ORIGINAL ARTICLE

Parents' accounts of wheeze and asthma related symptoms: a qualitative study

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Aims: To examine parents' accounts of how they recognise and judge respiratory symptoms in children, and to investigate their interpretations of respiratory survey questions about wheeze, shortness of breath, and cough.

Methods: Qualitative study using semistructured interviews. Data were analysed using the constant comparative method. Nineteen parents of children aged under 6 years were recruited from a cohort of parents who had responded to an earlier respiratory symptom survey and from one general practice.

Results: Parents judged respiratory symptoms using a range of cues, including changes in the sound of breathing and changes in appearance and behaviour. Experiential resources and contextual factors played an important role in parents' judgements. Interpretations of questions about respiratory symptoms were varied, particularly in relation to the terms "attacks of wheeze" and "shortness of breath". Parents' descriptions of wheeze differed from descriptions of the sound of wheeze used in some survey questionnaires. Parents drew fine distinctions between different "types" of cough and identified a distinct "asthma" cough.

Conclusions: Attention needs to be given to the complexity of reporting respiratory symptoms in children and to the importance of contextual factors in parents' judgements. We suggest that questions which require parents to report on children's internal feelings or states be avoided. Consideration should be given to providing parents with explicit direction on what cues to attend to or ignore in reporting symptoms, and to clarifying some questions that are currently used in clinical practice and in surveys.

Survey evidence indicates substantial rises in the prevalence of wheezing disorders in children,[1] with a recent repeated population survey in Leicestershire, UK,[2] suggesting a significant rise in the prevalence of reported wheeze in preschool children during the past decade. However, debates continue about whether the increased prevalence of reported wheeze in childhood represents a true increase in respiratory morbidity.[3] One possibility is that the reported rises are artefactal, created by the ways in which parents respond to survey questions. Recent quantitative research has found that parents' concepts of wheeze differ from those used in epidemiological surveys,[4] and that parents use the term "wheeze" to describe a range of respiratory noises, only some of which conform to a clinical definition of wheeze.[5 6] While these studies point to problems with the use of parent reports of children's respiratory symptoms, it is likely that epidemiologists will continue to use such reports, given the limitations[7] of the alternatives. How then can the use of parent reports be improved?

One way forward is to improve the design of survey instruments. To do this it is essential to understand how parents identify, classify, and experience their children's respiratory symptoms, and how they interpret key questions in survey instruments. Qualitative evidence has been extremely useful in highlighting how mothers use a range of cues and resources in making sense of their children's symptoms, and in gauging their children's deviations from wellness or normality.[8 9] However, little work of this nature has focused on the cues and resources used by parents to recognise and interpret respiratory signs and symptoms in children.

Our study aims to investigate parents' accounts of how they recognise and make judgements about respiratory signs and symptoms in their children, and how they interpret questions on respiratory symptoms and apply these to their children.

METHODS

Parents of children aged 1–6 years were invited to participate in semistructured interviews. This is a well established method for accessing parents' concepts of illness symtoms.[8 10] Participants were recruited from the cohort who had completed the Leicestershire Child Cohort Respiratory Symptoms Survey (LCCRSS) in 1998[2] and from one large general practice in Leicester. We aimed to recruit parents with different levels of experience of asthma related respiratory symptoms in their children. Therefore, we invited parents who had never previously reported wheeze in their child, as well as parents who had previously reported wheeze. We also aimed to represent social and cultural diversity in our sample. The study was approved by a local research ethics committee.

GF conducted all of the interviews, which were audiotaped and transcribed verbatim. A prompt list was devised to guide the interviews. All interview transcripts were systematically analysed using the constant comparative method.[11] BY and GF closely inspected each transcript, applying initial open codes to describe each unit of meaning. Through comparison across the transcripts, the open codes were organised into related sets of thematic categories which provided a framework to code the transcripts using QSR NUD*IST software (version 4).[12] The framework was continually checked and modified against the data to ensure a "fit" between data and the themes. We continued collecting data until agreement was reached that we had achieved theoretical saturation—that is, when additional interviews added nothing further to the properties of the themes and subthemes.

RESULTS

Of the 55 families who were initially contacted, 19 agreed to be interviewed. Thirteen of these families reported a previous or current history of wheeze in the child who was the focus of

our interviews. Eleven of these children were reported to have been prescribed medication for their symptoms. Six families reported no history of wheeze in their child, though all but two families reported having experience of another relative, friend, or child with asthma or wheeze. The sample comprised parents from a diverse range of socioeconomic groups according to their occupations; nine were from smoking households. Two of the families were of South Asian origin, while the remainder were white. Eleven of the children were aged 1–3 years, with the remainder aged 4–5 years; seven of the children were female. Two of the interviews were conducted with the father alone, 14 with the mother alone, and three with the mother and father together. All interviews took place in families' homes.

For presentational purposes, the data are presented under the three main symptoms of wheeze, shortness of breath, and cough, with an additional section on making judgements about symptoms. We include illustrative quotations from the transcripts of the interviews.

Wheeze

Parents used a range of words and phrases to describe the sound of wheeze. These included "crackly", "squeaky", "strangled", "gasping", "rasp", "rattle", "lisp", "animal sounding", and "an air noise". A few said they did not know what wheeze sounded like or were unable to describe the sound at all. The terms "high pitched" or "whistle" were the most frequently used descriptors. However, most parents who used the term "whistle" qualified it by pointing out that there were subtle but important differences between the sounds of a wheeze and a whistle.

> "I suppose it is slightly, slightly like a whistle where somebody is practising. Like a child learning to do that. It's a whistle that's not quite there yet." (Family 8; no reported history of wheeze in child)

> "Noisy breathing from the chest ... more like a rasp than a whistle. It's quieter than a whistle because a whistle is quite high pitched, this is lower. Sort of like a lisp that is coming from the chest." (Family 18; reported history of wheeze in child)

Though some of the terms used by parents refer mainly to sounds, others describe features associated with breathing that are also seen or felt, such as "strangled", "rattle", or "gasping". Use of terms that described changes in a child's appearance, chest movements, or the vibrations a parent might detect when holding a child, were particularly prominent, suggesting that parents do not detect wheeze by sound alone.

> "... working hard at breathing, and you could see that his chest was slipping in." (Family 15; reported history of wheeze in child)

> "... you can feel it in his back, the rattling and the coughing." (Family 6; reported history of wheeze in child)

When parents were asked what they thought the term "attacks of wheezing" meant, their comments revealed a range of views.

> "An attack would be quite severe wouldn't it, really struggling for breath." (Family 2; no reported history of wheeze in child)

> "I would say any time they wheezed. If they wheezed then it is an attack of wheezing isn't it." (Family 1; no reported history of wheeze in child)

> "Prolonged I would say, that's it, ... it isn't a bout, but she has had a bout. So she's had an occurrence, but whether it's an attack? An attack is something that is quite distressing." (Family 5; reported history of wheeze in child)

While some parents considered every episode of wheeze as an attack, others thought it referred only to episodes of wheeze that lasted longer than a given time period and/or to episodes of a given severity. A few parents used more subtle criteria; for example, one parent associated "attacks" with sudden onset, contrasting this with her own daughter's episodes of wheeze which she considered too gradual in onset to constitute an "attack".

Shortness of breath

Many parents had never witnessed shortness of breath in a child and found it difficult to describe in words or generate approximate synonyms. However, most were able to offer a brief description and these fell mainly into three broad categories:

- Changes in a child's breathing. This included changes in the pace, depth and duration of breathing. Some terms could be applied to more than one of these dimensions such as "having to take bigger air in" and "harder" or "heavier" breathing.
- Changes in a child's appearance. This included changes in complexion, and observable changes in a child's demeanour such as "struggling" to breathe and looking "panicky" or "worn out".
- Changes in a child's behaviour. This was one of the most frequently cited signs of shortness of breath. Parents' descriptions were inextricably bound up with the context in which symptoms of shortness of breath might occur, and affected children were described as having to stop what they were doing or "slow down".

As parents do not have access to their child's internal feeling of shortness of breath, they need to use a range of other cues in making judgements about external signs of breathlessness. These not only included the sound of their children's breathing, but also how their child looked and behaved when short of breath.

Cough

Most parents drew distinctions between different types of cough, their effects, and associated contextual features. The four main features that distinguished the type of cough were: dryness/wetness; depth; repetitiveness/persistence; and ticklishness. Parents used a variety of cues in drawing these distinctions, including sound, the amount of straining and movement a cough produced, and the sensations parents detected when holding their child. Several parents of children with a reported history of wheeze spontaneously drew a distinction between an "asthma cough" and other sorts of cough.

> "I can always detect what is an asthma cough and what isn't ... the asthma cough, they lie down at night ... and it starts and it's dry and it's repetitive and it's over and over and over again. It keeps them awake ... It's not a throaty, thick cough as I would describe it. It's a very dry [demonstrates] like that." (Family 11; reported history of wheeze in child)

Most parents tended to describe an asthma cough as short, dry, shallow, tickly, and repetitive. The absence of other symptoms that might indicate an infection was noted by some as indicating an asthma cough. Only two parents of children with a reported history of wheeze offered descriptions of an asthma cough that differed from the above, one describing it as sounding "wet", the other as sounding "quite deep".

Making judgements about symptoms

In making judgements about their children's respiratory symptoms parents drew on a range of experiential resources as well as sensory and contextual cues, but their special or intimate knowledge of their own children was particularly useful in establishing a criterion of normality for each child.

> "I did notice, when she was very little, although it's probably to do with her as an individual child, that if she got distressed ... and she got into a panic she would cough ... So whether it's to do with her being an anxious child, you know." (Family 5; reported history of wheeze in child)

Almost all parents said that their children did not talk about their symptoms, or that what their children did say was so non-specific and lacking in detail that it was of little use in helping to interpret their symptoms.

> "They might say they don't feel very well but that's it really. They're not very descriptive really." (Family 7; reported history of wheeze in child)

Most parents expressed confidence in interpreting and judging their children's respiratory symptoms. Cough was the main symptom on which they relied in making judgements, though the presence or absence of other symptoms and the context in which symptoms occurred were also important.

> "Well it just seemed like a chest infection or something like that with the cough and all. I mean my friend's child has asthma and she does cough. But although she coughs a lot it's more like she has problems breathing than a cough. I thought asthma would be more like finding it hard to breathe really." (Family 2; no reported history of wheeze in child)

> "I would be confident that I had picked up on a wheeze, although like I say, to determine what it were due to I would be looking at everything else like, did they have a cough or cold or things like that?" (Family 5; reported history of wheeze in child)

DISCUSSION

Our study has implications for health professionals seeking to interpret signs and symptoms described to them by parents, and for those involved in conducting respiratory symptom surveys. The findings suggest considerable variability in how parents characterise symptoms in their children and in how they interpret some commonly used questions and phrases.

As in previous studies,[4 6] parents in our study offered descriptions of wheeze which included terms that do not usually feature in classic clinical descriptions of wheeze. Several of these may describe symptoms other than wheeze, and some refer to cues that are seen or felt rather than heard. Our study highlights how, given the limited communication skills of young children and the subtle nature of mild respiratory symptoms to an observer, parents use a range of cues and resources to interpret symptoms, and to distinguish possible deviations from wellbeing. In view of this, it may be appropriate for questionnaire designers to explicitly direct parents to concentrate on just one set of cues when answering questions on wheeze. For example, if sound is considered to be the most appropriate means of detecting wheeze, parents could be directed to report only on the sound of their children's breathing, and to ignore other cues if these are not considered clinically important in detecting wheeze.

As many of the parents in our study had previously taken part in a survey which defined wheeze as "breathing that makes a high pitched whistling sound", it is not surprising that whistling or high pitched noises were the most common descriptors of the sound of wheezing. However, it is striking that most parents who used the term whistling felt it necessary to qualify its use, particularly in describing wheeze as being quieter than whistling. Many survey instruments, including the ISAAC questionnaire[13] and others,[14 15] use whistling as a descriptor for wheeze, but our findings suggest it might be misleading or confusing to use this description without some qualification.

The term "attacks of wheezing" caused much uncertainty among parents. For some, this term was associated with struggle and distress, and seemed to have a significance that may well go beyond its use in clinical settings. The term may be a source of considerable variability in parents' responses and questionnaire designers should consider using alternative, less ambiguous terms. Similarly, clinicians should be conscious of the possible significance of this term for parents.

While wheeze refers to an audible breath sound, shortness of breath is a symptom that is impossible for parents to report on directly because it refers to an internal sensation. Instead of including questions on shortness of breath as a symptom, we suggest that it may be more appropriate to structure questions around the cues and signs that parents use to detect shortness of breath, and our study has identified some possibilities. Of course, further work is needed to investigate which of these cues might generate clinically important information, and how they might be best incorporated into questionnaires.

Our study has a number of limitations. Firstly, over half of the parents to whom we sent letters of invitation did not reply or declined to be interviewed. However, in qualitative research the aim is not to quantify the proportion of a population in which particular characteristics are observed, but to describe the concepts that are likely to be held by members of that population.[16] One of the main considerations is to access a diverse sample, and we did achieve this in terms of the range of socioeconomic groups represented and their experience of asthma related symptoms. Secondly, it is probable that prior "exposure" to a survey questionnaire may have influenced parents' views, and it should be borne in mind that greater variability might be found among parents without such exposure. Finally, we only recruited two families of South Asian origin and therefore have insufficient data to describe separately the views of these parents.

This study has described parents' accounts of how they recognise and make judgements about their children's respiratory symptoms, and how they interpret key questions that are currently used in respiratory symptom surveys. Work of this nature has been strongly advocated in a recent systematic review of best practice in the design of questionnaires.[17] Our findings indicate that there may be considerable variability in how parents interpret key questions in surveys, and we offer some insights into the possible sources of this variability and some suggestions for how questions might be improved in both research and clinical settings.

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IMAGES IN PAEDIATRICS.....

An unusual rash

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While on holiday in Turkey a 7 year old boy had a henna "tattoo" applied to his back. His skin soon became inflamed and then secondarily infected (fig 1). He was treated with oral antibiotics and antihistamines. Four weeks later the skin has healed, leaving just a pale outline of the tattoo.

Contact dermatitis to henna or one of its additives has been described before,[1] and we would urge caution to anyone considering a similar decoration.

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