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ORIGINAL ARTICLE

Is my child sick? Parents' management of signs of illness and experiences of the medical encounter: Parents of recurrently sick children urge for more cooperation

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Abstract

Objectives. Parents of sick children frequently visit their general practitioners (GPs). The aim was to explore parents' interpretation of their child's incipient signs and symptoms when falling ill and their subsequent unsatisfactory experience with the GP in order to make suggestions for improvements in the medical encounter. **Design.** Semi-structured interviews. **Setting and subjects.** Twenty strategically selected families with a child from a birth cohort in Frederiksborg County, Denmark were interviewed. **Results.** Parents wanted to consult their GP at the right time, i.e. neither too early nor too late. Well-educated parents experienced a discrepancy between their knowledge about their child, the information they had sought about the illness and the consultation with the GP, when they were dismissed with phrases such as "it will disappear" or "it is just a virus". The parents went along with the GP's advice if the child only occasionally became sick. However, parents of children with recurrent illnesses seemed very frustrated. During the course of several consultations with their GP, they started to question the GP's competence as the child did not regain health. **Conclusions.** Parents want to be acknowledged as competent collaborators. The GP's failure to acknowledge the parents' knowledge of their child's current illness, and the parents' attempt to identify what is wrong with the child and make the child feel better before the encounter may have consequences for the GP's credibility. It is therefore recommended that parents of children with recurrent illnesses receive extra attention and information.

Key Words: *Cooperation, family practice, general practice, medical encounter, parents' management, sick children*

When a child falls ill the parents are the first in line to make a judgement concerning the illness, with regard both to its severity and what action to take. Parents try to read the signs of illness [1,2] and make a common-sense reflection [3,4] on the nature of the illness in an attempt to categorize and explain it [5]. The decision to seek medical advice is complex as parents have to rely on the child's bodily expression and their own interpretation of it.

Previous studies concluded that mothers were very watchful of what is normal in order to make judgements concerning their child's altered status and they were also reflective of their own beliefs and perceptions of their child's illness [6,7]. However, the signs and symptoms of a sick child could also cause the parents to be fearful. In a study of low-income families in England some years ago, meningitis was the parents' primary concern when they brought their feverish child to the emergency ward [8]. However,

these parents felt inadequately informed by the GP, which made it difficult for them to interpret the seriousness of the child's next febrile episode [8,9].

It could be of interest to find out how parents of today, who have ready access to medical information as well as to their general practitioner (GP), think and how they handle their child falling ill. The aim of this study was to explore parents' interpretation of their child's incipient signs and symptoms when falling ill and their subsequent experience of communication with the GP.

Material and methods

This study is based on a qualitative analysis of 20 in-depth, semi-structured interviews with parents. The children were strategically selected from a birth cohort of 389 children born between 1 and 28 February 2001, using a questionnaire and a

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Parents mediate their own observations and understanding of their sick child. They are limited in the process as they deal with an intuitive approach as well as interpreting the child's bodily signs, which can complicate making the decision to seek medical advice.

- This difficulty should be met by acknowledging the parents' actions and by exploring ground for fruitful collaboration, since it is the parents who know the child best.
- Parents of children with recurrent illnesses felt frustrated when their perspectives were not included in the professionals' assessments. They felt they were rejected from, instead of invited to participate in, the diagnostic process. Even if a biomedical diagnosis is not reached, the creation of meaningful understanding and systematic treatment of the sick child can make a difference to the well-being of the family.

three-month diary [10]. At the time of the interviews the children were 14–18 months old and the families were representative of the upper-middle class areas in which they lived. The interviews were conducted in the informants' homes and lasted for approximately one hour, were made anonymous and transcribed verbatim. After a pilot test of the interview guide it was left unchanged (Table I). During the interview, the parents were able to see the diaries again and they commented on the episodes of illness marked in the diary, as well as their experiences with their older children, even before the recording of the interview began. Mothers participated in all and fathers in 10 of the interviews.

The texts were analysed according to Giorgi's phenomenological approach to qualitative data [11], modified and described by Malterud [12,13]. The focus of interest was chosen to correspond to the main topics of the interview: how a child becomes ill, perception of illness, the decision when to consult the GP, good/bad experience with the GP, what the parents wanted from the GP. After careful reflection on the empirical material it was condensed and described in four main themes: reasoning about the signs of illness, when to take the child to the GP, parents' unsatisfactory experiences of the encounter with the GP, and parents' questioning the GP's competence.

Even if parents described many consultations where they were satisfied they also described episodes where they were dissatisfied. Those unsatisfactory experiences were used as an analytic entity and formed the base for the third and fourth themes.

By choosing those experiences we hope to uncover possibilities for development in the medical encounter with the sick child.

Results

Reasoning about the signs of illness

Parents have intuition and their own know-how of what is normal, which they use to make judgements on their child's indications of possible illness. The parents describe this process in phases, like a journey. They noted signs such as tiredness or reluctance to eat and described this particular stage in the recognition process as the child feeling unwell; however, the condition was not considered serious enough to be characterized as an illness. If fever arose they were sure that the child was ill.

The parents were attentive to the child's needs, and tried to decode their child's bodily expression, respond to it, appraise and reappraise it.

Family 063: You just know when your child is really sick; that she is not just a cry-baby; you do feel and can see that she is not well; reaches for her ears and hangs her head; just leans on me then she is sick; if nothing else interests her, then she is sick.

The parents' dilemma: when to take the child to the GP

They describe the awareness of how their decision was based on their own ability to see and interpret the child's signs and symptoms. It seemed that parents did not rely on their ability to judge the nature of the illness and thus a second opinion from a GP

Table I. Interview guide.

1. Tell me about a time when your infant was ill, for example the last time?
2. Do you do anything specific to make him/her feel better when he/she is ill?
3. What worries you most, when he/she is ill?
4. When do you consult the GP with your sick infant?
5. Do you have positive or negative experiences of the GP?
6. What are your thoughts and experiences when giving your infant medication?
7. Do you have any idea why your infant becomes ill?
8. What do you think makes your infant well again?
9. What about the other children and your relationship with your spouse?
10. How do you manage caring and doing your everyday activities when your infant is ill?
11. Do you have any experience of alternative and complementary medicine?
12. Looking back, is there anything you would wish were different?
13. Anything else you want to say?
14. What did you think of the interview?

was needed. They talked about their awareness of how important it was to consult the GP at the right time, neither too early, making inappropriate visits, nor too late, afraid of overlooking a disease that needed treatment.

Family 109: ... running a fever of 40 degrees C three days in a row ... are they ill or is it nothing, are they simply wimpy or have you been too hard on them by not seeing the GP.

And finally, they talked about their awareness of having a strong emotional response to the child's illness, which led them to consult an expert who could confirm or dismiss their worry. Ultimately they were aware that there was a threshold level of symptoms, which would lead them to seek a consultation, and that this threshold changed with their own experience of sick children. Experienced parents (parents with older children) reported that their threshold for deciding on a medical consultation changed as they became more used to handling sick children.

Where there is room for improvements in the consultation

We have found three fields where unsatisfactory experiences with the medical encounter can arise: first, when the GP was questioned as to why the parents had made an appointment, second, the GP's evaluation of the severity of the illness and third, confusion over understanding the nature of the illness.

Parents could have difficulties making sense of the response they received from the GP. The parents perceived the GP's attitude as considering them to be "overprotective parents", implying that the consultation was irrational and not based on sound judgement. Such an experience made the parents stress their own responsibility for the child. They wanted to be "safe rather than sorry" and said that it was not their intention to "disturb the GP". Other parents declared that, as taxpayers, they had the right to have their child assessed by the GP.

Parents were uncertain as to what kind of illness the child had and were bewildered and confused about how the GP determined the severity of the illness. Altogether, this made it difficult for the parents to understand and accept the GP's thoughts and actions when the GP said that "the signs are nothing" or that "the signs will disappear", as the parents could both see the signs and hear that the child had, for example, respiratory difficulties.

Family 146: ... that it was nothing – "nothing wrong" – sounds like a pair of bellows and having smoked 24 cigarettes.

The parents were often told that the children had a virus or a self-limiting illness. The GP's explanation was, in such cases, often experienced by the parents as confusing and provocative. Parents expressed ambivalent feelings: on the one hand they felt that they had received a vague response regarding the diagnosis and on the other hand they felt that it was a relief to hear that the child was not severely ill and did not need antibiotic treatment.

Questioning the GP's competence: the child with recurrent illness

The parents went along with the GP if the child only occasionally became sick. However, parents of children with recurrent illnesses (parents' estimate) seemed very frustrated with the communication. If the child did not seem to thrive or continued to be sick, the parents began to think something was wrong with the child's immune system. When the parents' interpretation of the child's illness did not agree with the GP's explanation the parents became defensive. They felt unable to estimate the seriousness of the signs and the return of the illness and said that they did not think that the GP took the episodes of the child's recurring illness seriously. When recounting what occurred in such consultations they said the following about the GP:

Family 154: Virus, that's a pretty worn-out word used by doctors, it can't be true that everything can be a virus – a sore throat, that's just a virus. It is such a nice explanation of things. You damn well don't need to study for so many years to become a doctor, one can inoculate oneself with those there [quick streptococcus test].

Family 024: Actually, you have just treated a symptom; actually it is basically wrong that you have not taken the time to look at it carefully! Maybe something could be wrong; ... actually, something must be wrong, you know, something you just didn't take the time to figure out.

Furthermore, they used expressions that suggested they felt as if they were fighting with their backs to the wall when the GP did not prescribe medicine or gave an explanation they found inappropriate.

Family 154: ... it beats me that we need to be pushed out there where you have to ... but we will not leave until ... ; well ... you need a little more back-up here.

They expected and wanted to be informed to supplement their already acquired knowledge (internet, books) about the child's illness, a specific diagnosis

and effective treatment and they wanted to know what they could do to avoid further episodes of illness.

Discussion

Main findings

The fields connected to the possibility for unsatisfactory experiences with the medical encounter concerned instances where the GP questioned why the parents had made an appointment, the GP's estimate of the severity of the illness and confusion over understanding the nature of the illness. One particularly interesting finding was that parents of children with recurrent episodes of illness episode seemed to have had many unsatisfactory experiences as they made critical and ironic remarks about the GP's qualifications and criticized the GP for failing to go into depth regarding their child's illness. One explanation could be that many small misunderstandings became important. It could be a psychological defence, but it may also be that they were right in their appraisal of the GP's competence. They urged for better cooperation and medical evaluation and a better diagnostic match or explanation.

Strengths and limitations of the study

The parents in this study were well educated, had internet access, and were aware of their rights as customers of the health care system. In 50% of the interviews both parents participated, which may indicate a general change in the traditional mother-child relationship [14]. The dialogues were facilitated by bringing up the very familiar questionnaires and the diary. In spite of the interviewer being a GP, the parents felt free to talk about experiences where they were not satisfied with the GP they had met. We are aware that we do not have the GPs' views.

Comparison with existing findings

Parents in our study confirm the results from studies of mothers' beliefs and preconceptions concerning their children's illnesses [6,7] and when parents seek medical help [15–20], but this study also takes as its perspective the importance of the parents accommodating the GP in the medical encounter. When the decision is taken to see the GP, parents have to relate to their observations of the child becoming ill. Kleinman [21] describes becoming ill as a concrete bodily experience that one has learned to relate to. However, parents have to interpret the child's bodily experiences, which complicates making the decision as to what action to take. Kleinmann regards the patient's and the GP's conception of

illness as equal, which illustrates the importance of taking the parents' perceptions and observations seriously. Today, well-educated parents express a wish to be acknowledged as competent parents when they respond appropriately to their child's illness or prevent illness by participating in preventive child health examinations [22]. Parents want [7] to "identify an illness" early and they want the child restored to health as quickly as possible, since it is a high priority for them to return to work [20]. But the parents may have an unrealistic faith in medicine and what medicine can do, which makes them dissatisfied with their GP.

Parents of children with recurrent illnesses found the consultations with the GP unsatisfactory [10,23]. We speculated that the parents' lack of respect for the GP could be rooted in misunderstandings concerning the way the GP handled the parents' account of how their child's illness developed [3]. Parents can be vulnerable at the consultation and can subsequently fail to make sense of the GP's vocabulary and explanations [24]. From the parents' perspective, the GP did not put enough effort into explaining why the child had a recurring illness – which was regarded by the parents as a rejection of their own interpretation of the illness and its negative consequences [10,25] for the whole family. It appears that the parents felt excluded from the professional's assessment, experiencing rejection from, instead of being invited to participate in, the diagnostic process [26]. These wishes are similar to those found by Russell and von Linstow [9,27]. According to Kleinman, parents' frustrations can be rooted in the GP's inability to satisfy the layman's need for short, single-phrased explanations [28], even if children today are seldom severely ill. The treatment of sick children (mostly sick with minor infections) can be seen as a relatively uncomplicated consultation from a GP's point of view, but analysing the encounter from the perspective of a triad consultation of child-parent-GP puts the complexity of the communication into perspective [29]. In a triad communication, everyone interacts at several levels – the GP communicates with the child, the child communicates and uses bodily expression towards the parents and the GP, the GP uses medical language to communicate with the parent, and the parent struggles to make the GP understand his/her observations – these are just aspects of patient-centred communication [30]. Research on the triad communication in primary health care would be welcome.

Implications

Even the barely ill child that the GP meets has been thoroughly assessed by the parents. Parents appraise

and reappraise the child's symptoms and try to make the right decisions about when they should seek medical advice; this needs to be acknowledged by the GP.

The GP could invite parents of children with recurrent episodes of illness for a discussion of the illness and of their perceptions and emotions. The significance of not knowing the reasons for recurrent illnesses and the impact on family life should also be discussed, as well as the availability of resources. Such an approach will give the GP an opportunity to prevent common parental misperceptions like "something is wrong with the child's immune system" and it may shift the focus from what the GP thinks the parents want, e.g. a prescription for antibiotics, to their desire for information.

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

References

- [1] Bruusgaard D, Kise SA, Nilsson D. Health service consumption and parent reported episodes of illness in children 0–3 years. *Scand J Prim Health Care* 1993;11:147–50.
- [2] Hay AD, Heron J, Ness A. The prevalence of symptoms and consultations in pre-school children in the Avon Longitudinal Study of Parents and Children (ALSPAC): A prospective cohort study. *Family Practice* 2005;22:367–74.
- [3] Helman CG. Culture, health and illness. London: Arnold; 1984.
- [4] Kelly K, Leventhal H, Andrykowski M, Toppmeyer D, Much J, Dermody J, et al. Using the common sense model to understand perceived cancer risk in individuals testing for BRCA1/2 mutations. *Psycho-Oncology* 2005;14:34–48.
- [5] Gross GJ, Howard M. Mothers' decision-making processes regarding health care for their children. *Public Health Nurs* 2001;18:157–68.
- [6] Cunningham-Burley S, Irvine S. "And have you done anything so far?" An examination of lay treatment of children's symptoms. *Br Med J (Clin Res Ed)* 1987;295:700–2.
- [7] Cunningham-Burley SMN. Mothers' beliefs about and perceptions of their children's illnesses. Readings in medical sociology. London: Routledge; 1990. p. 85–109.
- [8] Kai J. What worries parents when their preschool children are acutely ill, and why: A qualitative study. *BMJ* 1996;313:983–6.
- [9] Russell D, Luthra M, Wrigth W. A qualitative investigation of parents' concerns, experiences and expectations in managing otitis media in children: Implications for general practitioners. *Prim Health Care Res Devel* 2003;4:85–93.
- [10] Ertmann RK. What makes parents consult a physician? PhD thesis, Research Unit for General Practice in Copenhagen; 2007.
- [11] Giorgi A. Phenomenology and psychological research. Pittsburgh: Duquesne University Press; 1985.
- [12] Malterud K. Qualitative research: Standards, challenges, and guidelines. *Lancet* 2001;358:483–8.
- [13] Malterud K. Kvalitative metoder i medicinsk forskning [Qualitative methods in medical research]. Oslo: Universitetsforlaget; 2003.
- [14] Sommar D. Fra modercentrisme til fædre som social realitet [From mother-centrism to fathers as a social reality]. *Barndomspsykologi*. København: Hans Reitzels Forlag; 2003. p. 172–207.
- [15] Bruijnzeels MA, Foets M, van der Wouden JC, van den Heuvel WJA, Prins A. Everyday symptoms in childhood: Occurrence and general practitioner consultation rates. *Br J Gen Pract* 1998;48:880–4.
- [16] Saunders NR, Tennis O, Jacobson S, Gans M, Dick PT. Parents' responses to symptoms of respiratory tract infection in their children. *Can Med Assoc J* 2003;168:25–30.
- [17] Wyke S, Hewison J, Russell IT. Respiratory illness in children: What makes parents decide to consult. *Br J Gen Pract* 1990;40:226–9.
- [18] Cornford CS, Morgan M, Ridsdale L. Why do mothers consult when their children cough. *Fam Pract* 1993;10:193–6.
- [19] Voigt RG, Johnson SK, Hashikawa AH, Mellon MW, Campeau LJ, Williams AR, et al. Why parents seek medical evaluations for their children with mild acute illnesses. *Clin Pediatr (Phila)* 2008;47:244–51.
- [20] Ertmann RK, Söderström M, Reventlov S. Parents' motivation for seeing a physician. *Scand J Prim Health Care* 2005;23:154–8.
- [21] Kleinman A. The illness narratives: Suffering, healing & the human condition. New York: Basic Books; 1988.
- [22] Sondergaard G, Biering-Sorensen S, Michelsen SI, Schnor O, Andersen AM. Non-participation in preventive child health examinations at the general practitioner in Denmark: A register-based study. *Scand J Prim Health Care* 2008;26:5–11.
- [23] Forgays DK, Hasazi JE, Wasserman RC. Recurrent otitis media and parenting stress in mothers of two-year-old children. *J Dev Behav Pediatr* 1992;13:321–5.
- [24] Salmon P, Peters S, Stanley I. Patients' perceptions of medical explanations for somatisation disorders: Qualitative analysis. *BMJ* 1999;318:372–6.
- [25] Asmussen L, Olson LM, Sullivan SA. "You have to live it to understand it ...": Family experiences with chronic otitis media in children. *Amb Child Health* 1999;5:303–12.
- [26] Undeland M, Malterud K. Diagnostic interaction: The patient as a source of knowledge? *Scand J Prim Health Care* 2008;26:222–7.
- [27] Von Linstow ML, Holst KK, Larsen K, Koch A, Andersen PK, Høgh B. Acute respiratory symptoms and general illness during the first year of life: A population-based birth cohort study. *Pediatr Pulmonol* 2008;43:584–93.
- [28] Kleinman A. Patients and healers in the context of culture. Berkeley: University of California Press; 1980.
- [29] Tates K, Meeuwesen L. Doctor–parent–child communication: A (re)view of the literature. *Soc Sci Med* 2001;52:839–51.
- [30] Epstein RM, Franks P, Fiscella K, Shields CG, Meldrum SC, Kravitz RL, et al. Measuring patient-centered communication in patient–physician consultations: Theoretical and practical issues. *Soc Sci Med* 2005;61:1516–28.