



UNIVERSITY OF
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CITY OF
WOLVERHAMPTON
COUNCIL

Parents' views on barriers and facilitators to receiving asthma support for children in Wolverhampton: a qualitative study

December 2022

















Background

- Asthma is the commonest chronic disease in children with **1 in 11 children** currently treated with asthma medications
- Heterogenous presentation - can lead to hospital admission and death
- Parents play a pivotal role in the management of their children's asthma
- Rate of asthma-related admissions in Wolverhampton is higher than the national average

Asthma in the Black Country

Hospital admissions for asthma (under 19 years) 2020/21

Crude rate - per 100,000

Area	Recent Trend	Count	Value		95% Lower CI	95% Upper CI
England	↓	9,425	74.2		72.7	75.7
West Midlands region	↓	1,255	91.4		86.4	96.6
Walsall	↓	100	137.5		110.6	165.7
Birmingham	↓	395	131.0		117.8	143.9
Telford and Wrekin	↓	55	125.8		92.8	161.2
Sandwell	↓	95	109.4		87.4	132.4
Wolverhampton	↓	70	106.2		80.1	130.8
Stoke-on-Trent	↓	55	90.1		65.1	113.6
Herefordshire	↓	30	79.2		55.6	116.2
Shropshire	↓	50	78.6		58.3	103.6
Warwickshire	↓	90	71.9		59.2	90.1
Coventry	→	60	70.3		54.6	91.7
Staffordshire	↓	125	69.4		57.2	82.0
Solihull	→	30	59.6		40.2	85.1
Worcestershire	↓	70	55.8		44.2	71.4
Dudley	↓	35	47.8		33.3	66.5

Aim and objectives

- Explore the views of parents whose children have asthma with regards to:
 - Barriers and facilitators to receiving adequate asthma support.
 - Ways to improve support.
- Inform further research.

Methodology



Qualitative research

Critical realism position
Experiential approach
Pragmatic framework



Sampling strategy

Parents of children (5-16yo)
in Wolverhampton with
doctor diagnosis of asthma
Shopping vouchers offered

Social media (council and
patient support groups)

Schools

Parent champions

Snowball sampling



Data collection

Face to face and virtual
semi-structured interviews
30-45 mins each
Using topic guide



Data analysis

Thematic analysis
Iterative process
Using NVivo

Results: The sample

- 9 interviews with 10 parents
- 1-3 children with asthma, per household
- Variation in ages of the children (2 to 18) and severity of asthma

Characteristic	Number of participants
Gender	
Female	8
Male	2
Age (years)	
30-39	4
40-49	6
Ethnicity	
Asian/Asian British	2
White	8
Civil status	
Single	2
Married/Civil partnership	8
How participants heard about the project	
Social media	8
Schools	2

Results: Themes

A power
struggle

Diagnosis
process

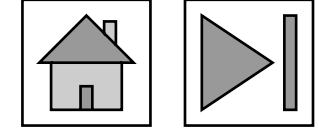
The role of
schools

Partnership
with health
services

A quest for
knowledge

Social network
support

Diagnosis process

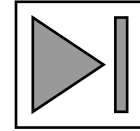
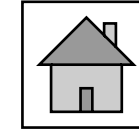


- Receiving diagnosis was a turning point
- It was a drawn out process with several obstacles along the way (particularly when child under 5):
 - Perceived unwillingness of healthcare professionals to consider a diagnosis
 - Disregard for parents' concerns
 - Parents had to press for a diagnosis
 - Parents felt unsupported during this turbulent process.
- What parents felt could be improved:
 - More information at the point of diagnosis
 - More information for children under 5 and those awaiting a diagnosis
 - A faster diagnosis process that is less dependent on parent prompts

"... prior to [having a diagnosis], we were just lurching from one hospital admission to the next. Sort of, we never knew which time she got ill would be the time that it would end up with her having to be taken in." (P7)

"I think if they'd have possibly listened a bit more and been a bit more understanding, it, it could have avoided us going into hospital and tying up their resources in four different instances before actually getting a diagnosis." (P6)

"So there needs to be a better system around diagnosing asthma in the under-fives. Because what is in place at the moment is non-existent. And it's appalling." (P8)



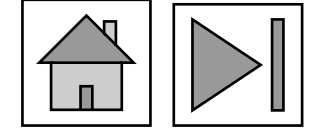
The role of schools

- Parents entrust their children to schools
- Schools' handling of inhalers :
 - Needing to ask to use the inhaler seen as a barrier
 - Poor communication of inhaler usage during school hours
 - Staff's lack of knowledge regarding inhaler usage
 - Lack of asthma education caused embarrassment when having to inhalers in front of colleagues
 - Inhalers went missing as they were given to other
 - Lack of communal inhalers
- Parents found it helpful when schools took a proactive approach:
 - Asking for updates on asthma management plans
 - Ensuring all staff knew which children had asthma
- Most parents had never met a school nurse for their child's asthma.

"That concerns me. That, as I say, I, I feel like I manage her at home. It's when she's [at school] that there may be a problem, which is when it's more likely to happen anyway, the asthma attack" (P10)

"[It] would have been easier if [my son] just had the inhaler with him. And he would have easily taken it, 100% if, if he felt a bit wheezy whilst playing sport. Rather than, kind of, erm, hoping that he'll tear himself away from something he's enjoying with friends to ask a teacher to get inhaler, which might take up most of the break time." (P5)

"The school nurse- I couldn't even tell ya what her name was, what she looked like... And you'd think, that having such a poorly child, that you would know who they were, or at least meet them once." (P4)



Partnership with healthcare services

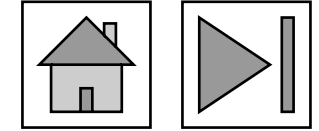
- Some barriers identified:
 - Parent's needing to be assertive to be taken seriously
 - Parent expertise not recognised
 - Over-medicalisation of the condition
 - Failure to acknowledge toll on parent's personal/family lives
 - Reactive primary care services
 - Disconnect between different parts of the health system
 - Conflicting information on when to seek medical help
 - Inconvenience of accessing medical support
- Facilitators and suggestions:
 - Continuity of care
 - Systems in place to facilitate access
 - Proactively contacting parents to check on asthma management
 - Long-term one-to-one asthma support by an asthma nurse.

"I work in the system, you know, so I, so I know to keep pushing at times. But if you're a parent that didn't know to do that, [my daughter] probably would have just fallen through the cracks." (P10)

"They were completely unwilling to see how it was affecting my mental health. The mental health of my husband. They were just dealing with this child in front of them and they weren't meeting the notes on the screen, and they were just reading from a script, and no one really cared that I aged ten years, or [my husband] aged ten years, and that it was putting huge stress on the family. There was just no understanding of that at all" (P8)

"I know children who have diabetes have diabetes nurses, don't they? And you're attached to them, and they have their numbers, and they can text them and stuff if they've got problems, or parents just have that one contact.." (P1)

A quest for knowledge



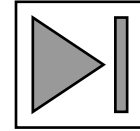
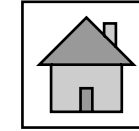
- Health professionals as a source of information
 - Insufficient information/education provided (particularly at time of diagnosis)
 - When education provided, parents' confidence increased and asthma management improved
 - Inhaler technique education is foundational and best when performed face-to-face
 - Education should be more focused on the child
 - There is a lack of advice on practical issues
- Other sources of information
 - Varied opinions on usefulness of what is available
- Information available to the public
 - Disproportionately low levels of information available on asthma
 - Not taken seriously enough
 - Parents tasked with educating others

"It's just felt like a fight, constantly, to learn instead of somebody taking control who is the expert in the subject!" (P7)

"[The nurse] showed us a video (...) But [my son's] still not that confident in using it because she didn't really show him how to use it. She just showed us the video. So, I've got the video on my phone, but I'm not sure that we're using it right. Erm, and she didn't actually physically show him how to do it." (P9)

"There isn't that much online, really. If you go and look you read the same thing over and over again, but it doesn't actually tell you anything." (P10)

So I've then got this child, who's really poorly, who's opening my eyes to what asthma actually looks like, and asthma actually is. And because people aren't educated enough on it, people don't really take it seriously. (...) And I think if I didn't go through what I've gone through with my son, maybe I too would be just as ignorant. But that's not an excuse." (P4)



Social network support

- Friends and family
 - For most, close family formed the support network
 - Sometimes grandparents and friends helped
- Wider social network
 - Not much support beyond family and healthcare system
 - Many did not know other parents whose child had asthma
 - Few had come across patient or parent support groups.
- The public's poor understanding of asthma meant they were not able to offer support.
- Some parents suggested
 - Setting up support networks
 - Better education of the public

"We don't have a massive support network. But those who do support us, have had to support us lots. If I had had every single day [my son] was off this year ill, if I had had that off work, I would no longer have a job. Neither with [my husband]. So we've had to rely on [family and friends'] support. They now all know how to give him his inhaler." (P8)

"For me personally, there isn't people around us whose children have got asthma." (P10)

"Yeah, it would be good to have more [peer support]. It's reassuring, if anything, to hear people who've got the same experiences and reassuring to know that you're doing the right thing, because that's what they're doing is. (P9)

Discussion, implications and recommendations

Diagnosis process

- **Similarly to other studies:**

- The diagnosis process was marked by uncertainty, inexperience and unmet parental needs
- A protracted process which does not accommodate small children.
- Parents' concerns were dismissed and the impact on family life was not recognised.
- Obtaining a diagnosis was a turning point in management and a relief to parents
- Timely education at the point of diagnosis identified as a facilitator towards better management

- **Specific to this study:**

- Lack of communication within health system was a cause for delays in diagnosis and mismanagement.
- Health professionals' unwillingness to diagnose young children with asthma as a substantial barrier.

- **Recommendations:**

- Action to improve the process of asthma diagnosis in children (e.g.: trigger point following multiple attendances with asthma symptoms)
- Targeted clinical support for parents of children awaiting formal diagnosis or under-5's likely to have asthma

Discussion, implications and recommendations

The role of schools

- **Barriers identified:**
 - School not taking the child's asthma seriously
 - Deviation from the written asthma plan
 - Failing to keep parents informed of symptom exacerbations
 - Inadequate staff training
 - School policies limiting accessibility of inhalers
- **Recommendations:**
 - Revision of local schools' approach to asthma is worth considering, namely:
 - Communication between schools and parents regarding asthma management
 - Staff asthma training
 - School policies and their impact on accessibility of children's inhalers
 - Consider role of school nurses in supporting parents

Discussion, implications and recommendations

Partnership with healthcare services

- **Similarly to other studies, parents face several barriers:**
 - Healthcare professionals dismissing parents' concerns, failing to acknowledge their expertise, and adopting a reactive approach to symptom control
 - Tendency for primary care to review asthma patients opportunistically or only when unwell
 - Inconvenience/impracticality of appointment and prescription systems cause access issues. These have been identified as causes for over-reliance on the emergency services, particularly in vulnerable groups
- Involving the child in decision making and continuity of care felt to improve quality of care
- **Recommendations:**
 - Increase health professionals' knowledge of parents' needs, including:
 - Awareness of the impact of asthma on family life,
 - The importance of timely education
 - The need for discussion of the practical, day-to-day aspects of asthma management.
 - Consider local asthma nurses who could be contacted by children and their families for non-urgent support
 - Coproduce any interventions or service provisions with carers and patients.

Discussion, implications and recommendations

A quest for knowledge

- **Similarly to other studies:**

- Access to timely, reliable, and relevant information is foundational for adequate asthma management.
- Health professionals were regarded as the ideal authoritative source for asthma education but failed to meet parents needs
- Education around inhaler technique was identified as particularly important, and a preference for face-to-face delivery of information was expressed.
- Parents expressed frustration at the lack of asthma awareness and education of the public which they felt also had an impact on their child's asthma management.

- **Specific to this project:**

- Participants did not identify their wider social network or contacts whose children also had asthma as a source of knowledge on the condition and its management.
- Parents were often the ones relaying information to others in their social sphere.

- **Recommendations:**

- More accessible and relevant information available for children with asthma, parents, families, school staff, and the public

Discussion, implications and recommendations

Social network support

- Families were felt to be supportive and understanding of the severity of their child's asthma and the need to manage it diligently.
- Most participants in did not receive much asthma-related support from their wider social network and few knew other parents whose children also had asthma.
- Several studies have pointed out the benefits of networking in these groups:
 - Provision of information and practical tips
 - Emotional support and material assistance
 - Normative guidance (parents compare their experience with those of people in similar situations)
- **Recommendations:**
 - Facilitate the establishment of a local support network for children with asthma and their parents, possibly through partnerships between the local authority and primary care services.

Strengths, limitations, reflections

- Issues with recruitment:
 - No access to NHS data
 - Coincided with school holidays
 - Most parents recruited through social media
 - Data saturation not reached
 - No PPI during study design
- Researcher inexperience and background
- One-sided perspective
- Council and school support



Thank you!