something that is genetic? Is it inherited? Or is it something that's caused by the environment? I think finding the triggers and the causes probably is the area which would need most research."

"I'd like them to research a simpler treatment...so that you can just take one convenient tablet or capsule rather than having a reliever, a preventer and the overnight montelukast. That would be the dream".

"As you get older, you've got arthritis in your hands, you've got different things...I think there should be options that you should be able to use different things."

All participants felt overlooked by research and were in agreement that asthma research needed to be more inclusive to all ages. Many believed that living with asthma changed as you grew older and there were many unique challenges specific to this population that could not be fully explored in research focused on younger age groups. "Well I think we are the forgotten age group...it would be nice for somebody to look at the older age group and work out what is actually happening with us."

"I want people to really understand what my asthma's like for me...not be thinking, 'oh, yes, well it's like that for 30 year olds' and then just actually superimpose that on somebody who's twice that age"

#### 3.6. Minor theme - COVID-19

The interviews coincided with the escalation of the COVID-19 global pandemic and was first mentioned by participant P9, whose interview took placed shortly after the first COVID-19 related fatality was recorded in the UK. Participants were concerned about COVID-19 and the potential risk of serious illness due to their age, having a long -term respiratory condition and other multimorbidities which made them vulnerable. In addition, participants were worried about the psychological impact on their families who were concerned about the participant becoming unwell and the potential of transmitting COVID-19 to them.

"what I'm worried about now is the coronavirus that's floating around... I'm in one of the higher age groups and with my asthma and my diabetes and everything I'm aware that I could be in one of those worst hit groups."

"my partner is very worried...She has a worry that if she contracts [COVID-19] that she might pass it onto me"

#### 4. Discussion

Older adults felt forgotten as younger populations with asthma were perceived as being a priority for healthcare and research. This qualitative study aimed to explore the experiences of older adults living with asthma in the UK, and how it impacts their lives. Participants encountered difficulties in managing their asthma as they aged due to balancing multimorbidities with complex medication regimens, increased burden of treatment and polypharmacy issues. Maintaining a routine was key for effective management and living with another person provided support in terms of medication reminders and symptom awareness. Technology has a role to play, but should not be the primary tool for selfmanagement for everyone in this age group. Extensive experience gained from years of living with asthma provided older adults with confidence in understanding their condition, but the COVID-19 pandemic highlighted how age can contribute to worse health outcomes. Experiences of ageism from healthcare professionals made older adults feel burdensome and resulted in a reluctance to report all health concerns or symptoms.

Physical changes and asthma symptoms restricted ability to engage in routine daily activites, such as housework and working [37]. Several participants reported avoiding activities and locations to evade potential triggers, which are techniques used by older adults to effectively manage their condition [6,37]. Inability to participate in social activities due to asthma symptoms and the lack of understanding surrounding the severity of asthma can damage interpersonal relationships, which raises concerns given the interactions between social isolation, loneliness and phsyical performance [38].

Depression is prevalent in people with asthma [39,40], however no participant in this study discussed experiencing depressive symptoms. Instead there were feelings of anxiety surrounding exacerbations and a heightened need to know medication location at all times [21,41]. The emergence of COVID-19 had also caused concern among some participants, especially due to the knowledge that older adults were more likely to be at risk of serious illness. The majority of participants were positive about their life and asthma, even those who were experiencing difficulties in managing multiple conditions and experiencing agesim from health care professionals.

Despite complex medication regimes and polypharmacy issues, none of the participants mentioned non-adherence to medication which contrasts with previous evidence [20,21]. However, the majority of participants identifed effective asthma management as essential due to the necessity to breathe, which could indicate the prioritisation of asthma medication. Inhaler use was challenging due to arthritis, muscle weakness and impaired visions but some issues were resolved by utilising a spacer for medication delivery [42]. There are many phenotypes of asthma and most symptoms start in childhood [43] so it is not surprising that many of the participants provided a long history of asthma. However, while people find ways to live with their asthma over time, their behaviour will be impacted by their experiences with asthma. People may potentially adopt inefficient inhaler techniques or become scared by episodes of exacerbations, therefore the best time to teach effective self-management skills is shortly after diagnosis [44].

All participants had attended an annual asthma review within 12 months which adheres to asthma guidelines [43], however our findings support previous evidence of older adults facing agesim in healthcare settings [45]. Dismissing symptoms and assuming poorer cognitive function due to patient appearance places strains on the patient-clinican relationship and worryingly results in older adults omitting potentially relevant and useful information to clinicians. There is a difficult balance between acknowledging the experience older adults have from living with their condition for multiple years, and providing the additional care needed as people age. This could be resolved by more tailored treatments, identification of high risk cases and training for clinicians on interacting with older adults. Older adults are the fastest growing population in the UK and there is a need to acknowledge and combat agesim within healthcare provision [46], and targeted interventions should be considered as older adults are more receptive to advice on asthma self-management than younger adults [24]. Gaining an understanding of older adults' perceptions and experiences of living with asthma is needed to allow tailored interventions and research aimed at improving the lives of this population.

To ensure scientific rigor of the study, we used a variety of techniques including: interviews conducted by two researchers (FF, LR); respondent validation of interview transcripts; double-coding of transcripts by two researchers (FF, LR). Themes were finalised by bringing in valuable perspectives in a multi-disciplinary team which included representation from patients, clinicians and academics. Telephone interviewing removed barriers to recruitment, such as restricted mobility, and increased external validity through UK-wide recruitment resulting in participants from three UK countries (England, Scotland, and Northern Ireland). All authors agreed data saturation had been achieved after 15 interviews, but we acknowledge the results reported may have differed with an alternative sample.

The REgister for Asthma researCH database (REACH) [33] members have registered to be contacted regarding asthma research, indicating an interest, knowledge and awareness of asthma research, therefore participants recruited through REACH may not be representative of the wider population of older adults living with asthma. Using emails for communication could have excluded older adults without email access and those with cognitive impairments. Access and ability to use emails could also indicate a sample more likely to use technological aids for asthma self-management, however this was acknowledged by participants and considered during data analysis. The majority of participants were aged between 65-79 years, however one participant was in their nineties (P1) and the themes emerging from their interview were similar to the other participants.

#### 5. Conclusions

Our study concludes that the lack of understanding, awareness and coverage of asthma in older adults led to participants feeling forgotten. Further research is needed to develop accessible medication devices, greater understanding in healthcare to improve patient/clinician relationships and inclusion in clinical trials to ensure treatments are effective for older adults with asthma. Results should be considered when developing and undertaking research aimed at improving the lives of older adults living with asthma.

#### Data Availability

The data that support the findings of this study may be available from the corresponding author upon reasonable request.

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#### Contributions

EE, TJ and MF designed the study. TJ was responsible for recruitment of participants. FF and LR were responsible for data collection and initial data analysis, with support from TJ. All authors were involved with final data analysis. TJ drafted the manuscript and all authors critically reviewed the manuscript, contributing important intellectual content and approved the final manuscript.

#### **Declaration of Competing Interests**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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#### Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.ahr.2022.100079.

#### References

- Global Asthma Network. The Global Asthma Report 2018. Available from: htt p://www.globalasthmanetwork.org/publications/Global\_Asthma\_Report\_2014.pdf [Accessed March 2021].
- [2] Asthma UK. Asthma facts and statistics | Asthma UK. Available from: https://www.asthma.org.uk/about/media/facts-and-statistics [Accessed March 2021].
- [3] Mukherjee M, Stoddart A, Gupta RP, Nwaru BI, Farr A, Heaven M, et al. The epidemiology, healthcare and societal burden and costs of asthma in the UK and its member nations: analyses of standalone and linked national databases. BMC Med 2016;14(1):113.
- [4] Levy, M., Andrews, R., Buckingham, R., Evans, H., Francis, C., Houston, R., et al. Why asthma still kills: the National Review of Asthma Deaths (NRAD): Royal College of Physicians; 2014.
- [5] Office for National Statistics. Living longer Office for National Statistics. Available from: https://www.ons.gov.uk/peopleopopulationandcommunity/birthsdeathsan dmarriages/ageing/articles/livinglongerhowourpopulationischangingandwh yitmatters/2018-08-13 [Accessed March 2021].
- [6] Gibson PG, McDonald VM, Marks GB. Asthma in older adults. Lancet North Am Ed 2010 Sep 4;376(9743):803–13.
- [7] Asthma UK. The forgotten generation. Asthma UK 2012.
- [8] Trivedi M, Denton E. Asthma in children and adults—what are the differences and what can they tell us about asthma? Front pediatrics 2019 Jun 25;7:256.
- [9] Gillman A, Douglass JA. Asthma in the elderly. Asia Pacific Allergy 2012;2(2):101.
  [10] British Lung Foundation. Asthma statistics | British Lung Foundation 2021. Available from: https://statistics.blf.org.uk/asthma.

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- [11] Bloom CI, Nissen F, Douglas IJ, Smeeth L, Cullinan P, Quint JK. Exacerbation risk and characterisation of the UK's asthma population from infants to old age. Thorax 2018 Apr 1;73(4):313–20.
- [12] Triebner K, Johannessen A, Puggini L, Benediktsdóttir B, Bertelsen RJ, Bifulco E, Dharmage SC, Dratva J, Franklin KA, Gíslason T, Holm M. Menopause as a predictor of new-onset asthma: a longitudinal Northern European population study. J Allergy Clin Immunol 2016 Jan 1;137(1):50–7.
- [13] Moorman JE, Akinbami LJ, Bailey CM, Zahran HS, King ME, Johnson CA, Liu X. National surveillance of asthma: United States, 2001-2010. Vital & health statistics. Series 3, Anal epidemiological stud 2012;1(35):1–58.
- [14] Baptist AP, Hamad A, Patel MR. Older women with asthma: special challenges in treatment and self-management. Annals of allergy, asthma & immunology: official publication of the American college of allergy. Asthma, & Immunol 2014;113(2): 125.
- [15] Boulet LP. Asthma in the elderly patient. Asthma res practice 2016;2(1):1-5.
- [16] Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. Lancet North Am Ed 2012;380(9836):37–43.
- [17] Gibson PG, Simpson JL. The overlap syndrome of asthma and COPD: what are its features and how important is it? Thorax 2009;64(8):728–35.
- [18] Bujarski S, Parulekar AD, Sharafkhaneh A, Hanania NA. The asthma COPD overlap syndrome (ACOS). Curr Allergy Asthma Rep 2015;15(3):7.
- [19] Salive ME. Multimorbidity in older adults. Epidemiol Rev 2013;35(1):75-83.
- [20] Melani AS. Management of asthma in the elderly patient. Clinical interventions in aging 2013;8:913.
- [21] O'Conor R, Martynenko M, Gagnon M, Hauser D, Young E, Lurio J, et al. Supporting asthma self-management behaviors among aging adults (SAMBA) investigators. A qualitative investigation of the impact of asthma and selfmanagement strategies among older adults. J Asthma 2017;54(1):39–45.
- [22] Horne R, Chapman SC, Parham R, Freemantle N, Forbes A, Cooper V. Understanding patients' adherence-related beliefs about medicines prescribed for long-term conditions: a meta-analytic review of the necessity-concerns framework. PLoS One 2013;8(12):e80633.
- [23] Allen SC, Jain M, Ragab S, Malik N. Acquisition and short-term retention of inhaler techniques require intact executive function in elderly subjects. Age Ageing 2003; 32(3):299–302.
- [24] Hira D, Komase Y, Koshiyama S, Oguma T, Hiramatsu T, Shiraki A, et al. Problems of elderly patients on inhalation therapy: Difference in problem recognition between patients and medical professionals. Allergol Int 2016;65(4):444–9.
- [25] Turan O, Turan PA, Mirici A. Parameters affecting inhalation therapy adherence in elderly patients with chronic obstructive lung disease and asthma. Geriatrics Gerontol Int 2017;17(6):999–1005.
- [26] Herrera AP, Snipes SA, King DW, Torres-Vigil I, Goldberg DS, Weinberg AD. Disparate inclusion of older adults in clinical trials: priorities and opportunities for policy and practice change. Am J Public Health 2010;100(S1):S105–12.
- [27] Reed CE. Asthma in the elderly: diagnosis and management. J Allergy Clin Immunol 2010;126(4):681–7.
- [28] Cooper V, Metcalf L, Versnel J, Upton J, Walker S, Horne R. Patient-reported side effects, concerns and adherence to corticosteroid treatment for asthma, and comparison with physician estimates of side-effect prevalence: a UK-wide, crosssectional study. NPJ primary care respiratory med 2015;25(1):1–6.

- [29] Linceviciute S. Making Sense of Older Adult's Lives with Asthma: Experiences from the Point of Asthma Diagnosis to Their Current Living [Doctoral dissertation]. University of Portsmouth; 2018.
- [30] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007;19(6):349–57.
- [31] I want to help with research. National Institute for Health Research (NIHR); 2021. Available from: https://www.nihr.ac.uk/patients-carers-and-the-public/i-want-t o-help-with-research/.
- [32] National Standards for Public Involvement. National Institute for Health Research (NIHR); 2021. Available from: https://sites.google.com/nihr.ac.uk/pi-standards/h ome.
- [33] Nwaru BI, Soyiri IN, Simpson CR, Griffiths C, Sheikh A. Building a recruitment database for asthma trials: a conceptual framework for the creation of the UK database of asthma research volunteers. Trials 2016;17(1):1–8.
- [34] NHS Employers. British medical association. quality and outcomes framework for 2012/13. Guidance for PCOs and practices 2021. Available from: http://www.nh semployers.org/.
- [35] Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant 2018;52(4):1893–907.
- [36] Braun V, Clarke V. Using thematic analysis in psychology. Qualitative res psychol 2006;3(2):77–101.
- [37] Woods EC, O'Conor R, Martynenko M, Wolf MS, Wisnivesky JP, Federman AD. Associations between asthma control and airway obstruction and performance of activities of daily living in older adults with asthma. J Am Geriatr Soc 2016;64(5): 1046–53.
- [38] Philip KE, Polkey MI, Hopkinson NS, Steptoe A, Fancourt D. Social isolation, loneliness and physical performance in older-adults: fixed effects analyses of a cohort study. Sci Rep 2020;10(1):1–9.
- [39] Oğuztürk Ö, Ekici A, Kara M, Ekici M, Arslan M, Iteginli A, et al. Psychological status and quality of life in elderly patients with asthma. Psychosomatics 2005;46 (1):41–6.
- [40] Ross JA, Yang Y, Song PX, Clark NM, Baptist AP. Quality of life, health care utilization, and control in older adults with asthma. The J Allergy Clin Immunol: In Practice 2013;1(2):157–62.
- [41] McDonald VM, Higgins I, Gibson PG. Insight into older peoples' healthcare experiences with managing COPD, asthma, and asthma–COPD overlap. J Asthma 2013;50(5):497–504.
- [42] Bellia V, Pedone C, Catalano F, Zito A, Davià E, Palange S, et al. Asthma in the elderly: mortality rate and associated risk factors for mortality. Chest 2007;132(4): 1175–82.
- [43] Global Initiative for Asthma. Global Strategy for Asthma Manage Prevent: Updated 2021 2021. Available from: https://ginasthma.org/wp-content/uploads/2021/05/ GINA-Main-Report-2021-V2-WMS.pdf [Accessed March 2021].
- [44] Daines L, Morrow S, Wiener-Ogilvie S, Scott C, Steed E, Taylor SJC, Pinnock H. Understanding how patients establish strategies for living with asthma: IMP2ART qualitative study. Br J Gen Pract 2020;70:e303–11.
- [45] van den Heuvel WJ. Discrimination against older people. Rev Clin Gerontol 2012; 22(4):293–300.
- [46] Kagan SH, Melendez-Torres GJ. Ageism in nursing. J Nurs Manag 2015;23(5): 644–50.