

What worries parents when their preschool children are acutely ill, and why: a qualitative study

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Abstract

Objective—To identify and explore parents' concerns when young children become acutely ill.

Design—Qualitative study making use of semi-structured one to one and group interviews with parents of preschool children.

Setting—Disadvantaged inner city community.

Subjects—95 parents of preschool children.

Results—Fever, cough, and the possibility of meningitis were parents' primary concerns when their children became acutely ill. Parents' concerns reflected lay beliefs, their interpretation of medical knowledge, and their fears that their child might die or be permanently harmed. Parents worried about failing to recognise a serious problem. Concerns were expressed within the context of keenly felt pressure, emphasising parents' responsibility to protect their child from harm. They were grounded in two linked factors: parents' sense of personal control when faced with illness in their child and the perceived threat posed by an illness.

Conclusions—Better understanding of parents' concerns may promote effective communication between health professionals and parents. Modification of parents' personal control and perceived threat using appropriate information and education that acknowledge and address their concerns may be a means of empowering parents.

Introduction

Children under 5 years old form the largest proportion of reactive workload in primary care,¹ with those from disadvantaged backgrounds having the highest contact rates¹⁻³ and morbidity.⁴ Parents inevitably worry about their children when they are ill. Gaining an understanding of what parents worry about is important if parents' anxieties are to be addressed effectively and if relevant information and education is to be offered. Previous work has described the beliefs and behaviours of mothers with young children but has paid less attention to what provokes concern for parents when their children are acutely ill.⁵⁻⁸ In this study and the accompanying paper⁹ I sought to identify what worries parents when their children become acutely ill and to understand what motivates their concerns.

Subjects and methods

I conducted pilot interviews initially with parents who were patients registered on the shared list of my general practice. I then recruited parents who were not my patients and had at least one child under 5 years old from a range of community settings in a disadvantaged area: a community centre, a hostel for single mothers, another inner city general practice, and three parent and toddler groups.

One to one interviews—Parents attending the community centre and parents living in the hostel were invited to participate in the research by a community worker. A random one in four sample of mothers registered with the general practice was sent a postal invitation. Purposeful sampling^{10 11} was then used to select willing parents for interview. Initially, parents from each of the three settings who might have had typical experiences (no specific characteristics) were interviewed. As the research progressed, I selected parents registered with the general practice who were thought to have particular experiences of caring for ill children and those who were thought to have atypical experiences after discussion with the practice. Such parents were actively sought to ensure that data and its interpretation were not distorted to one perspective and that all cases could be accommodated within the developing analysis. Sampling was intended to provide a range of experiences and perceptions so that the breadth of findings and concepts emerging might be understood. Table 1 describes those features of the resulting sample. The interviews were open ended, semi-structured, and conducted in parents' homes.

Focus group interviews—All parents attending three parent and toddler groups were invited by their group organisers to form a volunteer sample to participate in focus group interviews.¹² These were held where they usually met with the help of crèche facilities. Both one to one and group interviews were used to enhance the sufficiency and quality of data and facilitate comparison and confirmation of emerging concepts across different settings.

Data analysis—The interviews explored broad areas identified in the pilot but concentrated on encouraging parents to discuss freely what was important to them when coping with ill young children and how and why they thought as they did. All interviews were audiotaped and transcribed verbatim. Data collection and analysis were guided by grounded theory methodology.¹³ Transcriptions were analysed to identify concepts and categories embedded within them. Concepts and their relations were confirmed, modified, or discarded from ongoing analysis by re-examination of earlier data and during subsequent data collection and analysis. Interviewing continued until no new concepts were being generated. This suggested that the findings and conceptual scheme developed were a valid picture of parents' concerns and perceptions.

Study sample—Ninety five parents were interviewed in total. Of parents invited to participate in the one to one interviews, 16 of the 22 mothers at the community centre, all four parents at the hostel, and 29 of the 47 mothers registered with the general practice agreed. Ultimately, 32 parents were selected and interviewed at home (24 mothers alone and four mothers with their male partners). A further 63 mothers (of 82 attending the parent and toddler groups) participated in 10 focus groups (range 5-8 mothers). All the interviews lasted between one and two hours and were conducted over a

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Table 1—Purposeful sample of parents in one to one interviews

Key characteristic of family interviewed	No of mothers (n=28)
Single mother in temporary hostel accommodation	4*
Child with chronic problems (asthma, epilepsy)	4
Child admitted with acute illness in previous 12 months	3
Child with special needs (Down's syndrome, tuberous sclerosis)	2
Frequent user of general practitioner's out of hours service	5†
Mother with health professional background	3‡
Others with preschool child or children	7

*Two aged 16, one aged 18, one aged 25.

†Two or more out of hours visits by general practitioner to ill children under 5 years old in past 12 months.

‡One auxiliary nurse, one registered general nurse, one health service manager (sample included four fathers).

Table 2—Characteristics of participants

	No of households (n=91)
Unemployed household*	34
Living in rented housing	58
Mother left full time education at 16 or under	64
Mother without formal qualifications since leaving school†	54
Single parent household	29
Household with one child	31

*No parent in employment.

†Educational or vocational.

period of 14 months. Most parents were from socio-economically disadvantaged backgrounds. All were white and English speaking. The mean age of mothers was 26 years (range 16-41 years). The characteristics of participants are summarised in tables 1 and 2.

Respondent validation—To establish that the dataset was complete and parents' experiences were fully described, three further focus groups were held to feed back and review findings.¹⁴ Nineteen parents, six who had been interviewed individually and 13 who had been part of a focus group, took part. The description and interpretation of the data seemed to be true to their experiences, the additional information from these discussions confirming rather than modifying the analysis.

Results

Fever, cough, and the possibility of meningitis consistently emerged as parents' primary concerns when their children became acutely ill. These provoked particular anxiety because of fears that their child would

die or be irreparably harmed. These concerns are discussed below to illustrate an explanatory scheme of parents' management of ill children developed through the analysis. Two key linked factors were involved: perceived threat and personal control. Other concerns and difficulties parents described are discussed in the accompanying paper.⁹

PERCEIVED THREAT

Parents' anxieties about fever and cough, and the importance that they attached to them during an episode of illness, related to how parents interpreted their apparent effects on their child. This shaped their assessment of risk or the perceived threat posed by an illness. Of initial concern were changes in behaviour that parents associated with their child becoming unwell, such as not eating or sleeping or not being herself or himself. Parents became more concerned if their child was uncomfortable—for example, hurting from coughing or flushing from fever. They became more anxious if they thought their child was suffering—for example, from the physical effect of a fever or from difficulty in breathing because of coughing (box 1). At this stage parents often worried that the problem might herald more severe illness or potential harm. In the case of fever this included the development of meningitis or fits; permanent impairment of some kind, such as brain damage; or even death. A fever without other common signs of illness, and therefore an explanation (such as a cold), was especially likely to cause concern and vigilance. For some parents a rising fever posed a more intangible, ill defined threat (box 1).

Coughs that were perceived as "chesty" due to phlegm or that provoked vomiting or retching caused concern about infection "on the chest." Some feared development of a more chronic problem such as asthma or worried about death of their child from the sudden infant death syndrome, from inhaling vomit, or, more usually, from choking. Perceived threat, then, comprised categories reflecting the observed effects of a problem and beliefs about the potential harm that might result (fig 1).

PERSONAL CONTROL

Monitoring and maintaining control of symptoms was seen as paramount to minimise discomfort and reduce the threat of harm. Parents continuously assessed their child's temperature (most often by touch) and diligently performed cooling procedures. They were preoccupied with the fever becoming too high: their common fear was of a temperature rising inexorably, eventually spiralling out of their control and bringing the threat of harm nearer. Management of

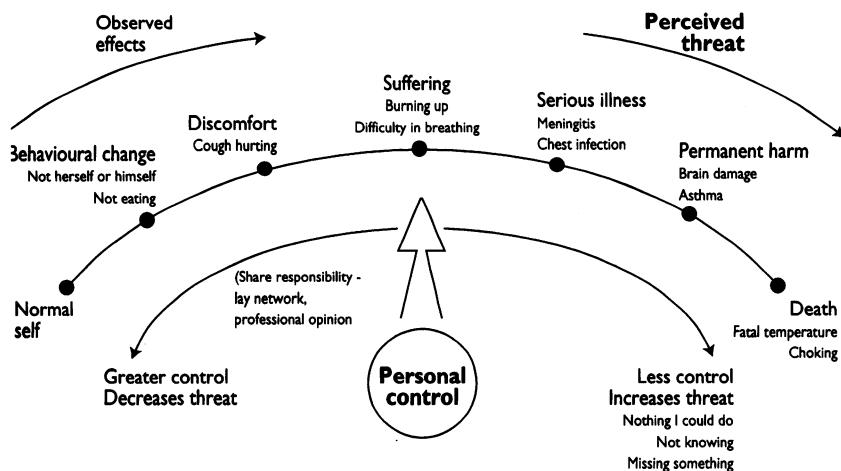


Fig 1—Interaction of personal control and perceived threat

Box 1—Suffering and potential harm

Suffering

"I hate it when you see them like that, they're just burning up, lying there crying and not eating" (Parent 11)

"I worry about him getting chesty...he really can hardly breathe sometimes he's coughing that much" (Parent 5)

Potential harm

"When their temperature goes too high it's worrying, you worry about brain damage and things, and they could die, or there might be something more deeply worrying than I could imagine" (Parent 20)

Box 2—Managing the problem

"I always keep an eye on the temperature, I like to get their temperature down,...that's the frightening stage when it keeps rising and rising" (Parent 23)

"He sounded like he was choking, I kept making sure he was okay during the night" (Parent 6)

"I panicked and called the doctor...she was choking and it was a horrible barking cough and she brought loads of phlegm up making her sick...there was nothing I could do...I thought she was going to die" (Parent 3, group 5)

Box 3—Lack of control

"If I knew what the problem was I don't think I'd be as worried, it's not knowing that gets to me" (Parent 16)

"When she's got a bug...I'm worried that it's something else, and I'm missing something...it could be something nasty...I don't know" (Parent 4)

cough entailed a similar process of checking and trying to reduce the effects of the cough, particularly at night when the child was seen as more vulnerable and difficult to monitor. Parents felt increasingly powerless when their efforts were failing to keep a problem under control and the perceived threat increased (box 2).

Analysis of parents' strategies showed that they watched, checked, and tried to make sense of their child's illness. At the heart of this lay an imperative responsibility to ensure the safety of their child. Parents expressed frustration at feeling ignorant, and they worried about failing to recognise a serious problem, about missing something (box 3). A parent's personal control encompassed her sense of being able to control the observed effects of an illness and to protect her child from potential harm. This was conditioned by her knowledge, beliefs, and experiences and informed her

Box 4—Sharing responsibility and meningitis fear

Sharing responsibility

Father: "Once the doctor's been out and had a look you feel a lot easier in yourself"

Mother: "You think, 'Am I phoning him up for nothing?'...but at the end of the day if you didn't and something happened to your baby you would never forgive yourself" (Parents 15A and B)

Spectre of meningitis

Parent 5: You don't really know what you're looking for do you?

Parent 6: No, I mean you hear about it on the telly and it starts from 'flu symptoms, things like that, and you think straight away they're not getting better, that's it, it must be meningitis

Parent 4: You always worry about meningitis...in case you don't catch it quick enough

Parent 5: Well you get no symptoms at the beginning...meningitis does not give any warning (Group 3)

evaluation and management of a problem. Figure 1 depicts a model of the interaction of personal control regulating perceived threat.

The need to share responsibility with others within their lay network or by seeking professional advice could be irresistible when parents were concerned about their child. Some parents felt guilty about bothering their doctor in these circumstances but thought that they had little choice (box 4). These issues were foremost when parents talked about meningitis. Discussion about meningitis was often emotive. Parents' deepest fears of death or handicap befalling their child crystallised in the form of meningitis. There was a common understanding that symptoms could be non-specific and the illness rapidly overwhelming, heightening anxiety about not detecting the disease. For some parents the spectre of meningitis haunted them whenever their child showed signs of being more than slightly unwell (box 4). The specific feature of meningitis most often identified was appearance of a rash. Parents were ever vigilant for this sign of meningococcal illness, but few parents had accurate knowledge of the rash. For many parents any unexplained rash could herald immediate danger and the need to seek medical advice.

Discussion

METHODOLOGICAL CONSIDERATIONS

This study has highlighted the primary concerns of parents when young children become acutely ill and has explored why they worry about them. A qualitative approach was used to provide insights into parents' concerns and thinking rather than produce statistically representative results. Most parents were willing to participate. I did not gather comprehensive information about non-respondents, however, as I did not want parents to feel uncomfortable or under pressure to participate when many had hectic schedules, particularly in the community centre and toddler groups. Moreover, I wanted a sample of parents who were willing to articulate their experiences.

The systematic methods described were used to increase the reliability and validity of the study: selecting a broad range of parents with different experiences; obtaining data in both one to one and group settings; and reviewing and confirming the findings with participants themselves. In the focus groups parents were already familiar with each other. This may have reduced the artificiality of the discussions. These groups explored one of the social contexts in which ideas might be formed and decisions made about young children's illness. Conversely, respondent validation used discussions between previously interviewed participants who were not known to each other and allowed comparison of parents' experiences in another context.

Differences between the researcher and respondents may have influenced parents' responses and their interpretation: I am a male middle class health professional and the respondents were largely women from disadvantaged backgrounds. Parents' public accounts may have been selective and excluded that which might be considered unacceptable to a health professional. Participants were aware that I was a doctor, and discussion may have been biased towards medical rather than lay concepts. However, the study has attempted to place emphasis on the perceptions of the parents interviewed. I was also able to identify with some of the respondents' experiences as I have worked as a general practitioner in their community for the past five years. Few fathers were interviewed—the study reflects the contemporary reality of child-care, which remains largely the responsibility of mothers.

When parents' concerns were explored, two factors emerged that appeared fundamental in shaping their responses: parents' sense of personal control when faced with illness in their child and the perceived threat posed by an illness. Germane to personal control was parents' experience of comparative ignorance and difficulty in establishing the severity of illness, which is discussed further in the accompanying paper.⁹ Parents' concerns were expressed within the context of keenly felt pressure to protect their child from harm. The perceived threat could be seen as a continuous process corresponding to the effects a problem was believed or observed to cause and regulated by a parent's personal control (fig 1). This scheme has resonance with the folk model of illness beliefs proposed by Helman.¹⁵ For example, fever was perceived as serious and its development outside personal control (thus requiring professional advice) in contrast to a common cold, in which the elements of personal responsibility and control are strong, its development being influenced by things such as not wrapping up well.

Parents' concerns about fever and cough reflected erroneous beliefs and use of biomedical concepts, albeit in a rational framework. Beliefs about fever rising relentlessly and the need to control temperature may be viewed as logical and congruent with fairly common knowledge of febrile convulsions and delirium in young children. In addition, advice from professionals commonly reinforces cooling children regularly, particularly in relation to febrile fits. However, controlling temperature is not necessarily preventive—the main purpose is to keep the child comfortable.¹⁶ Quantitative research from North America has pointed to similar beliefs.^{17, 18} Parents may benefit from education about the probable positive effects of fever¹⁹ and the body's central regulatory thermostat.

The depth and nature of parents' concerns about cough accord with the high proportion of consultations for children in general practice that are for respiratory illness.¹ Similar beliefs have been described among mothers who recently consulted a general practitioner about their child's cough.²⁰ The qualitative construction of perceived threat in the current study is also consistent with the characteristics of a child's cough which have been found to predict likelihood of consulting a general practitioner.²¹ Increasing parents' knowledge of the nature of upper and lower respiratory tract infections and the physiological function of cough in response to infection may be helpful.

Parents' anxieties about meningitis must be interpreted in the light of recent media coverage and campaigns about the illness. The pressure parents experienced may have been intensified by messages such as "knowing the symptoms of meningitis could mean the difference between life and death."²² Parents readily identified the need to be vigilant for a rash, yet self-limiting rashes are common in young children. This may be creating unnecessary anxiety and increased contacts with health services. It underlines the need for information to include good photographs to show how to distinguish the rash of meningococcal illness, such as those in the material produced by Meningitis Research.²³

Parents' anxieties about failing to recognise a serious illness serve as a reminder that what constitutes common knowledge for doctors may not be readily accessible to parents. Information and education that address parents' concerns may empower parents by influencing perceptions of threat posed by an illness and enhancing personal control. This forms the basis of a hypothesis for further exploration. The findings emphasise the importance of acknowledging and addressing parents' fears and beliefs if a consultation is to help the

Key messages

- When faced with acute illness in their children, parents' concerns were shaped by their sense of personal control and the perceived threat posed by an illness
- Parents worried about fever, cough, the possibility of meningitis, and failing to recognise a serious problem
- Better understanding of parents' concerns and what causes them may promote more effective communication between health professionals and parents

parent and not be regarded as inappropriate by the health professional. With much current activity in general practice focused on managing the rising demand for out of hours care,^{24, 25} this research highlights a source of mutual dissatisfaction between the parents of ill young children, who generate much of this workload, and their general practitioners. Better understanding of parents' concerns and what motivates them may promote more effective communication between health professionals and parents.

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