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Understanding childhood asthma in focus groups: perspectives from mothers of different ethnic backgrounds

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Abstract

Background: Diagnosing childhood asthma is dependent upon parental symptom reporting but there are problems in the use of words and terms. The purpose of this study was to describe and compare understandings of childhood 'asthma' by mothers from three different ethnic backgrounds who have no personal experience of diagnosing asthma. A better understanding of parents' perceptions of an illness by clinicians should improve communication and management of the illness.

Method: Sixty-six mothers living in east London describing their ethnic backgrounds as Bangladeshi, white English and black Caribbean were recruited to 9 focus groups. Discussion was semi-structured. Three sessions were conducted with each ethnic group. Mothers were shown a video clip of a boy with audible wheeze and cough and then addressed 6 questions. Sessions were recorded and transcribed verbatim. Responses were compared within and between ethnic groups.

Results: Each session, and ethnic group overall, developed a particular orientation to the discussion. Some mothers described the problem using single signs, while others imitated the sound or made comparisons to other illnesses. Hereditary factors were recognised by some, although all groups were concerned with environmental triggers. Responses about what to do included 'normal illness' strategies, use of health services and calls for complementary treatment. All groups were concerned about using medication every day. Expectations about the quality of life were varied, with recognition that restrictions may be based on parental beliefs about asthma, rather than asthma itself.

Conclusion: Information from these focus groups suggests mothers know a great deal about childhood asthma even though they have no personal experience of it. Knowledge of how mothers from these ethnic backgrounds perceive asthma may facilitate doctor – patient communication with parents of children experiencing breathing difficulties.

Background

Diagnosing childhood asthma is dependent upon parental symptom reporting. We have previously reported problems in the use of words and terms [1,2]. The purpose of this study was to identify how mothers from different ethnic backgrounds understood a boy's 'asthma' shown on video. The mothers were not told the name of the condition and did not have direct experience with di-

agnosed asthma. In this way an exploration of public understanding about the condition could be achieved. A better understanding of public perceptions of an illness should improve communication and management of the illness with those seeking health care [3]. By studying understanding with respect to ethnicity, the greater risk of underdiagnosis of asthma in children from minority ethnic groups may be reduced [4]. The use of focus groups is an accepted method of understanding and exploring people's knowledge [5–9]. In this study the focus groups' discussions were semistructured. The six preplanned questions were devised to elicit lay 'explanatory models' [10] in this case for understanding the condition shown on the video.

Table 1: Structure for each session

Questions asked in each session	Abbreviation
*What do you think about what you have just seen?	Initial prompt
What do you call the difficulties this child has?	Description
What do you think causes it?	Explanation
*Have you met children who had similar difficulties?	Experience
What would you do if your child had difficulties like this?	Action
Do you think this affects the child's life in any way?	Expectation

**Prompt questions only (not analysed separately)*

Method

Sixty-six mothers aged 22 – 45 years and resident in east London, were recruited by advertising and by direct approach to a 'discussion group on child health'. Using a recruitment questionnaire that asked about a number of family illnesses including asthma, it was possible to enrol mothers who had no family members with this disease without simultaneously introducing the particular subject. In addition to issues about cultural perceptions, there are translation issues for symptoms central to asthma such as 'wheeze' [11]. Groups of mothers were therefore arranged on the basis of similar language and ethnic backgrounds. These were 'Bangladeshi', 'White – English' and 'Black – Caribbean'; the largest population groups for the area projected from the 1991 census (unpublished from the London Research Centre).

Three experienced moderators of the same ethnic backgrounds as the participants, conducted 3 semistructured focus group sessions each. Each session had 5–9 participants, lasted between 40 minutes – $1^1/_2$ hours and took place over three months (November 1999 – February 2000). Two of the Bangladeshi sessions were conducted in, and translated from, Sylheti dialect. In order not to make volunteers feel privacy was being threatened we elected not to ask about country of origin, education and other questions of status.

At the start of each session a one minute long video clip was shown. This was of a six year old boy with audible wheeze and cough (used in a previous study [2]). He was shown undressed to the waist so that chest movements could be seen clearly. He held a small microphone so that his breathing (although amplified) could be clearly heard. Thus visual and audible signals would be available to the observers, mimicking as far as possible what would be observed by a parent of a child having an asthmatic episode. Participants were not told that the diagnosis was 'asthma'. Sessions were semi-structured (see table 1). The focus groups took place in convenient community settings and were recorded by video and / or dictaphone. Ethics approval for the study was granted from the local Health Authority. Participants completed consent forms and were paid.

Each focus group session was transcribed verbatim. A preliminary analysis reviewed the features of each page of text (e.g. consensus, disagreement). Two readers then reviewed the text for responses to each of the preplanned questions. Comparison between the texts from each session aided analysis. Responses to each of the pre-planned questions were elicited from within each session, then compared to the other sessions of the same ethnic group, before an overall ethnic group response was derived. Results were then checked backed to the preliminary analysis to ensure proper representation in the extent of agreement.

Results

Question 1: Description

Some Bangladeshi mothers quickly and confidently identified the boy's difficulties as 'asthma'. The other participants generally agreed with little discussion. Mothers in one Sylheti session discussed the equivalent Sylheti terminology. A feature of that discussion was reference to breathing difficulties as 'called asthma generally'. There was some evidence in each of these sessions that some mothers may use the term 'asthma' broadly, for example; 'sometimes parents take their children to the clinicians and say that it is asthma when it's just a cough' and mothers who knew children who had asthma when 'they were born'.

English mothers described the boy's difficulties using general terms like 'difficulty in breathing', visual descriptions, imitation and individual signs ('wheeze', 'rattle', 'cough'). 'Asthma' was a more immediate response in one session. Other respiratory illnesses were discussed and discounted on various grounds; age ('too old for croup',

too young for smoking related problems), duration (unlike 'panic attacks') and intensity ('whooping cough is more violent'). 'Asthma' was generally recognised and accepted but with varying degrees of conviction. That the boy had breathing difficulty was agreed in one session but the main discussion was about child health. In contrast, mothers in another session discussed the concept of asthma (see Additional file 1: [extract 1]). There were some references to 'asthma' as a particular diagnostic practice (given after a certain age), that can change over time ('they used to say bronchitis, didn't they, but now the modern word is asthma'), that diagnosis can be problematic and applied to a range of symptoms.

There was less discussion by the Caribbean mothers about this question. They described what they saw both in terms of symptoms ('breathing difficulties', 'wheeze', 'cough', 'rattle') and illness ('asthma', 'bronchitis', 'pneumonia', 'whooping cough'). Although they discussed the symptoms and possible illness, they were less confident than the other two groups in attaching a precise label. Discussions were often related to their own children's coughs and colds. However they clearly understood this boy had more than a cough or cold.

Question 2: Explanation

Common to all nine sessions, although to differing extents, were 'pollution' (particularly traffic) and 'the environment' (weather, urban and home surroundings, and parental smoking). Mothers used phrases such as 'brought on by', 'contributing factor' and 'related to' more than 'caused by' to discuss their explanations.

In addition to these themes, most Bangladeshi mothers mentioned 'hereditary' influences. Several mothers also recognised 'the cold' or 'catching colds' as important. This was explicitly related to asthmatic children that some knew saying that once they caught a cold, 'that's it'. Damp and dust in the home were also mentioned. Mothers in two sessions discussed that other (non-specified) Bangladeshi people think it is 'contagious' (see 1Additional file 2: [extract 2]).

In the English sessions, the association between pollution (including industrial emissions) and breathing difficulties was made explicit by some e.g. 'in the media everyone is telling you, there is more cars on the road ... exhaust fumes are not good for you so you try and piece it together'. 'Pollution' was also related to contamination of soil and the production of food; e.g. preservatives and food intolerance. In one session this was related to broader issues of social organisation, economic systems, and health care practice (breast feeding, vaccinations and immunity). In each session the relationship of allergies was discussed (either as a related condition or as inducing breathing difficulties) but hereditary factors were only considered in one group.

Many Caribbean mothers related their own observations and experiences about poor health generally, emphasising nutrition, concerns about 'junk food' and the importance of a 'good' diet for a strong immune system, and factors in the home and urban environment to respiratory problems. Climate comparisons between London and the West Indies were considered in part responsible. For example, one mother's niece whom 'you'll never even know she is an asthmatic child' when she goes to Jamaica. The West Indies was perceived as less 'boxed in', with 'the sea, fresh air, good food' and less stress as central to good health.

In relation to the onset and exacerbation of breathing difficulties, exercise and psychological references were occasionally made (particularly 'stress').

Question 3: Action

All groups said that precipitants of breathing difficulties should be avoided (described above).

Some Bangladeshi mothers mentioned avoiding certain foods; e.g. banana since it 'contains a liquid that irritates the throat', and cold milk or ice cream. Going to a doctor was considered the first move, although a few mentioned that 'doctors here don't even mention restricting foods'. Mothers said they knew 'automatically whether a cough is serious or not' as indicated by severity and duration (2–3 days). Mothers in one session said that if their doctor thought it serious or if they were unable to be seen, they would go to an accident and emergency (A&E) department. Paracetamol and menthol preparations were mentioned.

Some English mothers decided what to do according to the context e.g. a first occurrence or acute illness. Duration, severity, and 'assessing' (from practice and learning from others) informed some responses. Some said they would go 'straight to the GP' (general practitioner), while others suggested menthol rubs, 'alternative stuff' (e.g. breathing techniques), getting advice from other mothers or by 'reading up on it'. Some mentioned 'hoovering a bed down' and special bedcovers. There was concern about long term medications. In two sessions there was debate about health care systems in other countries ('where all GP routinely treat children under seven with homeopathy first'), a lack of complementary therapies and 'unbiased information' (i.e. not drug company funded) available on the NHS.

Some Caribbean mothers said they would utilise their normal strategy of what they do when their child is un-

well with respiratory difficulties (e.g. menthol rubs, types of foods). In two sessions discussion involved remedies e.g. honey and lemon tea or West Indian remedies such as 'bush tea'. These 'remedies' are either consumed (and included foods considered nourishing) or rubbed on the body (e.g. soft candle wax). Mothers learnt about remedies from family members. Some would not mention these to their GP. Only one mother said she would find out what was wrong before trying a remedy. Most would first seek advice from their own family, friends and medical books (see 1Additional file 3: [extract 3]). As with the other groups, decisions about the need to seek medical advice were context dependent (e.g. severity of symptoms, the age of child). Some mentioned that attending A&E would be preferable to their GP (mentioning their GP was unhelpful, that surgery hours are limited and if symptoms were severe enough), however others were just as critical of junior doctors in hospitals.

Question 4: Expectations

Bangladeshi mothers in the Sylheti sessions were the most divided about the possible outcomes of the boy's condition (see 1Additional file 4: [extract 4]). Some responses were specific to the perceived condition (e.g. sometimes being unable to do sports) while others were generalised (e.g. 'weariness'). Medication was recognised to 'control' and help normalise the child's condition, but there was also worry about long term use. Despite the discussion about stigma of respiratory illness in Bangladesh, a mother gave the provision that maybe 'children growing up here don't worry about these things'.

Most of the English mothers discussed exercise limitation. The general perception was that this condition is manageable, normality was possible provided things were 'in moderation'. Psychological dependency on 'drugs' and missing school (from illness and attending appointments) were frequently mentioned. Some mothers said parental anxiety would itself affect this child's lifestyle.

Most of the Responses from Caribbean mothers addressed the general effects of being unwell e.g. lack of energy and susceptibility to infections. Like English mothers, the effect on education and lifestyle was emphasised. Mothers expressed their concerns largely from the child's point of view, but the effect on the parents was also mentioned.

Discussion

This study demonstrates the range and depth of mothers' approaches to and knowledge about children's respiratory health generally. Mothers had been recruited to a 'discussion on child health' and shown a video clip of a boy with unnamed respiratory symptoms. This child had been formally diagnosed with asthma and mothers were not told this in order to explore their own understandings of the presentation. There were many ways of talking about the boy's difficulties; from describing single signs (general terms, specific sounds, visual descriptions and imitation) to naming specific diseases, how they differ and when they may be considered the same. This breadth helps explain the previously identified differences between health care workers' and parents' reports of symptoms [1,2,12]. These mothers describe the condition observed far more broadly than health care workers, who tend to limit questions to cough, wheeze and shortness of breath. These findings are similar to those of a study about what health means, where patients considered 'health' more broadly than do general practitioners [13].

A central explanation for the boy's condition was pollution, particularly from traffic. It is impossible to know whether this is instinctive or informed (occasionally the media was specified). Although some studies have shown that children living near busy roads may have more respiratory symptoms, the overall understanding about pollution causing or exacerbating asthma is unclear [14]. However the concern about 'junk food' (particularly in the Caribbean groups) has since been confirmed by a study showing a direct link to childhood asthma [15]. Similarly the role of the common cold with asthma discussed in the Bangladeshi groups is well established [16]. Complementary approaches suggested by some English mothers had been used by 59% of asthma patients in one study [17]. Finally, many of the expectations these mothers had about the effect of the condition (restriction in activity, changes to be made in the home, effect on school and parental worry) are similar to the experiences of asthmatic children and their families' [18,19]. The evidence from these studies supports the mothers' understandings in this study. However stress, which is considered an important precipitant of asthma attacks [20], featured little in these discussions.

The employment of moderators from ethnic backgrounds similar to the mothers' was positively received and commented on (particularly in the Caribbean groups). However participation and organisation of the sessions in terms of ethnic background was sometimes considered 'unnatural', particularly when groups were formed from a larger social and ethnically diverse group. Although a few mothers initially expressed concern about the filming and showing the boy, they later acknowledged its purpose. Precise demographic information (e.g. husbands occupation) was not collected as it was considered too intrusive and could have affected recruitment and the discussion. Since no information about participants' education was collected, some of the

differences within and between groups may be related to other variables such as education rather than ethnicity.

The prevention of bias was attempted at each stage of the study; from not saying it was about 'asthma', to using the video to prompt discussion and by utilising the mothers' own terms and exploring their understanding [21,22]. However, some participants said it was difficult to know what was wrong with the child without having any contextual information. In this way, mothers' reasoning is similar to that of health care workers'. Since the aim of the study was to explore mothers' own explanatory models for the condition presented on video, mothers' responses were both general about respiratory conditions and specific to 'asthma'. It may have been helpful to present other clips of different respiratory symptoms to extrapolate that which they considered specific to asthma. Other limitations of the method is that not all participants contribute equally, discussion is more influenced by dominant members than those who are shy. In presenting general views between the groups overall, an individual comment may be lost. Additionally there may be issues concerning translation even though the facilitator who conducted the Sylheti sessions also undertook the transcribing. Finally, it is important to acknowledge the difficulty in predicting how the responses given would correspond to action in 'real life'.

Conclusion

One of the benefits of using focus groups is that the wider community understanding can be reflected as much as the individual response [23]. Also, by organising the groups according to language and ethnic background, cultural influences that may be relevant to outcomes in respiratory health generally and asthma specifically may be identified [24]. The clearest example of these points was in reports that some (other) Bangladeshi people consider asthma to be contagious. Each session, and ethnic group overall, developed a particular orientation to the discussion. The Bangladeshi group did not generally perceive the issues as problematic (particularly here in England and particularly in the Sylheti sessions) and were the most accommodating of the groups to the medical profession and approach. The English mothers were generally more questioning and critical and related broader issues of context and practice. The Caribbean mothers related their responses to their own direct experience and observations. No one approach should be considered 'more correct' or 'better' than another. Whether these approaches are indicative of general approaches to health would require more study. The perceptions of these members of 'the public' then, are rich, complex and insightful. By recognising these, communication in the partnership between health care worker and parent for the care of the child with breathing difficulties could be facilitated.

Additional material

Addtional files

1. Coding section is key to symbols used in the extracts presented.

Additional file 1. 'Coding used in extracts'. 'Extract 1- English mothers in one session discussing the concept of asthma'
[http://www.biomedcentral.com/content/supplementary/1471-2296-2-4-S1.rtf]

Additional file 2. 'Extract 2- Bengali mothers in a Sylheti session discussing the perception of asthma'
[http://www.biomedcentral.com/content/supplementary/1471-2296-2-4-S2.rtf]

Additional file 3. 'Extract 3- Caribbean mothers in one session discussing action they would take'
[http://www.biomedcentral.com/content/supplementary/1471-2296-2-4-S3.rtf]

Additional file 4. 'Extract 4- Bengali mothers in a Sylheti session discussing the possible effect of the condition'
[http://www.biomedcentral.com/content/supplementary/1471-2296-2-4-S4.rtf]

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