Managing pre-school wheeze: A qualitative study of parents' views and experiences

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ABSTRACT

OBJECTIVE: The aim of this study was to explore parents' views and experiences of managing preschool wheeze, including opinions on the use of investigations to inform treatment pathways.

DESIGN: Purposive sampling was used to recruit 16 participants from 14 families across England and Wales. Qualitative data were collected via semi-structured interviews with parents of children aged 1 to 5 years with preschool wheeze, conducted on Microsoft (MS) Teams. Data were transcribed and analysed using thematic analysis, facilitated by NVivo software package.

RESULTS: Analysis generated four themes (1) Pathway to diagnosis (2) Medication management (3) Living with preschool wheeze (4) Improving preschool wheeze healthcare. Findings suggest a negative impact of preschool wheeze on families' lives, including high levels of worry and limiting capacity for work and travel. Barriers to effective management of preschool wheeze included inconsistent terminologies and diagnostic uncertainty alongside limited education and management support. Other barriers related to parental concerns about medications, delayed investigations, and challenges with accessing specialist care. Parents were in favour of performing investigations to guide treatment pathways.

CONCLUSION: Parents' views highlight the problem of diagnosing and treating preschool wheeze at multiple system levels. To improve management and ensure services for children with preschool wheeze are effective, there is an urgent need for consistent terminology, a unified approach to guide investigations and treatments, and to upskill healthcare professionals in primary and secondary care.

WHAT IS ALREADY KNOWN ON THIS TOPIC:

Preschool wheeze results in significant morbidity, healthcare costs and impaired quality of life for child and parent. Currently, there is no diagnostic pathway or definitive guidelines to inform effective management of preschool wheeze.

WHAT THIS STUDY ADDS:

- Parents' views highlight the problem of diagnosing and treating PSW at multiple system levels.
- Parents emphasise the need for consistent terminologies and integrated treatment pathways to improve management of PSW.
- Parents are in favour of using investigations to guide treatment for preschool wheeze.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- There is a need for preschool wheeze management policies and treatment pathways, that are evidence-based and co-developed with parents.
- Training programs for primary care health professionals are needed, to upskill their ability in managing preschool wheeze in community settings; to include education on initial assessments and providing consistent guidance to parents regarding disease prognosis and medications.
- Including parents' views is important for conducting further research into the role of treatable traits in managing preschool wheeze.

Introduction

Preschool wheeze (PSW) is common. Approximately 30-40% of all children will experience recurrent wheeze attacks in the first six years of life (1). Seventy five percent of all children with wheeze admitted to hospital are aged between 1-5 years (2). The United Kingdom has the second highest prevalence of wheeze during the second year of life in Europe (3). PSW results in significant morbidity, healthcare costs, and impaired quality of life for child and parent (4). Children with PSW account for a third of all healthcare costs for childhood asthma (4). Recurrent wheeze attacks predict long term diminished lung function and increase all cause morbidity and mortality in early adulthood (5).

Optimal therapy for treating and preventing episodes of PSW is not well-defined and remains a matter of investigation and debate (6). Thus, in clinical practice, there are no diagnostic tests and no definitive pathways for treating PSW. Current management is based on expert consensus, history-taking and symptom patterns (6). Medications prescribed for PSW are often those used in school age children and adults with asthma. Recommendations for treatment by the British Thoracic Society (7) and European Respiratory Society (8) are based on parent or child reported symptoms. Inhaled steroids, salbutamol, montelukast are some of the medications recommended to prevent wheeze attacks, but acute presentations to healthcare continue (9).

A recent review of literature by the European Respiratory Society taskforce (8) indicates that diagnosis and management of PSW may be improved by identifying treatable traits, such as blood eosinophils and aeroallergen sensitization, which could help to identify children who will have a differential response to inhaled corticosteroids. However, the taskforce notes that further prospective validation of using blood eosinophils as a biomarker in preschool children is needed before recommendation as an evidence-based clinical approach. A further gap in evidence relates to biomarkers that could identify children unlikely to respond to inhaled corticosteroids (8).

While the introduction of objective tests for identifying treatable traits (blood eosinophils and aeroallergen sensitization) may present opportunities for more effective management of PSW (pending further validation), acceptability to parents is unknown. Acceptability is a key consideration in the implementation of healthcare innovations; if new treatments or interventions are considered acceptable, patients are more likely to adhere and benefit from them (26). Parent acceptability of managing PSW with steroids is also unclear, given that adherence to inhaled steroids, even in those with severe recurrent wheeze attacks, is only 30% (11). In-depth understanding of parents' illness and treatment perceptions, including acceptability of blood/allergy tests and steroid use, is therefore important for understanding current PSW management and for determining feasibility of implementing new approaches, from a parental perspective. The aim of this study was to explore parents' views and experiences of managing children with preschool wheeze, including their perceived acceptability of steroids and blood/allergy tests to guide treatment pathways.

Methods

Sampling and recruitment

Parents were purposefully recruited based on their child's age (1-5 years) and wheeze symptoms as confirmed by a health professional, to include variation in demographics and a mix across primary, secondary and tertiary care. We excluded parent participants whose children were less than 1 year or more than 5 years old and those with co-existing co-morbidities (Congenital Lung or heart disease, Interstitial Lung Disease, Cystic Fibrosis, Bronchiectasis, Chronic Lung Disease of Prematurity). Parents were recruited via adverts displayed in a hospital outpatient's clinic and via social media. Potential participants who responded to study adverts received a study information pack via email, including information sheet and consent form.

Data collection

A favourable ethical opinion was obtained from Wales NHS Research Ethics Committee 4REC (#23/WA/0109). A semi-structured interview guide was informed by existing literature (6, 7, 8), experiences of the clinical team and research objectives (see supplementary file 1). Open questions covered parents' views and experiences of preschool wheeze and approaches to management, use of blood and allergy tests and barriers to accepting or performing such tests. LW conducted the interviews at a mutually convenient time via Microsoft Teams (April–August 2023). Interviews lasted 30–90 minutes and were recorded. Data collection continued until saturation was determined, that is the point at which little new information was generated. This was established during interviewing as well as by listening back to interview recordings, through concurrent data analysis, and discussion of data with the research team (12).

Data analysis

Interview data were transcribed verbatim and analysed using Thematic Analysis (13, 14). Transcripts were auto generated by Microsoft Teams and checked manually by the first author. LW (female Clinical Research Fellow) took the lead on data analysis, becoming familiar with data through reading and re-reading transcripts. Codes were then generated inductively from the data, leading to the creation of an initial coding frame. Coding was carried out by LW with a sub-section double coded by GH (female Health Psychologist) and discussed with PN (male Paediatric Respiratory Consultant). Following team discussion and iteration, an agreed coding frame was applied to all transcripts. Codes were then compared within and between participants and grouped into themes that were further discussed by the team. Coding and data retrieval were supported via qualitative data analysis computer software package NVivo V12 (15).

RESULTS

Participants

A total of 22 expressions of interest were received from parent participants. Six did not respond on follow up contact or were no longer interested in participating. Hence there were 16 participants from 14 families in total. Families were recruited from a wide UK geographical area including Northwest England, West Midlands and Wales. The sample comprised of those cared for in primary, secondary and tertiary care. 57% (8/14) of participants' children were on low dose inhaled corticosteroid (ICS) and needed short-acting beta agonist (SABA), corresponding to Step 2 of Global Initiative for Asthma (GINA) guidelines (16). 21% (3/14) were on SABA, ICS and montelukast, 14% (2/14) were on SABA, ICS and long-acting beta agonist (LABA), 7% (1/14) was on SABA, ICS, LABA and montelukast. Further participant characteristics are presented in Tables 1 and 2. The words most (>14), many (>10) and few (>5) are used to describe the strength with which parents supported the points made.

Thematic findings

Analysis generated four themes (1) Pathway to diagnosis (2) Medication management (3) Living with PSW (4) Improving PSW healthcare. Illustrative quotations are presented in Table 3.

1. *Pathway to diagnosis: "If it's not asthma, what is it?"*

Many parents highlighted inconsistent terminologies and diagnostic uncertainty for their child's pre-school wheeze (asthma, suspected asthma, viral wheeze, allergy) as confusing and problematic, with instances of receiving different views from different clinicians regarding symptoms and causes. For some parents, referring to wheeze as viral provided (potentially false) reassurance that their child was not being diagnosed as Asthmatic. Others described frustration at not being provided with a definitive diagnosis, particularly where the child had experienced multiple wheeze attacks and hospital admissions.

Related to issues with diagnosis were parents' dissatisfaction with perceived delays in initiating investigations, particularly while being managed in primary care. Investigative tests were often described as only being initiated following extreme cases (multiple hospital admissions, severe wheeze attacks), and in all instances were initiated by specialist (tertiary care) health professionals. Many parents expressed relief once tests were initiated, constructing them as vital for treatment decision-making. Parents were keen to identify a cause for their child's wheeze which could inform management options, rather than starting on inhalers and only initiating tests following poor wheeze control. Most parents were united in their view that investigations formed a key component to informing management of their child's condition, echoing frustration with a wait and watch approach.

Despite parental preference for timely tests, the importance of a sound rationale for child testing was emphasized by parents, for example, explaining why the investigations were being undertaken, differences between the types of tests and how each test would inform their child's wheeze management. Many parents further highlighted that to be acceptable, more invasive tests (e.g., blood tests) needed to be performed in a considered and personalised way to minimise child distress, ensuring that the child was not subject to repeated tests unnecessarily.

2. *Medication management: "An acceptable cost"*

In all cases, wheeze was managed using a combination of steroid and salbutamol inhalers. While acceptable to parents and described as helpful in reducing exacerbations, a few parents described limited education and support in administering inhalers and using spacers. Specifically, parents perceived a lack of knowledge at District General Hospitals and in primary care, describing inconsistent instruction from different professionals, leading to them seeking alternative advice (e.g., from other family members, internet).

Many parents also expressed concerns regarding side effects of steroid inhalers for young children, including long-term dependence, dependency on relievers for physical exertion tooth decay. The risks, however, were weighed up by parents and generally it was felt that the benefits of using inhalers in terms of reducing wheeze attacks and hospital admissions, outweighed the risks associated with side-effects, deeming the medication an 'acceptable cost'.

Management was also discussed in relation to childcare providers with a few parents expressing concerns about pre-school nursery staff administering inhalers incorrectly and in a timely manner, despite providing a wheeze plan. These anxieties extended to worry about how the child would cope once attending school. Many parents also described reassurance from having regular follow-up checks following a PSW attack and being able to access specialist care when required.

3. Living with PSW: *"We are terrified".*

Witnessing a severe attack of PSW was frequently described as 'traumatic' and had a significant psychological impact on some parents, particularly in cases where the child was admitted to a high dependency or intensive care unit because of their wheeze. In some families, parents had decided to reduce or stop working to manage the child's recurrent wheeze, where others described high levels of anxiety and vigilance because of the unpredictability of their child's condition. Many parents described missing work to attend appointments and accompany their child to hospital which presented a financial burden.

In addition to the impact on work, some families felt unable to go on holiday for fear of a wheeze attack and worry about accessing healthcare abroad. A few families expressed a desire for social support from a peer network so they could meet other parents and share experiences of PSW.

4. Improving PSW healthcare: "*The problem is accessibility".*

While acknowledging the convenience of primary care (closer to home, less waiting time, less time away frow work), most parents preferred secondary and tertiary care where it was felt they could access specialist support. In hospital settings, parents felt that their concerns were validated, and that investigations and treatment could be initiated, whereas GPs were perceived as having little training in childhood wheeze, leading to a loss of confidence.

A few parents appreciated opportunities for open access to local secondary care when the child did have a wheeze exacerbation and emphasised the importance of wheeze management plans. However, there were barriers to attending secondary care including untimely availability of ambulances, arranging childcare and financial factors (car park fees, congestion charges) and some families suggested a need for virtual, as well as face-to-face appointments.

Ultimately, most parents called for a more co-ordinated and integrated approach between primary, secondary, and tertiary care providers, who make use of shared care plans for PSW that can be accessed by primary and secondary care, and the emergency services when required.

Discussion

To our knowledge, this is the first study in United Kingdom to explore parental views and experiences of managing PSW and the acceptability of steroids and blood/allergy tests to guide treatment pathways. We are unaware of other qualitative studies that have explored parents' perspectives of preschool wheeze. Findings suggest a negative impact of PSW on families' lives, including high levels of worry, limiting capacity for work and travel. Barriers to effective management of PSW include inconsistent terminologies and diagnostic uncertainty, limited education and management support, delayed investigations, concerns about medications and challenges accessing specialist care. Many parents were in favour of performing blood and allergy investigations to guide treatment pathways.

Current management of PSW was perceived as unsatisfactory by parents, characterised by inconsistent diagnostic terminologies, diagnostic uncertainty, delayed investigations, and recurrent presentation to hospital. Parents felt that obtaining a formal diagnosis of PSW, even as an umbrella holding term (from which other diagnoses including asthma might filter out), earlier in the care journey would help them manage their child's condition more effectively, improving their and their child's quality of life, as well as improving access to specialist care. These findings resonate with other studies highlighting uncertainty (17) and frustration (18) of the pre-diagnosis phase, as well as those describing the negative impact of childhood asthma on family wellbeing (19). British Thoracic Society (20) and the Global Initiative for Asthma (21) have published guidelines for diagnosis and management of 'asthma' in children less than 5 years. However, these guidelines do not describe 'preschool wheeze' and health professionals may find it difficult to label every child under 5 with wheeze to have asthma.

Consistent with a 'Common-Sense Model' of managing health threats (22), parents in our study were keen to understand the causes of recurrent PSW in their children. Not feeling able to understand their child's symptom aetiology and frustration with a lack of diagnostic labels or specified treatments, parents supported investigations being performed, and earlier in the care pathway; conceiving investigations as a gateway to appropriate management based on objective results rather than (variations in) clinical experience. Domains of illness representations, including perceived timeline, consequences, cause, and controllability of symptoms have previously been shown to impact treatment adherence in those with asthma (23). To improve concordance, it is important that a child's treatment plan is coherent with parents' understanding of their child's condition. Good history-taking, that elicits parental concerns, establishes symptoms, trigger factors and parent-reported outcomes may reassure parents regarding diagnostic uncertainties, negating their calls for objective investigations. Upskilling health professionals across healthcare settings and involving parents in PSW management could thus influence healthcare utilization patterns, including emergency department visits, hospital admissions, and primary care consultations.

While most parents in this study expressed concern about the long-term effects of inhaled corticosteroids, they felt that dealing with side effects was better than frequent hospitalisation. Parents described a sense of reassurance when given instruction on the daily use and side effects of preventer inhalers. This was achieved through signposting to NHS resources, as well as providing demonstrations, verbal and written instruction. In terms of service improvement, the current study reflected others in demonstrating a need for co-ordinated and integrated care across the healthcare system (24). In our study, education on PSW and management plans often differed between healthcare professionals leading to inconsistent information provided to parents. Managing PSW care via community-based diagnostic hubs may help to meet the needs of parents requiring access to specialist care, closer to home.

Strengths and limitations

A key strength of this study is the diverse representation of views from parents of children with varying degrees of PSW and sharing experiences from management at various levels of care. The parent participants were from across England and Wales. One of the limitations, is that participants were mainly mothers, meaning fathers were underrepresented. Mothers are often the main care givers of children with chronic health conditions and accompany their children to seek healthcare services (25). A second (potential) limitation is that some members of the research team (SS, PN) are involved in the clinical management of children with severe wheeze in a tertiary care setting, which could have influenced the analysis. However, neither the first author (LW, Research Fellow) nor the lead author (GH, Health Psychologist) are involved in the clinical management of children with severe wheeze. Furthermore, the thematic analysis was based exclusively on data provided by parents who were not under the clinical care of the research team. This further reduces the potential for bias from clinical involvement. While a sub-section of data were coded by two analysts, not all transcripts were. However, the final coding frame was reviewed by all authors with team discussions used to develop and agree on salient themes.

RECOMMENDATIONS/CONCLUSION

Parents views highlight the problem of diagnosing and treating PSW at multiple system levels. To improve management of PSW, there is a need for need for consistent terminologies, unified guidelines and a diagnostic pathway to guide investigations and commence treatment. To achieve this, there is a need for prospective clinical trials to determine the efficacy of treatment decisions made according to the results of investigations. To ensure services for children with PSW are effective and sustainable, there is a need to upskill health professionals in primary and secondary care and to enable access to investigations in primary care. To be acceptable to parents however, investigations need to have a sound rationale and be personalised to the child's need; ensuring children are not subjected to diagnostic tests unnecessarily.

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Table 1 Participant demographics

Parent/Carer interviewees	
Mothers	14
Fathers	2
Current age of children of parents interviewed with PSW Diagnosis	
Median	4 years
Range	2-5 years
Interquartile Range	1.25 years
Ethnicity of parents N (%)	
White	
English, Welsh, Scottish, Northern Irish or British	10 (62.5%)
Asian or Asian British	
Indian	3 (19%)
Pakistani	1 (6.25%)
Southeast Asian	1 (6.25%)
Other ethnic group	
Arab	1 (6.25%)

Geographical area	
West Midlands	12
Northwest England	2
Wales	2
Clinical history	
Children in education placement N (%)	12 (86%)
Children with allergy to food/aero-allergens N (%)	7 (50%)
Atopy N (%)	10 (71%)
Family history of Asthma N (%)	8 (57%)
Parent smokers (N)	1
Number of GP visits for PSW in 1 year (Median)	1
Number of Hospital visits for PSW in 1 year (Median)	3.5
Number of children with courses of oral steroids in last 1 year	11/14
Current medications N (%)	
SABA+ ICS	8/14 (57%)
SABA +ICS + montelukast	3/14 (21%)
SABA + ICS + LABA	2/14 (14%)
SABA+ ICS + LABA + montelukast	1/14 (7%)

Table 2: Age and employment of participants, age of children and setting of care at time of interview.

Parent	Parental Age (years)	Employment	Age of child at the time of interview	Setting of care for PSW
P1 (Mother)	35-40	HR manager	Son, 3 years	Secondary care
P2 (Mother & Father)	35-40	Mother Nurse	Son, 4 years	Secondary care
P3 (Mother)	30-35	Housewife	Daughter, 3 years	Secondary care
P4 (Mother)	30-35	Housewife	Son, 2 years	Secondary care
P5 (Mother)	35-40	Self-employed	Daughter, 4 years	Secondary care
P6 (Mother)	40-45	Housewife	Son, 2 years	Secondary care

P7 (Mother & Father)	40-45	Nurses	Son, 4 years	Secondary care
P8 (Mother)	30-35	Housewife	Daughter, 4 years	Secondary care
P9 (Mother)	35-40	Clinical Scientist	Son, 2 years	Secondary care
P10 (Mother)	30-35	Self-employed	Son, 4 years	Primary care
P11 (Mother)	30-35	School Teacher	Son, 4 years	Primary care
P12 (Mother)	30-35	Customer Care services	Son, 4 years	Secondary care
P13 (Mother)	30-35	Self-employed	Son, 4 years	Secondary care
P14 (Mother)	30-35	Survey Office Manager	Son, 4 years	Secondary care

Table 3: Illustrative quotations

Pathway to diagnosis	*Inconsistent terminologies and diagnostic uncertainty*	*Yeah, there's some that was saying it could be severe asthma. There's some that said it could just be normal asthma and he's having some attacks from that or it's this viral induced wheeze. (Parent 2, son 4 years)* *I'm reading D's paperwork and it will say severe asthma, severe asthma attack and you know. It's got some pretty strong language in the discharge paperwork, but then on the other hand they'll say, but it's suspected asthma and you think. It's, there's a real grey area around it all and you know that could cloud judgement and so I think whilst if you're gonna categorise children like D in that grey area, then they need to back that up by saying, well, if it's not asthma, what is it? (Parent 14, son 4 years)*
	Delayed investigations	*The only one they did is when she was on her 7th one [hospital admission] I think. When I mentioned she's on her 7th one this year. And that's when they thought they will start investigating it, which I wasn't happy with, to be honest, because we were hospitalised so many times. (Parent 8, daughter 4 years)* *I personally had a big problem with all the doctors telling me "It's a mystery" because it didn't necessarily have to be a mystery if they did the tests that needed to be done, that could have, you know, helped them find out what's happening inside him to get that diagnosis. "But it's a mystery" - was used for a long time before any blood tests were even taken. Yeah, you know, and that's not a diagnosis. That doesn't help a parent when you're so stressed and watching your child suffer for so long (Parent 2, son 4 years)*
	Guiding investigations	*I know what a blood test would entail, but obviously what could come out of it? What sort of benefits are there? So, knowing all right, this will give us a more specific idea of which thingy is allergic to, so we can avoid that and they reduce the use of medicine. And I would*

		appreciate it, stuff like that. Yeah. I'm all for science, so I would be happy for them to be investigated. (Parent 11, son 4 years) *I think to actually explain to the two different types of allergy tests, because I know there's I think a prick test or something like that and a blood test. And do they write down what test they need? For example, they say blood test, do they kind of tell us we're going to do a blood test like for milk egg, or does that just all come up at once? (Parent 8, daughter 4 years)* *It's gotta be done, I think. But I think we were very much mindful that some children in my opinion have or what I would only explain is an astronomical amount of blood tests done and a lot of those tests are failed tests and so there repeat attempts to gain blood. Um and and I think sometimes as professionals they don't consider the impact on the child and their family and how traumatic that is. (Parent 7, son 4 years)*
Medication management	*Limited education and support*	*I don't think there's a specialist respiratory team in in local hospital. This was a major flaw I think in local city. The nurses haven't got a clue how to give the inhaler themselves. So to educate somebody, one of the nurses was forcing it onto his face. R had a really deep mark on his face from the mask, being pushed on and being held there while he was struggling. (Parent 2, son 4 years)* *We were sent home with Brown and Blue inhaler. So we're at that point where were given a brown inhaler and we weren't advised that that was something we should be doing daily. It was never discussed how often we were using the brown inhaler. So I feel like, If say, when D got wheezy and we went to either A&E or to the GP, depending on the time of day and felt to get some assistance for his chest and we were sent home being prescribed steroids. Nobody at that point said, "What's your prevention like? (Parent 14, son 4 years)*
	Medication concerns	*For me, like, inhalers was always something that meant "Ohh. My gosh. You're depending on something to sort of have to breathe", you know. He was always in a very intense form of medication, especially when the word steroid you always relate to something that's quite intense, so… Yeah. For me it was quite upsetting that he had to be on inhalers. (Parent 3, daughter, 3 years)* *I think the medication overall was quite strong for him, I think because he was on oral steroids as well as inhaled steroids as well as a montelukast. I did feel a bit like this is a lot going into a little boy at such as, you know, without testing to see if one medication is working first. (Parent 2, son 4 years)*
Living with PSW	*Impact on families*	*My wife's had to give up work just to kind of care for for him. Yeah. So because we don't know what's gonna happen to him. Right. We had to kind of sacrifice a few things just to make sure he's okay because that's priority for us. (Parent 2, son 4 years)* *For the last two years it's had a significant impact on where I'm willing to travel with my family. So always looking at wherever we*

		go, anywhere, where's the nearest paediatric A&E and how do I access emergency paediatric services, so we've never travelled abroad with [son]. (Parent 1, son 3 years)
Improving PSW healthcare	*Accessing specialists*	*I find people take me more seriously at the hospital, um, you know, being honest. But I would prefer to just be able to go to the GP and not have to trek all the way to the hospital and waste a lot of time. Not so much of the waiting time in the hospital, I feel like, It's just a distance, isn't it? It's just like it's not, it's not local. (Parent 11, son 4 years)* *I think the GP needs more training with viral induced wheeze because their answer to J's wheeze is "Ohh will give him antibiotics and steroids". (Parent 6, son 2 years)*