Patient preferences for asthma management: a qualitative study

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ABSTRACT

Objective Preference for asthma management and the use of medications is motivated by the interplay between lived experiences of asthma and patients’ attitudes towards medications. Many previous studies have focused on individual aspects of asthma management, such as the use of preventer and reliever inhalers. The aim of this qualitative study was to explore the preferences of patients with mild–moderate asthma for asthma management as a whole and factors that influenced these preferences.

Design A qualitative study employing qualitative descriptive analysis situated within a constructionist epistemology to analyse transcribed audio recordings from focus groups.

Setting Three locations within the greater Wellington area in New Zealand.

Participants Twenty-seven adults with self-reported doctor’s diagnosis of asthma, taking short-acting beta-agonists alone or inhaled corticosteroids with or without long-acting beta-agonist, who had used any inhaled asthma medication within the last month.

Results Four key areas described preferences for asthma management. Preferences for self-management: participants wanted to be in control of their asthma and developed personal strategies to achieve this. Preferences for the specific medications or treatment regimen: participants preferred regimens that were convenient for the specific medications or treatment regimen: participants preferred regimens that were convenient and reliably relieved symptoms. Preferences for inhaler devices: devices that had dose counters and were easy to use and portable were important. Preferences for asthma services: participants wanted easier access to their inhalers and to be empowered by their healthcare providers. Participant preferences within each of these four areas were influenced by the impact asthma had on their life, their health beliefs, emotional consequences of asthma and perceived barriers to asthma management.

Conclusions This study illustrates the interaction of the lived experience of asthma, factors specific to the individual, and factors relating to asthma treatments in shaping patient preferences for asthma management. This aids our understanding of preferences for asthma management from the patient perspective.

Trial registration number Australian New Zealand Clinical Trials Registry (ACTRN12619000601134).

Strengths and limitations of this study

► A broad approach to exploring the patient experience of asthma, its management and preferences for management enabled a novel analysis of patient preferences and patient experiences of asthma that influence their preferences.

► Participants were from a wide range of backgrounds, with over 50% identifying as Māori, the indigenous people of New Zealand, who have a higher prevalence of asthma and poorer asthma outcomes.

A limitation of the study was that the majority of participants were women (23/27), which may affect the transferability of these finding to men.

INTRODUCTION

Living with asthma has a significant impact on patients’ physical and psychological well-being. 1 2 Patients describe shortness of breath, chest tightness and impact of asthma on physical activities as specific troubling symptoms. 3 4 Previous qualitative studies 5 and a meta-synthesis of qualitative studies 6 found people with asthma are motivated by the interplay between lived experiences of asthma, the effect asthma has on desired activities and their attitudes towards medications. People with asthma learn to live with their asthma and adapt how they take medications and access healthcare according to their preferences and experiences.

In asthma, poor adherence to daily inhaled corticosteroids (ICS) and inappropriate reliance and overuse of short-acting beta-agonists (SABA) for symptom relief are commonplace 7 8 and represent significant problems as these patterns of behaviour are associated with increased symptom burden and exacerbations. 9 The intermittent nature of symptoms and overestimation of asthma control 10 means treatment is often suboptimal and adherence to daily preventer inhalers problematic. 11 This is particularly true for indigenous peoples, 12 including Māori of New Zealand 13 who are disproportionately affected by asthma and adverse asthma outcomes. 14 Qualitative and population-based studies show patients preferentially take reliever...
inhalers over preventer inhalers,\textsuperscript{7, 15} this is supported by pharmacy records as more prescriptions for SABA are dispensed than ICS.\textsuperscript{16} When deciding whether to take inhalers, patients weigh-up (consciously or subconsciously) the perceived risks and benefits.\textsuperscript{17, 18} Decisions relating to treatment engagement are influenced by patients’ expectations and perceptions, which may be misinformed. For example, patients may have low expectations of what treatment can achieve,\textsuperscript{19} have concerns about taking inhalers and use of inhaled corticosteroids or believe they are only needed intermittently.\textsuperscript{20, 21} In addition, there is evidence that patients would prefer to take a combined preventer and reliever inhaler in response to symptoms over a daily preventer inhaler with a reliever inhaler for symptom relief.\textsuperscript{22}

Previous studies such as these have examined specific aspects of patient preferences for asthma management, but there is a paucity of information from a holistic perspective investigating patient preferences and priorities for asthma management as well as the factors that might influence preferences. To improve asthma management and outcomes it is important to understand the patient perspective for asthma management as whole as they experience it rather than individual components such as preferences for inhalers. In this qualitative study, the aim was to explore adult patients’ experiences of asthma and preferences for asthma management.

**METHODS**

**Study design**

Methods and results are reported according to the Consolidated Criteria for Reporting Qualitative Research guidelines (see online supplementary file).\textsuperscript{23} A qualitative descriptive analysis situated within a constructionist epistemology was employed to describe patient preferences for treatment.\textsuperscript{24} All participants were given written information prior to attending and provided written informed consent. Characteristics of the research team are provided in the online supplementary file.

**Participant recruitment**

We recruited adults aged 18–75 years with a self-reported doctor’s diagnosis of asthma, who had a current prescription for one or more asthma inhalers and used an inhaler for asthma within the last month. We excluded people who were not fluent in English, had other respiratory diagnoses or who had severe asthma based on the use of step 4 or 5 treatments according to the 2018 Global Initiative for Asthma (GINA) strategy.\textsuperscript{25} We undertook purposive sampling with the aim of achieving a mix of ages, gender and ethnicities; we intended to recruit Māori, at least in proportion to the current New Zealand population (15%). We predominately advertised via social media. Tu Kotahi Māori Asthma Trust (a Māori-led asthma service in Wellington) assisted with the recruitment of Māori participants, in line with recommendations for research with indigenous peoples.\textsuperscript{26} All participants received 50NZ$ for attending and could bring a support person if they signed a confidentiality agreement.

**Data collection**

We collected data via five one-off focus groups conducted between 7 May 2019 and 19 August 2019 at the Medical Research Institute of New Zealand (central city), an after-hours medical centre (urban site) and a community centre in an outer suburb. We used a variety of locations to increase the participation of people from diverse backgrounds. Focus groups were conducted face-to-face. Before the discussion started, participants were asked to complete a short survey collecting basic demographics, information on current inhaler use and asthma control (online supplementary file).

Focus groups were audio-recorded and transcribed verbatim. Groups lasted 60–80 min with two facilitators—either CB (a respiratory specialist doctor), AC (a pharmacist) or SH (a nurse)—experienced in qualitative methodologies and began with an introduction to the research. A discussion guide was used, developed prior to the commencement of the study (online supplementary file) informed by the study aims, review of the literature on patient preferences for asthma management, beliefs about asthma medications and the Necessities Concerns Framework proposed by Horne et al.\textsuperscript{27} MH provided a review of the discussion guide from a Māori perspective. The discussion was semi-structured, between participants with prompts and questions from facilitators. The discussion guide was iterated as appropriate based on preliminary analysis of data from preceding groups. Focus groups continued until thematic saturation was achieved—when two groups had been conducted with no new themes emerging. Brief notes were made during the group, and CB reflected on each group afterwards. For participants who requested it when giving consent, a transcript of their own data were provided, but none requested alterations.

**Data analysis**

Descriptive statistics summarise information on demographics, asthma control and medication use. NVivo V.12 was used for management and coding of the qualitative data. Thematic analysis was used to analyse the data,\textsuperscript{28} themes were derived from the data. Initial coding was done on a line-by-line basis with an iterative process of reading, reviewing and refining themes and subthemes to develop overarching concepts. All the data were coded by CB with AC peer coding 20% of the data. Emerging themes and concepts were discussed and iterated following each focus group between CB, AC and WL with MH providing the Kaupapa Māori research oversight.\textsuperscript{26} The supplement includes additional quotes in (online supplementary tables S1–S8).

**Patient and public involvement**

There was no public or patient engagement in the study development or design. Participants were given the
opportunity to edit their transcripts and provided with a summary of the results.

RESULTS
Participant characteristics
We held five focus groups, each with three to eight participants (total n=27), mean age 37 years; 56% of participants identified as Māori and participated across all focus groups, 56% had uncontrolled asthma as per GINA asthma symptom control, and 70% reported urgently visiting their doctor at least once in the last year for asthma (table 1). Most participants (59%) were taking ICS/long-acting beta-agonist (LABA) maintenance therapy with a SABA reliever (table 2), corresponding to step 3 of then-current New Zealand asthma guidelines.29

Overview of findings
Participants’ descriptions of their experience of asthma and its management comprised four factors: (1) the impact of asthma on life, (2) emotional consequences of asthma, (3) health beliefs and (4) perceived barriers to asthma management. Preferences for asthma management fell into four key areas: (1) preferences for self-management, (2) specific preferences for medications or regimens, (3) preferences for inhaler devices and (4) preferences for asthma services.

Patient experiences of asthma and its management
Impact of asthma on life
Asthma had far-reaching effects on participants’ lives. Physical experiences of asthma symptoms were forefront in all participants’ narratives. Breathlessness was the most common symptom and had the greatest impact. Night waking due to asthma and cough had a greater impact on participant’s lives than other asthma symptoms such as wheeze, chest tightness and sputum. Asthma frequently limited physical exertion such as walking up inclines and restricted participation in sports.

Asthma affects me from like my day to day with like just a lot of the simple things that a lot of people can do and almost they take for granted… I used to always really like to play sport, I played cricket and soccer, but I had to give it up because it just got so bad that I couldn’t even walk without it just flaring up and me almost conking out on the floor. (G5P2)*

* Following each quote is the participants’ focus group number and participant number.

Participants’ perception of their asthma severity ranged from very mild to ‘nowhere near cope-able’ (G1P1). Asthma could flare up very suddenly. Experiences of asthma flare-ups had short-term effects from the impact of worsening symptoms but also longer-term effects as some participants experienced worsening symptoms for several months that they struggled to control.

One minute you’re standing up and the next minute you’re on the floor. (G3P6)

Table 1  Participant characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N=27</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex N (%)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>23 (85)</td>
</tr>
<tr>
<td>Male</td>
<td>4 (15)</td>
</tr>
<tr>
<td>Age—years</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>37.1 (15.3)</td>
</tr>
<tr>
<td>Range</td>
<td>19–67</td>
</tr>
<tr>
<td>Age at asthma diagnosis—years</td>
<td></td>
</tr>
<tr>
<td>8.8 (12.0)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity N (%)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>2 (7)</td>
</tr>
<tr>
<td>Māori</td>
<td>15 (56)</td>
</tr>
<tr>
<td>(Māori+another ethnic identity)</td>
<td>11 (73)</td>
</tr>
<tr>
<td>NZ European</td>
<td>10 (37)</td>
</tr>
<tr>
<td>Highest level of education N (%)</td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>3 (11)</td>
</tr>
<tr>
<td>Some college</td>
<td>8 (30)</td>
</tr>
<tr>
<td>Three or more years at college or university</td>
<td>16 (59)</td>
</tr>
<tr>
<td>Smoking status N (%)</td>
<td></td>
</tr>
<tr>
<td>Current smoker</td>
<td>8 (30)</td>
</tr>
<tr>
<td>Ex-smoker</td>
<td>9 (33)</td>
</tr>
<tr>
<td>Never smoker</td>
<td>10 (37)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of urgent visits to a doctor for asthma in the last year N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>≥3</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>GINA 2018 level of asthma symptom control N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well controlled</td>
</tr>
<tr>
<td>Parity controlled</td>
</tr>
<tr>
<td>Uncontrolled</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current asthma medication use N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SABA monotherapy</td>
</tr>
<tr>
<td>ICS+SABA</td>
</tr>
<tr>
<td>ICS/LABA (SMART therapy)</td>
</tr>
<tr>
<td>ICS/LABA+SABA</td>
</tr>
</tbody>
</table>

Data are means (SD) unless otherwise stated. See Beasley R29 for NZ asthma guidelines that applied at the time of the focus groups. GINA, Global Initiative for Asthma; ICS, inhaled corticosteroid; LABA, long acting beta-agonist; NZ, New Zealand; SABA, short acting beta-agonist; SMART, single maintenance and reliever therapy.

Asthma affected the participants’ ability to interact with their peer group and engage in social activities and contributed to frustration and isolation. Asthma had a direct monetary cost, through the costs of general practitioner (GP) appointments and repeat prescriptions, and
some felt asthma negatively impacted on employment opportunities.

When I go for a job I don’t put down I’m an asthmatic, cause otherwise they don’t want you. (G4P4)

Asthma treatments interfered with participants’ lives, including time taken to use inhalers properly, medication side effects, numbers of medications and inconvenience.

**Emotional consequences of asthma**

Asthma flare-ups were frightening experiences; some were severe enough that the patients feared they might die. Anxiety about timely access to emergency help influenced behaviour and life choices, such as avoiding certain activities like hiking. Participants discussed people they knew or had read about in the media who died from asthma, which affected how they felt about asthma and its treatment.

Cause I thought I was going to die and then my kids are standing there going Mama going to die, you know, and then I come up with all these beautiful words. (G4P5)

The unpredictable and variable nature of symptoms led to feelings of fear, worsened by concerns about access to reliever inhalers or reliever inhalers may not work when symptoms were severe.

I was so heavily reliant on [salbutamol] being my saviour when I needed it. And when I would run out of it, I would have this massive rush of, oh crap, what’s gonna happen if I have an asthma attack? (G2P1)

When discussing the interplay of asthma and mental health, some participants acknowledged having mental health problems because of their asthma experiences, or mental health problems could lead to worsening asthma. Anxiety was the most commonly discussed mental health problem; pre-existing anxiety was worsened by asthma symptoms, use of SABA, or by concerns about access to medications. For some, weight gain from oral steroids contributed to eating disorders.

It's like a feedback loop, your asthma causes your anxiety and your anxiety causes your asthma. (G2P3)

**Health beliefs**

Participants’ beliefs about benefits and the perceived necessity of preventer and reliever inhalers, together with personal experiences, shaped their management strategies. Most participants admitted to episodes of poor adherence to preventer inhalers, and some had stopped them completely. Some felt their preventer inhalers were necessary and noticed the benefits of using them, while others preferred to live life without them—considering preventers optional. Some participants doubted the efficacy of preventer inhalers and admitted to not using them at all. Not feeling the medication working immediately or being required to take it even if they did not have asthma symptoms reinforced these perceptions.

Yeah, I don’t really use it [the preventer inhaler] though. I think it’s probably because I think it’s not going to work. (G1P3)

In contrast, participants did not express doubts about the necessity of their reliever inhalers. Many participants expressed some scepticism about medicines in general, discussing concerns about medications or the need to minimise the use of medicines altogether. They worried that overuse of preventer and reliever inhalers could cause them to become addicted to or dependent on their medications or had concerns about overdosing.

I try and make my body starve a little bit [i.e. take less medications], cause of the toxins I’ve been on. Cause I class it [asthma preventer and reliever medications] as toxin. (G4P5)

**Barriers to asthma management**

Barriers to managing asthma were widely discussed. Some participants described a lack of understanding or education about asthma as a barrier to managing asthma. Interactions with healthcare professionals did not always meet their expectations or healthcare needs—and asthma and
its treatments were not appropriately explained. Participants wanted a deeper understanding of asthma and their medications and wanted to feel their doctor had assessed their asthma and response to treatment properly.

For my asthma inhalers I find that I don’t know whether I’m taking my asthma inhaler right because my doctor never asked me anything about it. It’s just like, here’s your repeat prescription, there you go. It’s not an in-depth conversation. (G1P1)

Most participants had experienced conflict with healthcare professionals over their asthma management. When they sought help for worsening asthma, some felt they were being judged, they were overreacting or responsible for their situation.

I went and got an emergency inhaler and was treated at the pharmacy like I should be in jail for even asking for an emergency [reliever inhaler]. (G2P1)

There were instances where participants described conflicting advice or misinformation from healthcare professionals.

Participants felt family and friends often did not understand asthma properly, including it could be life threatening. This led to feelings of embarrassment about their symptoms or using asthma inhalers in front of others, which affected social interactions and delayed use of reliever inhalers.

I think asthma is tough in terms of believability because people who don’t know what to look for don’t believe you until you are literally on the floor because you can’t breathe. (G2P3)

**Patient preferences for asthma management**

**Asthma self-management**

Participants wanted to be in control of their asthma and wanted it not to prevent them from doing things that I want to’ (G2P4). They developed their own strategies to feel in control. Routine was a positive strategy, which promoted regular use of preventers whereas lack of routine and forgetfulness contributed to erratic use of preventer inhalers. Access to inhalers and control over inhaler supplies were important to participants’ management strategies, and included stockpiling inhalers, using out-of-date inhalers, or borrowing them from others.

Running out of inhalers or restricted access due to dispensing rules at pharmacies (online supplementary file) led to anxiety and worsening asthma in some participants. Some participants responded by ‘training’ their healthcare providers to improve their access to inhalers. For some written asthma action plans were a useful aid to managing asthma, which gave them legitimacy when seeking help for uncontrolled asthma. However, others did not like these plans because they were complicated or difficult to follow.

Most participants recognised their specific asthma triggers such as animals, perfume or viral infections, and would limit their exposure to triggers or adjust their treatments.

**Regimen and medication preferences**

Participants wanted a treatment that would ‘get rid of my asthma’ (G1P7); some felt that preventing or relieving asthma symptoms did not really count as treatment because it did not ‘cure’ it. They valued medicines that had observable effects, particularly in times of worsening asthma. This included combination ICS/LABA inhalers that ameliorated symptoms quickly, although many said SABAs were their best treatment option because of their obvious and reliable effects.

That’s what I like about [budesonide-formoterol], you take it when you’re wheezy and you’re not wheezy anymore, it’s great. (G3P7)

Trust in the effectiveness of asthma medications was important. Participants trusted reliever inhalers they had used as children, could feel working or inhalers that gave some physical sensation when used. The taste of inhalers, even if unpleasant, reassured participants that ‘something’s gone in’ (G5P1). Lack of a physical sensation meant some questioned if the inhaler had actuated properly, or if the medication was working. Participants did not like side effects from their inhalers, for example, ‘shakes’ from SABAs or oral thrush from ICS.

Some participants described high use of SABA inhalers, driven by their personal strategies for managing worsening asthma and beliefs regarding its effectiveness for symptom relief, for example, 30 puffs for an attack or an entire inhaler (200 doses) in a week.

Yeah, so I always make sure I’ve got three of those [reliever inhalers]. Cause when it’s really bad I can go through an inhaler in a week. (G5P1)

Participants wanted convenient, simple treatments. Some found their treatment regimens confusing and were not sure when or how to use their medications. Participants liked adjusting their medications themselves; some were on a regimen that allowed increased doses of ICS-formoterol in response to symptoms (single maintenance and reliever therapy (SMART)), while others had adapted their treatments themselves by increasing or decreasing use of preventer and reliever inhalers in response to different situations. Being able to use a preventer only when needed was considered preferable. Many described wanting to reduce their use of medication, particularly preventer inhalers.

Taking preventers every day was ‘annoying’; participants felt ‘put off’ by a two times per day prescription. One time a day use was easier to remember and was preferred, particularly if it meant reliever inhalers were not needed for the rest of the day.

The ideal inhaler for me would just be a once a day and it takes you throughout the whole day and night, you don’t need to worry about it again. (G1P1)
Device preferences
Participants liked inhaler devices that were small, easy to use, portable and would fit in a pocket. Some were happy to use spacers, whereas others were not and valued inhalers which did not need a spacer. They wanted their inhalers to contain more doses and last longer. A dose counter (not included on some preventer and reliever inhalers in New Zealand) was important for all participants because it allowed them to plan when to get another inhaler and avoid using empty inhalers.

If you take pills you can see how many you’ve had, but with an inhaler it’s just like all of a sudden there’s none left. (G4P2)

There was variation in preference for dry powder inhalers or metered dose inhalers. Many didn’t like the noise of metered dose inhalers because it drew attention to them taking the inhaler. Participants had environmental concerns about inhaler devices, particularly the quantity of plastic generated and wanted inhalers to be recycled or refillable.

Preferences for services
Participants wanted a positive relationship with healthcare providers; however, many described negative interactions such as being made to feel ‘shame’ or not receiving a ‘warm reception’ when seeking care for asthma or felt they were ‘getting a lecture’. When they went to see healthcare providers, participants wanted to be taken seriously, and feel their asthma and treatment had been properly reviewed. They wanted to be empowered by health professionals to manage their asthma.

I want when I go to a doctor or to ED [emergency department] or somewhere, I want to stop feeling shame. (G3P6)

Participants wanted their inhalers to be easier to obtain, and for there to be less ‘red tape’. They felt obtaining asthma inhalers was more difficult than other prescription medications, and the system of organising and collecting repeat prescriptions confusing and unfair. Some described being limited to one preventer inhaler at a time, but were given several SABA inhalers. This, combined with difficulty getting to see their doctor or having to wait for repeat prescriptions meant some had times without inhalers. They wanted the frequency of routine appointments for repeat prescriptions and medications reduced and to be dispensed more inhalers each time. They wanted the process of going for a review and collecting prescriptions and medications to be ‘streamlined’ and flexible.

Gosh, for something that assists your breathing, it [inhalers] should be more accessible. (G3P8)

An overview of patient experiences and patient preferences for asthma management, is given in Table 3.

Table 3 Overview of factors influencing patient preferences for key areas of asthma management

<table>
<thead>
<tr>
<th>Patient experiences that affected preferences</th>
<th>For example, experience of symptoms, restriction of activity, flare-ups, interactions with peers, cost, inconvenience and side effect of medications.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.Impact of asthma on the patient’s life</td>
<td>For example, frightening asthma experiences, concern about access to medications and emergency services, awareness of deaths due to asthma, interplay between asthma and mental health.</td>
</tr>
<tr>
<td>2.Emotional consequences of asthma</td>
<td>For example, lack of understanding and education, negative interactions with healthcare professionals and embarrassment.</td>
</tr>
<tr>
<td>3.Health beliefs</td>
<td>For example, beliefs about benefits and necessity of inhalers and concerns about medications.</td>
</tr>
<tr>
<td>4.Barriers to asthma management</td>
<td>For example, personal strategies, control over inhaler supplies, management of triggers and written asthma action plans.</td>
</tr>
</tbody>
</table>

DISCUSSION
This qualitative study explored patient experiences of asthma and its treatment and provides an overarching narrative of the patient experience of asthma and preferences for asthma management (Table 3). Patient experiences of asthma influenced their preferences for the different aspects of asthma management in varying degrees.

We found that there was no single version of what ‘ideal asthma management’ was. However, there was general agreement that less frequent use of preventer medications was preferable. Participants wanted to feel their medications working quickly, have control over their treatment
and be able to adjust it as necessary. They wanted a dose counter on all their inhalers to let them know how much medication remained and wanted barriers to timely and accessible healthcare removed. From the participants’ perspective, management of asthma in clinical practice could be improved if clinicians acknowledged how asthma impacts on their life, where possible tailored treatment regimens to their preferences and empowered them to manage their asthma.

Consistent with previous qualitative studies, shortness of breath was a distressing symptom with a substantial impact on the participants’ lives. Asthma led to activity limitation, but participants adapted by changing their activities or normalising their experience. Similar to other qualitative studies, we found fear was a common part of participants’ asthma narrative. In our study, fear was linked to previous experiences of uncontrolled asthma or anxieties about availability or effectiveness of asthma medications, for some participants anxiety and asthma were closely interrelated. Similar to previous research, our participants had a range of health beliefs surrounding their preventer inhalers; however, they did not doubt the necessity of their reliever inhalers. Barriers to asthma management led to participants feeling they did not have the necessary control over their management. This study fills an important evidence gap about what patients themselves perceive as ideal ways of managing asthma, and their own priorities for asthma management, an understanding of which is essential to improving asthma outcomes.

We did not anticipate the negative reactions from healthcare professionals that many participants described experiencing when seeking care for their asthma, or the difficulty they had in obtaining inhalers for their asthma (additional quotes are given in online supplementary tables S4 and S8 in the online supplementary appendix). These reactions were not confined to one professional group and included doctors, nurses, pharmacists and paramedics. This was an issue that was spontaneously bought up in all focus groups across ages and ethnicities. While it is possible this issue is unique to New Zealand and could be related to the national dispensing regulations, it is an issue which requires further investigation to ascertain if it is widespread and whether, as our participants described, it negatively impacts on asthma management.

Use of focus groups to collect data is a strength of this study, as it led to a discussion between the participants rather than directed by the researchers. This generated rich, naturalistic data and some insights that the research team did not fully anticipate. Use of thematic analysis was appropriate given our research question, and themes were explored as they emerged. Peer coding and collaborative approach to analysis enhances the validity of the findings. Transcription verbatim and use of qualitative software to code the data enhanced the reliability. We achieved data saturation after the third focus group; then conducted two subsequent groups to check this assumption. Participants were recruited predominantly through advertising on social media so were not restricted to patients attending a clinic or GP practice. Holding groups in several locations increased the diversity of our sample.

We used purposeful sampling; however, despite efforts to recruit male participants, the majority of our participants (85%) were women. This is a limitation of our study, which may affect the generalisability of our results. Nonetheless, the men in our sample did not express notably different opinions from the women. In other studies, beliefs around medicines and illness perceptions, often described in terms of necessities and concerns, predicted poor adherence more robustly than any particular sociodemographic or clinical factors, suggesting asthma management is not a strongly gendered issue. Other limitations include there was no public or patient engagement in the study design, and only 20% of the data were peer coded; however, the data were widely discussed, and coding reviewed with in the research team. There may have been a potential for researcher professional bias. However, we attempted to limit this through the use of a multidisciplinary team, some of whom have a lived experience of asthma, and application of self-reflective practices through memo writing and team debriefing. Finally, caution should be taken when generalising the findings of qualitative research.

While we collected data on current asthma treatments and level of asthma control we did not systematically collect data on whether the participants had a personalised asthma action plan or were under the care of a specialist respiratory physician both of which may have influenced preferences for asthma services and experiences of asthma self-management. However, as we excluded people who were taking medications at step 4/5 asthma treatments in a New Zealand context this means that most patients under the care of a respiratory specialist would have been excluded as most patients with asthma are under the care of their GP unless they require treatments such as maintenance oral steroid or biological agents.

We specifically intended to recruit Māori, at least in proportion to the current New Zealand population (15%) and were more than successful as over 50% of our participants identified as Māori. Our aim was to explore patients’ experience of asthma and their preferences for asthma management as an overarching concept, therefore, we did not analyse the data separately for Māori and non-Māori participants, in line with comparable qualitative research. It is relevant, however, that the results reflect similar themes of self-management and health service obstacles described by other Indigenous and non-Indigenous peoples living with asthma.

Future studies exploring patient preferences for asthma management in broader populations, in combination with the insights from qualitative studies would provide a deeper understanding of the management strategies that patients prefer. In clinical practice, asthma management could be improved through a better understanding of patient preferences and perspective on treatment.
In conclusion, the findings from this study suggest that the impact of asthma on life, health beliefs, emotional consequences and barriers to asthma management influence patients’ preferences for different aspects of asthma management. This aids our understanding of asthma management from the patient perspective. This information can be used to improve shared decision-making, help patients navigate through asthma services, identify appropriate treatments and empower them to have ownership and control over their asthma management.

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Contributors CB, HKR, JF, RB and WMML conceived the idea. The study protocol was written by CB, AC, JF, HKR and WMML in consultation with MH on Māori perspectives. CB, AC and SH collected the data. Transcription was conducted by a commercial company, all transcripts were checked against the audio recordings by CB. Coding was undertaken by CB and AC. Data analysis and interpretation were undertaken by CB, AC, MH, HKR and WMML. All authors had full access to the audio files, transcripts and coding. CB and WMML wrote the first draft of the manuscript, and all authors contributed to the final version.

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Competing interests CB reports personal fees from AstraZeneca and Novartis. AC reports grants from Maurice and Phyllis Paykel Trust, Innovate UK, NZPERF, U21, A+Charitable Trust and consultancy fees from Janssen-Cilag, and Spoonful of Sugar Ltd. JF reports grants from Health Research Council of New Zealand, AstraZeneca, GlaxoSmithKline and Genentech; and personal fees and non-financial support from AstraZeneca, GlaxoSmithKline and Boehringer Ingelheim. RB reports grants from Health Research Council of New Zealand, Genentech, AstraZeneca, GlaxoSmithKline; and personal fees from AstraZeneca, Avillon and Theravance. MH reports grants from Health Research Council of New Zealand. HR reports grants from GlaxoSmithKline, AstraZeneca and Novartis; personal fees from AstraZeneca, GlaxoSmithKline, Merck, Novartis, Teva, Sanofi Genzyme and Boehringer Ingelheim; and is chair of the Global Initiative for Asthma scientific committee.

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Data availability statement Data are available upon reasonable request. De-identified access to transcripts from focus groups will be shared 2 years after article publication with no end date. These data will be available to researchers who provide a methodologically sound proposal for the purposes of achieving specific aims outlined in that proposal. Proposals should be directed to the study sponsor the Medical Research Institute of New Zealand by emailing Prof Richard Beasley (richard.beasley@mrinz.ac.nz). Requests to access data to undertake hypothesis driven research will not be unreasonably withheld. To gain access, data requesters will need to sign a data access agreement and to confirm that data will only be used for the agreed purpose for which access was granted.

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