Mothers' concepts of normality, behavioural change and illness in their children

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SUMMARY. Several sociological models have been put forward to explain illness behaviour. However, little research has examined general practitioners' understanding of mothers' perceptions of their children's health and illness. The aim of this study was to attempt to understand the cultural context of children's illness. Mothers' concerns about their children's health and illnesses were examined by describing the mothers' own perceptions of alterations in their children's behaviour. The mothers' perceptions of normality appeared to underpin their negotiation of illness. The concept of normality was found to change over time, to be uniquely based on individual experience, to be related to health, and to a process of normalization. The mothers' perceived importance of children's behavioural changes are discussed: they may be precursors or results of illness, causes for concern in their own right, or a management problem for the household. Identifying and acknowledging the unique way in which mothers perceive health and illness in their children may lead to enhanced understanding and satisfaction for both the general practitioner and mother in the consultation process.

Introduction

IT is probably a common experience at the end of a consultation for a general practitioner to feel that, inexplicably, the patient is dissatisfied, despite the general practitioner having done all the right things. Recent literature has highlighted the differing perceptions of health between professionals and lay people, and about the relationship between symptoms and illness.[1] Helman[2,3] outlined the concepts of illness held by middle class Londoners, which were at variance with conventional medical beliefs. Blaxter[1] reported that mothers in deprived families 'may have cultural values and definitions of health and illness which may differ from those of the medical profession'. The Royal College of General Practitioners' report *Health and prevention in primary care*[4] stressed that careful attention should be paid to patients' beliefs about health and disease.

Over the past 50 years several sociological models have been advanced to account for illness behaviour.[5-7] However, authors such as Suchman[8] have assumed that there is an established process through which every individual passes in becoming ill. In the case of mothers of young children, writers have sought to measure knowledge of illness and reaction to professionally pre-defined symptom categories.[9,10] They have seldom addressed the problems of lay perception or definition of illness. Most studies have focused on particular medical encounters,[11-13] or interactions with services.[14-16] In addition, there has been a tendency to study deprived populations[15,17] or to focus on symptoms heralding potentially life threatening disease.[10,18] This paper is based on a Scottish study of the cultural context of childhood illness[19-21] and it examines mothers' perceptions of childhood health and illness. A qualitative approach is used to examine the process of defining health and illness and the concepts and beliefs underlying such negotiation. Through this kind of intensive data collection and analysis the processes that are otherwise implicit or 'taken for granted' can be explored.[22]

Method

The study sample was drawn from a non-deprived predominantly lower middle/working class community in a new town in Scotland. Fifty six women with at least one child under five years of age were randomly selected for the study from one health centre's register. Each mother was initially visited at home and invited to take part in the study. Having gained consent, each mother was then asked to complete a health diary for her family over a four week period, and be interviewed by one of the researchers (S C-B) in the mother's own home. The interviews were tape-recorded. The study employed qualitative, sociological techniques to explore the mother's perspective in relation to childhood health and illness, and to examine this within the context of the family.

After piloting, a broad topic guide for interviews was developed, covering a range of issues including recognition of illness, self-care, lay referral and health maintenance activities. The mothers were encouraged to talk about their own concerns, and to describe how they went about dealing with the various illnesses and health problems, however minor, that occurred in their children. An informal, unstructured approach to the research interviews was used to encourage the women to talk freely, and in depth. The health diaries were used to examine how the mothers recognized and managed symptoms on specific occasions. The form of the diaries was relatively unstructured. The mothers were asked to make daily entries in a booklet over a four week period, and were visited twice during this period by one of the researchers (S C-B) to encourage completion of the diaries and to discuss any health issues raised. The mothers were asked to note down each day whether they had noticed any symptoms in their children and whether they had taken any action, and to comment on the day in general.

The data were analysed inductively, using techniques of coding and indexing with categories that were data driven rather than predefined by the researcher. Thus professional definitions are avoided in the results, and the analysis is grounded in the point of view of the mothers. Quotes from the interviews and diaries are used to illustrate points.

Results

Fifty four of the 56 mothers contacted agreed to take part in the study. The median age of the sample was 28 years; 53 of the women were married. The families were not necessarily involved in any professional encounters, or experiencing episodes of illness at the time of sampling. Forty two of the 54 women interviewed filled in the diary, although not all managed to do

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so for the whole four week study period. A total of 927 days were collected in all. There were differences in the amount of data obtained depending on the morbidity experience of different families. However, the range of concerns was consistent across the sample.

Normality

The recognition of illness and symptoms appeared to be embedded in a commonsense knowledge about what was normal and acceptable, particularly in relation to a child's behaviour. Normality was not a static concept. For these mothers it changed over time as the child developed from baby, to infant, to school child. Thus, for example, a baby not eating was a worrying deviation from the normal, and a cause for concern:

> 'When she was a baby ... she couldn't tell you that she wasn't hungry and you used to worry because you would think there was something wrong with her.'

A toddler not eating was seen as being part of a normal 'fad', and not anything to worry about.

> 'He is a wee bit of a picky eater ..., depends on what kind of mood he's in as to what he eats.'

Thus, normality was related to the developmental stage of the child.

The concept of normality, while having similarities across the sample, was embedded in everyday experience. The mother's perception of what was normal was closely related to her child's individual behaviour, and to that mother's unique knowledge of her child or children. This element of the concept of normality was important in the process of recognizing illness. Mothers said they could tell if something was wrong because the child differed from his or her normal self:

> 'She gets kind of cross if she is getting anything. C used to go off his food for a whole week and ... he was bad with eating but he went right off it if he was going to be ill. L gets fretty and under the weather, you can tell.'

The mothers' ideas of normality were related to health: a normal child who developed well, ate well and slept well, was healthy. The mothers were guardians of their children's well-being and a concern for health in a general sense underpinned their notion of normality. A healthy child was not necessarily one who was never ill since a range of minor illnesses were considered normal, and unrelated to health as such:

> 'Well, they quite often just get the runny nose, but as I say they are quite healthy children.'

> 'They've never had anything to really worry about other than normal childhood illness.'

Similarly, some illnesses became normalized, even though they were not routine. In the following example, M's croup became normalized, and the mother's overall assessment of her child as healthy was left intact:

> 'They have been great. They catch colds like every other child. M's bothered with croup, but apart from that, that's all.'

One mother described her daughter's fit as a 'one off thing':

> 'S took a fit, but it was just a one off thing, you know, she was in Sick Children's and she has got a wee touch of eczema just now but that's about all. They get coughs and colds and ... but they are very healthy.'

Behavioural change

Much of the process of recognizing illness was grounded in behavioural changes in the child, instead of or in addition to physical symptoms such as a runny nose or stomachache. The noting of behavioural changes, and the extent to which these were concerns for mothers were built on the concept of normality. The diaries provided a clear statement of the mothers' concerns, and of how they monitored their children. Overall, something was noticed about a child on 49% of all the diary days. Often more than one change was noted on the same day, and the mothers were as alert to behavioural changes as they were to traditional physical symptoms.

Physical symptoms were noted on 311 occasions, with cough, runny nose, cuts and bruises being the most common. Fever/temperature was noted occasionally, and was regarded with concern, especially in a very young child. Pallor was not noted.

Behavioural changes were recorded 315 times, with changes in sleep patterns, either sleepy, tired, or wakeful, figuring prominently (124 recordings in the diaries). From a doctor's point of view, tiredness may be considered to be a specific symptom, but for the mothers it was seen as a behavioural change, important because the child was not his or her normal self. Concerns about eating were particularly important for these mothers, and although recorded in the health diaries only 39 times, were mentioned by mothers in all of the interviews, together with concerns about sleeping. Changes in mood were also recorded in the diaries, with irritable/grumpy behaviour noted 88 times, and positive behaviour (indicating positive health or recovery) noted 52 times. Other behaviours were noted 12 times. Remarks from the mothers' health diaries show the various ways in which behavioural changes were related to health, illness and everyday experience (Figure 1).

Deviation from normal behaviour could be perceived in any one of the four following ways and could be a reason for going to the doctor, if the mother was worried enough, as illustrated in these quotes from the interviews.

It could be seen as a precursor to illness:

> 'But you ken when he's no well when he does nae want sweeties and crisps, that's a sure sign there is something wrong with him.'

> 'If you had a couple of broken nights then you knew there was something wrong with the wee one and then it would stop because they slept very well and quite good through the day.'

It could be perceived as concomitant or a result of illness, as illustrated by statements interpreting both positive and negative behaviour:

> 'Well she never really went off her eating, I think that was why the doctor never bothered because she was still eating and drinking and running about.'

> 'And I kept on thinking it is not natural to have this cough. I mean he couldn't sleep at night for this cough.'

or as an illness or problem in itself:

> 'He could eat and eat for about three days and for the next three days he'll just pick. He just has days off and on ... it did bother me at first. I used to get bothered that he would lose weight and they would think I'm no feeding him.'

> 'She has been really good, I have not really had any bother, apart from not sleeping. That was a great big problem at the time.'

or as a problem for the family:

> 'It got to the stage that my husband was coming out of work at tea time and I was going to bed until he was ready for

Sleep patterns/tiredness (n = 124)

'S a bit tired late afternoon. She wanted to lie down on the sofa. Bit of a cold starting.'

'I noticed A was very tired and irritable and hanging around me all the time. M was his usual self but only slept one hour in the afternoon to his usual 2½ hours.'

Eating/not eating (n = 39)

'Slightly sore bottom, not eating much. (She often goes off food for a day or two then gets back to normal).'

'S's throat still sore. Still off food and drink.'

Irritable/grumpy (n = 88)

'He seemed grumpier than usual, as though he was sickening for something, but nothing came of it.'

'P pretty bad tempered today and cried a lot.'

Positive behaviour (n = 52)

'He's picking up nicely although his appetite is not back to normal.'

'L's cough is slightly worse, but she is otherwise just the same, bright and quite cheerful.'

Figure 1. *Examples of children's behavioural changes recorded in mothers' health diaries.* n = *total number of times recorded in all of the diaries.*

bed because it was the only way I was getting a sleep. She just doesn't need sleep.'

'He's the kind of child that you've got to sit with and you've got to be with him and that puts a strain on you all.'

Discussion

This investigation focused on the meanings which the mothers attached to children's symptoms and behaviours seen as relevant to health and illness. The strength of the qualitative method employed here lay in the researcher's ability to elicit the respondent's (research subject's) viewpoint. It would have been counterproductive to begin data collection with a predefined set of issues and questions: 'appropriate or relevant questions are seen to emerge from the process of interaction that occurs between the interviewer and interviewees'.[22]

The limitations of the method lie in its inability to test hypotheses, and to produce statistically significant results, and the results cannot be presented in the traditional scientific manner. However, through the use of illustrative quotes from both the health diaries and interviews, the way in which the mothers in this sample routinely negotiated health and illness within the family is demonstrated. The identification of the specific dimensions of normality, and the development of the four categories interpreting behavioural change may be useful in practice.

In common with other studies,[23,24] the mothers' recognition of illness and symptoms appeared to be embedded in a commonsense knowledge about what was normal and acceptable. The mothers' perceptions of normality underpinned negotiation of their children's illnesses. Normality could be interpreted as a yardstick that operated in a variety of ways, as a measure of whether or not the child was 'ill' with the condition, for example a cough, whether the child was sickening for something, was experiencing normal illness or was experiencing illness normally. It was only through understanding the features of their concept of normality that deviation in their children's behaviour took on any meaning. Interpreting what the women said in this way helped to provide some understanding of how they constructed illness, other than simply recognizing pre-defined or commonly known conditions.

As we have reported elsewhere,[21] mothers closely monitor their children's well-being. It is important to examine the recorded behavioural changes in detail because these are based on the mother's unique knowledge and may not be readily perceived by the doctor. These behavioural changes, especially regarding eating and sleeping, were found to be problematical concerns for the mothers. Given the emphasis which society places on the nurturing role of the mother, and on the adequate physical and emotional development of children, it is not surprising that changes in eating and sleeping emerged as major concerns among the mothers. A concern for healthy development, and the ability to resist disease seemed implicit in their concern for good eating and sleeping behaviours. However, the relationship between these behaviours and illness was found to be varied and complex. Unlike previous investigations,[23-25] behavioural changes were not simply interpreted as cues to an underlying problem. Although they were sometimes interpreted as a symptom of illness, their relationship to health and illness was more complicated. In fact, whether or not illness was present was not necessarily the primary concern for the mother.

While some illnesses were normalized by the mothers,[24] deviation from normal behaviour could be recognized as a precursor, concomitant or result of illness, as illness itself, or as a problem because of its effect on the well-being of the child and of other family members. Such changes in behaviour may be all of these things at different times or some of these at the same time.

Although general practitioners may make a rapid global assessment of a child's state of health, they are searching for the presence or absence of specific signs and symptoms of high discriminative value, for example dysuria or a red ear drum. On some occasions this will allow a definite diagnosis to be made; on many others the diagnosis will remain tentative, but collation of whatever 'hard' information is available should allow the general practitioner to decide how to act. Mothers, on the other hand, recognize illness largely through behavioural change, that is, data of low discriminative value from a medical diagnostic point of view, for example, changes in eating and sleeping. This variation in the meaning of a 'soft' non-specific symptom is not necessarily recognized by those professionals to whom the mother goes for help.

What are the consequences of these potentially divergent needs and viewpoints? The doctor's response is critically important. If he or she operates solely on the basis of signs and symptoms, he or she may be perplexed to find a mother worrying excessively over a seemingly trivial diagnosis such as a cold. If he or she is aware that the consultation has been unsatisfactory despite, in his or her terms, having done all the right things, feelings of anxiety and inadequacy may be engendered, particularly in the less experienced doctor. Alternatively, the doctor may make a judgement about the coping skills of mothers who seem to bother him with trivia, thus creating and sustaining the stereotype of the neurotic or inadequate mother. Cartwright recognized that general practitioners often respond to perceived trivia with a prescription.[26] Children with upper respiratory tract infections form the largest single component of general practice workload, and consume a vast quantity of prescribed medicines.[19] Might this cost be reduced if general practitioners had a different understanding of the processes involved when mothers consult with young children? The argument that busy general practitioners must prescribe to keep going is not valid, as there is evidence that short term gains are offset by increased

overall workload.[27] It ignores the potential within the consultation for education and for the enhancement of help seeking behaviour,[28] and is not compatible with aspirations for a quality service.[29]

What are the consequences for the mother if she feels that she has been unable to communicate her concerns or that her concerns have not been acknowledged? If she has been made to feel that she has wasted the general practitioner's time she may be left with doubts and anxieties about her own adequacy as a mother. The sense of rejection is likely to be felt most keenly by those whose self esteem is already vulnerable, such as the depressed or the young first-time mother, the more so if she is no nearer to resolving the anxieties about her child which caused her to consult initially. The more experienced and confident mother may feel anger that her legitimate status as the expert on her child's behaviour is not being acknowledged. Her perception of being fobbed off may be heightened if, in addition, she receives an unlooked for prescription. In both instances, the process of deciding to seek professional help on a subsequent occasion will be much more fraught and might involve significant delay. Credibility, trust and respect will have vanished from the relationship.

It was possible to test the validity of our findings in practice, and one off us (S I) did so while working as a general practitioner. This consisted of focusing on what the mother presented as her major concerns, no matter how 'soft' these were from a diagnostic point of view. The method was not time consuming and is likely to be used already by doctors who are good communicators. It was in keeping with the observations of Illingworth and Illingworth, that failure to determine the cause of a mother's concern is a potent source of further anxiety.[30] After further direct questioning and then examination of the child, the findings, diagnosis, advice or treatment were discussed in the context of the mother's concerns. On the basis of a subjective and informal assessment this appeared to result in successful consultations. Eating and sleeping difficulties arising during the course of a minor illness, such as a cold, were often mentioned by mothers. If concerns about these particular issues were not volunteered, but their discussion was subsequently initiated by the doctor, this also appeared to increase the chances of a mutually satisfactory consultation.

Mothers have a unique and intimate knowledge of their children, and their concept of normality in their children's behaviour underpins their negotiation of illness. Although much illness in children is taken for granted, considered normal, and treated at home,[21] changes in eating and sleeping were of particular concern to mothers, even when these behaviours were not overtly related to illness. These are important and emotive issues, linked to ideas of the mothers' competence, and to their perceptions of the general health and development of their children. If health professionals can become more sensitive to these issues and recognize mothers' concerns, their quality of communication with mothers of small children can be enhanced, resulting in more effective client–professional relationships, and greater satisfaction to both parties.

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