



## **What makes parents consult a physician?**

### **Patients' experience with their sick child**

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# What makes parents consult a physician?

Parents' experience with their sick child

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## **What makes parents consult a physician?**

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# Table of contents

|  |    |
|--|----|
| <b>Preface</b> .....   | 3  |
| <b>Researcher's preconception</b> .....  | 5  |
| <b>1 Introduction</b> .....  | 7  |
| Children in general practice.....  | 7  |
| <i>Occurrence of symptoms</i> .....  | 7  |
| <i>Children's consultation rates</i> .....                                     | 8  |
| <i>Predictors of consultation frequency for children</i> .....                 | 9  |
| Parents' understanding of symptoms in their children.....                      | 10 |
| <i>Symptoms that worry parents</i> .....                                       | 11 |
| <i>How to assess symptoms</i> .....  | 11 |
| The child-parent-physician communication .....                                 | 12 |
| Parents' experiences with sick children.....                                   | 13 |
| <b>2 Aim of the study</b> .....  | 15 |
| <b>3 Design and Methods</b> .....  | 16 |
| Design .....   | 16 |
| Informants and study populations .....   | 16 |
| Families chosen for interview .....  | 17 |
| <i>Figure 1. Flow chart of the study population</i> .....                      | 18 |
| Data collection instruments.....   | 18 |
| <i>Interview guide and pilot interview</i> .....                               | 18 |
| <i>Development of the questionnaires and diary and the pilot study</i> .....   | 19 |
| Data collection.....   | 19 |
| <i>Questionnaire and diary</i> .....   | 19 |
| <i>Interview</i> .....   | 20 |
| <i>Figure 2. Time table of the study</i> .....                                 | 21 |
| Data sources for analysis of the interviewed families.....                     | 22 |
| <i>Table 1: Demographic data on interviewed families</i> .....                 | 22 |
| <i>Analysis of the interview</i> .....   | 23 |
| Ethical considerations.....  | 27 |
| Presentation .....   | 28 |
| <b>4 Theoretical perspective</b> .....   | 29 |
| Introduction .....   | 29 |
| Explanatory models.....  | 29 |
| <b>5 Results</b> .....   | 36 |
| I. Trigger factors inducing parents to call upon the physician for advice..... | 36 |
| II. Uncover parents' experience of their child's illness signs .....           | 38 |
| <b>6 Discussion of methods</b> .....   | 40 |
| Reflexivity .....  | 43 |

|   |           |
|---|-----------|
| Validity.....   | 44        |
| <i>Internal validity</i> .....  | 45        |
| <i>External validity</i> .....  | 46        |
| <b>7 Summary of results</b> .....   | <b>48</b> |
| Signs of illness.....   | 48        |
| Parents' experience from the consultation .....   | 49        |
| <b>8 Discussion of results</b> .....  | <b>52</b> |
| The decision-making process .....   | 52        |
| <i>Interpretation</i> .....   | 52        |
| <i>Intuition</i> .....  | 54        |
| The meeting in the consultation room.....   | 54        |
| <i>The contradictions in fever</i> .....  | 55        |
| <i>The frustrations upon recurring episodes of illness</i> .....  | 55        |
| <i>A meeting that does not take place</i> .....   | 56        |
| <i>Lack of acknowledgement</i> .....  | 57        |
| <i>The premises of the consultation</i> .....   | 57        |
| <i>Two explanatory models in the same boat</i> .....  | 58        |
| <b>9 Conclusion</b> .....   | <b>59</b> |
| <b>10 Implications for clinical work</b> .....  | <b>61</b> |
| <b>11 Implications for future research</b> .....  | <b>63</b> |
| <b>12 English summary</b> .....   | <b>64</b> |
| <b>13 Dansk resume</b> .....  | <b>67</b> |
| <b>14 Reference list</b> .....  | <b>70</b> |
| <b>15 Enclosures</b> .....  | <b>83</b> |
| Enclosure A: Literature search.....   | 85        |
| Enclosure B: Diary.....   | 87        |
| Enclosure C: Questionnaires.....  | 89        |
| Enclosure D: Dropouts and questionnaires to the non-participating families .....  | 99        |
| Enclosure E: Families chosen for possible interview.....  | 101       |
| Enclosure F: Development of the questionnaires and diary and the pilot study .....  | 102       |
| Enclosure G: Presentation .....   | 103       |
| Enclosure H: Paper 1:.....  | 105       |
| <i>Ertmann Ruth K, Söderström Margareta, Reventlow Susanne. Parents' motivation for seeing a physician. Scand J Prim Health Care 2005; 23:154-8.</i> .....  | 105       |
| Enclosure I: Paper 2:.....  | 113       |
| <i>Ertmann Ruth K, Reventlow Susanne, Söderström Margareta. Parents' situated experience and knowledge of their infant's illness signs – a key to better doctor-patient communication. Submitted.</i> ..... | 113       |

## **Preface**

This thesis is based on studies carried out at the Research Unit of General Practice, University of Copenhagen, during the period 2000-2006.

While writing this dissertation, I have been helped and encouraged by many people in ways both large and small. However, there are several I would like to single out for special thanks: Professor Hanne Hollnagel for inspiration and support during the work with the protocol. I am grateful for the support and the constructive feedback from my two supervisors Margareta Söderström and Susanne Reventlow.

I owe a lot to my colleagues at the Research Unit of General Practice for all the discussions, comments, help and their friendship. A special thanks to Ann Dorrit Guassora for encouraging me through the last difficult part of writing this thesis. I am also very grateful to Annie Keldebæk, Lise Bergsøe and Lene Kibenich for all their secretarial assistance, and Maj-Britt Glenn Lauritsen, Arvid Frank Jørgensen and Jørgen Lous for inspiring discussions in the idea phase of this study.

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Furthermore, I want to thank all the participating infants and their families.

Names and addresses of the infants were obtained through the kindness of the administration of Frederiksborg County to whom I am grateful for their helpfulness in the study period.

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Hillerød, November 2006

Ruth Kirk Ertmann

## **Researcher's preconception**

The concept of pre-understanding is the knowledge and experience we bring with us to a research project and which shapes the research process from idea to data selection and presentation of results <sup>1;2</sup>.

As a general practitioner and the mother of four children and having worked with children of different ages at infant homes, kindergartens, youth centres and residential institutions, I have considerable practical experience in working with children and young people, gained over more than 20 years. Apart from the kindergarten children, all the children in the homes and institutions had a complicated relationship with their parents; the children had been removed from their homes because the authorities considered that the parents were unfit parents. The pedagogical dimension in the relationship between helper, children and parents was a major factor in my choice of professional career and it lies at the very centre of parent-physician communication about the young, sick child without language. From personal experience with an 'ear child', who had many contacts to specialists, I got the idea for the research project one night working on emergency duty when I visited a family in their home. They were extremely upset and agitated because of a child with asthma who had just started Spacer treatment and had a fever. Due to the critical situation and for pedagogical reasons, the child was hospitalized so that the parents could learn to cope with a child who would occasionally need Spacer treatment.



## Background

When meeting parents with 'sick' children, quite often my impression is that the child is not particularly ill, and the parents are, actually, often of the same opinion. But they just want to make sure that there is nothing seriously wrong with their child or they want one to listen to the child's lungs. This situation invites the questions of why it is so important for them to see a physician at that stage, and of what motivates parents to set aside time for a visit to the physician on this basis during a busy workday.

It is also surprising to observe that parents today, despite being well-educated and having easy access to health care, seem to feel insecure if the child has been ill several times, for instance, a child with an ear infection, asthma or eczema. Even if parents have already paid a number of visits to the physician about a particular health problem, they apparently remain at a loss and are continuously frustrated over how to handle the problem. The parents report information given by physicians on recurrent health problems that could be both ambiguous and contradictory.

This study includes 8-month-old infants but the majority of the families have experiences with older siblings. Therefore I will mainly use the word child/children in this thesis.

The main purpose of this study is to ascertain, from the parent's experiences, whether in their opinion the consultation with the physician with regard to sick children could be changed or improved. Special attention will be given to situations where parents and the general practitioner possibly misunderstand each other.

# 1 Introduction

Research on sick children has been done for over 50 years. The first well-known epidemiological study on children's everyday illness was carried out in 1964 in Cleveland, USA<sup>3</sup>. This study followed 86 families (443 individuals) for 5 years. The mother made daily entries in a diary. Each family was visited weekly by a field worker and at the time of illness the patient was examined by a staff physician. The result mirrored the infection panorama of that time and these findings have contributed to a better understanding of children's everyday illness. Since then, numerous studies have been carried out which examine various children's illnesses. Most of the studies are epidemiological statements on the symptom frequencies and appearance of illness. There is also research available on consultation frequencies and factors that influence the frequency of consultation. Patient-doctor communication has also been the subject of research, including studies on child-doctor-parent communication. Finally there are studies examining how parents have experienced having a sick child, but these are often studies where the child suffers from a critical illness, chronic illness or has a handicap – situations which lie beyond the focus of this project. Studies on how parents experience 'common, minor illness' with their children are very rare, something which will be reverted to after an introduction of some of the comprehensive literature about sick children. For further information on the search strategy for literature – see enclosure A.

## Children in general practice

### *Occurrence of symptoms*

Children's illness from the parents' point of view has been studied by means of diaries of symptoms, weekly telephone recalls and questionnaires on daily symptoms. All studies have reported symptom frequency that varies with the age of the child and with the season of the year<sup>3-6</sup>.

The common cold is the most frequent symptom/diagnosis among small children, at least according to longitudinal studies of children in the western world <sup>3-5;7;8</sup>. Among Danish children 1-2 years of age, fever was the most frequent single symptom reported, followed by the common cold <sup>9</sup>.

In a Nordic study, the child or family was asked about the occurrence of specific symptoms such as pain in the stomach and dizziness <sup>10</sup>. According to the questionnaires 15.6% (2-6 years) to 34.0% (13-17 years) of the children frequently (i.e. every or every other week) suffered from at least one of these symptoms. The frequency of at least one symptom every or every other week was highest in Finland (31%), medium high in Denmark (26%) and lowest in Sweden (20%) <sup>10</sup>. Stomach pain and dizziness are common psychosomatic symptoms and the occurrence may mirror the situations of the families of that time. The Danish National Institute of Social Research interviewed parents in 1994 and 2000 about illness among children during the past 14 days (children between 0 and 16 ). The frequency of illness reported by parents did not rise from 1994 (13.4%) to 2000 (14%). In 2000, the year-specific illness <1 year of age was 21% and 29% among the 1-2-year-olds<sup>9</sup>. Pre-school children have symptoms quite frequently and parents therefore very often have to appraise and reappraise symptoms. There is, however, only limited information available about what parents think about the individual symptoms and how they appraise them.

### *Children's consultation rates*

Pre-school children suffer frequent episodes of illness which means that they have more consultations in primary care than any other age group. The most frequent consultations among children are for children who are 6-18 months old <sup>3-6;8;11;12</sup>. Even though some of these studies are old their findings are confirmed by more recent studies.

A Nordic comparative study was done in 1984 and 1996. In 1996, 43% of the 2-6-year-old children had had a consultation with a physician within the past three months, and the consultation rate per year was estimated to be 2.2. The consultation rates rose approx. 8% from 1984 to 1996. One of the explanations was that in 1996 more children were attending the prophylactic child care programs. However, it was difficult to compare the

rates of consultation even between the Nordic countries because of the very different structures of their health care systems <sup>10</sup>.

Another Nordic comparative study on physician-attended visits among children between 2-18 years of age with 'handicaps' (e.g. cystic fibrosis, spinal hernia, haemophilia) found that nearly 50% had visited the physician at least once during the past 3 months <sup>13</sup>.

Children in Denmark had the lowest consultation rates and Iceland the highest. These high visit rates could reflect the fact that the children had a known illness and that attendance thresholds were low because the parents knew that the child was vulnerable and that minor illness could quickly turn into severe illness.

Some children seem to have a higher morbidity than others and were also characterized as frequent consultation visitors. These children (0-4 years old) were found to suffer from diseases typical of their age and sex (otitis media, respiratory diseases but also injuries), but to a much greater degree than controls. These children seemed to be more vulnerable than other children of the same age <sup>14;15</sup>. Such vulnerability could continue for several years, which was found in follow-up studies of pre-school children with recurrent bacterial respiratory tract infections<sup>16</sup>. The empirical results singled out the vulnerable child as a particularly interesting subject for further research. Questions were raised about such things as how the parents cope with this vulnerability and whether the children/the family need special attention from the physicians.

#### *Predictors of consultation frequency for children*

As well as actual illness <sup>17-19</sup>, consultation rates for children are related to parental illness behaviour <sup>18;19</sup> and attendance at prophylactic child care programs <sup>10</sup>.

Other factors may also influence the parents' visiting patterns. Thus, chronic or frequent episodes of illness in one of the child's siblings caused such parents to bring the child to a physician more often than parents of children who did not have siblings with increased morbidity<sup>20</sup>.

Parents' perceptions of a threat to general health (i.e. the child's susceptibility to disease and their perception of general health threats) and their beliefs about symptoms and illness influenced their consultation frequency <sup>19-23</sup>.

The mother's state of anxiety, stress and depression have been found to be predictors of a high consultation frequency for the child <sup>18;24;25</sup>. If the parents were frequent users of primary medical care, so were their children <sup>25-27</sup>. First-time mothers were strongly and consistently associated with a higher consultation rate than mothers of three or more children <sup>5;27</sup>. The influence of the father's mental state or experience with older siblings on consultation frequencies has not yet been studied.

Demographic and socioeconomic factors act as powerful predictors of consultation patterns, but the results are conflicting. Children who had frequent consultations were associated with low social class, parental unemployment and sick-leave <sup>26-31</sup>. According to a Swedish study there is an almost over-explicit pattern of increased consumption of care and antibiotics among 7-year-old children where the family situation was characterized by: lone/divorced parents, at least one parent of foreign origin, parents with manual occupations, and a smoking mother<sup>32</sup>. In a Danish study of out-of-hours attendance, on the other hand, single parents and parents without vocational training were not overrepresented in the group of frequently attending children, but in the group of frequently attending adults <sup>33</sup>. But how do parents think and what kind of considerations do they have before deciding to take their children to a physician?

## Parents' understanding of symptoms in their children

Parents assume a critical role in the care of sick children. If they fail to recognise the warning signs of severe illness, medical treatment may be delayed or cannot be started <sup>34</sup>. Previous studies have dubbed this aspect of care as 'maternal nursing care'. Today, the role of fathers has changed and they are assuming a role similar to that of mothers <sup>35-37</sup>. Thus, today 'parental nursing care' may be a more accurate name.

'The mother is supposed to assume a complex set of duties that includes watching regularly the health of the children, noting any symptoms and complaints, deciding the appropriate action to be taken, administering home management type of treatments or arranging for medical help' <sup>38</sup>.

However, it is not always an easy task to practise parental nursing care as described above because it is so complex and especially first-time parents find it difficult to make sense of the illness <sup>39</sup>.

### *Symptoms that worry parents*

Parents react if they observe many symptoms at the same time and if they believe one of the symptoms to be serious <sup>7;40;41</sup>. Those that cause them most concern seem to be high fever <sup>42</sup> and difficulty in breathing <sup>40;43;44</sup>. Parents find symptoms such as high fever and cough to be more 'risky' than other symptoms. Some parents are really frightened and suspect meningitis when the child becomes acutely ill with high fever <sup>42</sup>. Other parents believe that a fever could cause brain damage or death <sup>45</sup>. Parents who have had a frightening experience of febrile seizure fear that it will happen again the next time the child has a fever <sup>46</sup>. Some parents had been taught to bring the child to a physician if signs of ear ache or symptoms persisted for more than 24 hours <sup>41</sup>. Symptoms such as difficulty in breathing seem an obvious reason for calling a physician. It is more difficult to understand what motivates parents to seek a physician's advice if the child has a tiny rise in temperature or a cold for a few days. The present study will therefore focus on how parents notice that their children have signs of illness and their initial worries.

### *How to assess symptoms*

To estimate the seriousness of an illness is difficult, for parents as well as for physicians <sup>47;48</sup>. The temperature is not a reliable guide to the seriousness of an illness. For example, fewer than 2% of children (3 months to 3 years) with a temperature over 39 degrees Celsius had manifest bacteraemia <sup>47</sup>. The concordance between physicians in assessing the severity of illness in babies has been found to be 80% <sup>49</sup>. A baby check score system has been developed to assess baby illness <sup>49;50</sup>. Used by physicians, nurses and parents, the system deployed a combination of symptoms and signs to achieve high sensitivity and specificity. The parents' score cards used the same symptoms, signs and scores as the physicians' score cards, but had more detailed descriptions and appropriate illustrations of the 7 symptoms and 12 signs used. The comments on the first two symptoms on the parents' score cards were as follows: Has the baby vomited at least half the feed after

each of the last 3 feeds? Has the baby had any bile-stained (green) vomiting? The comments on the first two signs were as follows: Now examine the baby while it is awake: Is the baby's muscle tone reduced? Talk to the baby. Is the baby concentrating on you less than you would expect? The baby check was found to help parents recognize when their babies were becoming seriously ill and gave them the confidence they needed to ask for medical help <sup>49;50</sup>. This indicates that parents do appreciate specific information.

Even though parents have difficulty assessing symptoms, parents in general manage to care for most of their children's illness episodes themselves.

Thus, 67-99% of all child health problems did not require a physician-attended visit <sup>4;5;7;34;41;51;52</sup>. In a Danish study, physicians were only contacted in 32-52% of all cases of illness, even though the child morbidity reached 75% within an 8-month observation period <sup>12</sup>. Thus, parents do not visit a physician each time the child has symptoms. The initial impression that the reason for parents' frequent visits to physicians was because they reacted to the first small sign of illness in the child, but this could not be confirmed by other studies. This observation invited the question of what other factors make parents seek the physician's advice and judgement.

## The child-parent-physician communication

Recent years have seen a plethora of studies of patient-physician communication of which very few have involved parent-physician-child communication <sup>53;54</sup>. Furthermore, when such studies have, indeed, included children, direct communication with the child had often been very limited <sup>53;55;56</sup>, even though inclusion of the child's contribution to the communication has increased during recent years <sup>57</sup>. These studies dealt with the outcome of the communication, e.g. in terms of satisfaction and adherence to treatment from the parents' point of view <sup>54;58;59</sup>.

Most Danish parents are satisfied with the health care system <sup>10</sup>. Among parents with 2-17-year-old children, 37-47% were fairly satisfied and 35-51% were very satisfied with the

health care system according to a questionnaire on continuity, quality of the health care system, information, need, time use, friendliness and accessibility<sup>10</sup>. However, we do not know what makes the communication between the child/physician/parent go well or what kind of misunderstanding arose when the parents were less satisfied. Analysis of the reasons for parental satisfaction/dissatisfaction with the consultations requires that the views of the parents and children are known, e.g. through the paediatric interview, which differs from interviews with adult patients in the sense that the setting is triadic, involving the child, the parents and the physicians.

Furthermore, such communication is multidimensional, involving (a) parent/physician communication (b) child/physician communication and the (c) child/parent communication. The smaller the child, the less able it is to communicate verbally, but the parents as well as the physician can communicate verbally with a child and have non-verbal answers such as a smile or a cry of fear or pain. In a study of a group of single mothers from socio-economically disadvantaged backgrounds in England, the mothers said that there was a disparity between their beliefs and expectations about the illness and the physicians' decision, behaviour and information<sup>39</sup>. One of the focuses of this study is to investigate the parent's experiences of the physician's examination and diagnosis of the children.

## Parents' experiences with sick children

A search of the literature uncovered only a few studies where parents were directly asked about how they experienced 'young children's common illnesses'. Straite<sup>60</sup> researched the problems faced by mothers nursing young children with acute otitis media and how the mothers dealt with worry, the child's pain, broken sleep, stress, fatigue and marital problems. Kai<sup>42</sup> investigated what it was that worried parents most when their children were ill and found that they were afraid of fever. Cornford<sup>44</sup> investigated why parents seek a doctor when their children coughed and found that they feared that their children would die when they coughed up thick phlegm or coughed so much that they threw up.



Allen investigated parents' view of minor illness in children and parents reported feeling disempowered and anxious<sup>61</sup>. To summarise, these studies indicate problems with parents' understanding and handling of the child's symptoms/illness and my experience as an on-call general practitioner observing communication breakdowns between physician and the family has greatly inspired me to giving this study a user's perspective.

## **2 Aim of the study**

This PhD study aims to heighten our understanding of parents' experience with their sick child and their reasons for visiting a physician.

The primary aims of the study were:

- 1 To investigate and uncover parents' experience with and understanding of the child's illness
- 2 To investigate the reasons triggering the decision to see a physician
- 3 To discuss possible misunderstandings in the communication between parents and the physician

Papers 1 and 2.

This study has given rise to the following Papers.

Paper1: Ertmann Ruth K, Söderström Margareta, Reventlow Susanne. Parents' motivation for seeing a physician. *Scand. J. Prim. Health Care* 2005;23:154-8.

Paper 2: Ertmann Ruth K, Reventlow Susanne, Söderström Margareta. Parents' situated experience and knowledge of their child's illness signs – a key to better doctor-patient communication. Submitted.

### 3 Design and Methods

#### Design

An inductive qualitative interview study was chosen to explore parents' experiences with sick children <sup>62;63</sup>.

#### Informants and study populations

The interviewed families were strategically selected among 194 participating infants. The infants and their families live in Frederiksborg County, which is situated north of the Danish capital, Copenhagen.

Families selected for interview were chosen among a birth cohort of 389 infants born between the 1st and the 28th of February, 2001, of whom 197 agreed to participate in the study. The families were contacted by mail by RE on the 15th of November 2001 when the infants were 8 months old, and a reminder was sent three weeks later.

The 194 infants were first followed prospectively from the age of 9 months to the age of 12 months by means of a diary (January- February- April) (Enclosures B) and retrospectively from birth to the age of 9 months by means of a questionnaire (Enclosures C) <sup>64;65</sup>, that is to say, all the 194 participating families filled in the 3-month diary and the questionnaire. For the non-participating families and dropouts, see Enclosure D.

In this study the data from the questionnaires and the diaries were used to select families. Families with a variety of experiences with a sick infant and with physician-attended visits with the infant were selected.

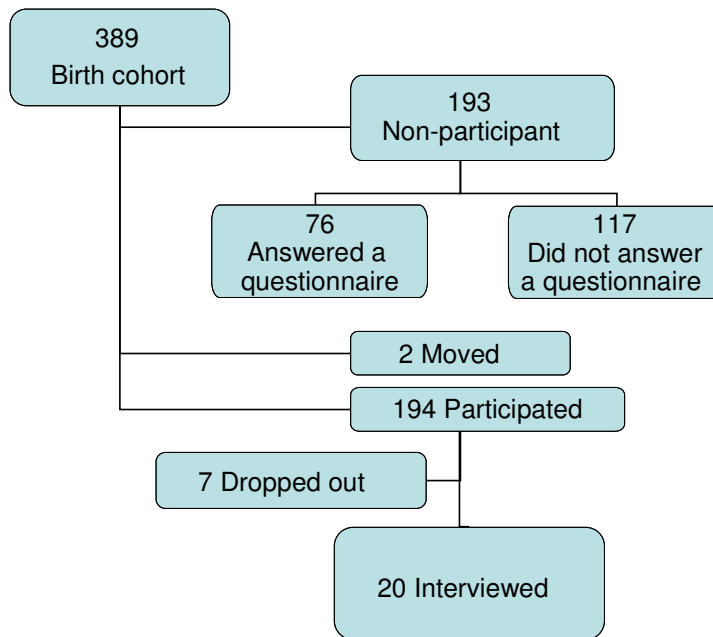
## Families chosen for interview

The present selection of interview families was guided by the wish to obtain diversity and analytical depth, which required a strategic data selection. The twenty families were selected on the basis of diary information. The selection procedure covered the following steps: first, all the diaries and the questionnaires were read and divided into one group with infants who had had several illness episodes and another group with infants with no or only a few illness episodes. The first group of diaries was re-read and families were selected who seemed to cover a wide range of experience:

- Infants with several illness episodes with/without physician-attended visits
- Infants with an episode of pneumonia or acute otitis media
- Parents with illness experience from older siblings
- Infants without significant episodes of disease, but with anxious parents
- Healthy infants without older siblings
- Infants who were prescribed medicine
- Infants whose parents had child-care problems
- Infants who had had an illness episode as newborns

Several families from each group were identified. They were chosen at random and phoned by the author. If a family did not answer the telephone, the next family in the same pile was phoned. All the families answering the telephone call accepted the invitation to participate in the study. For further information about the experience of the selected groups and the number of eligible families (in italics), see Enclosure E: Families chosen for possible interview.

Figure 1. Flow chart of the study population



## Data collection instruments

### *Interview guide and pilot interview*

The interview guide was inspired by an interview guide from the Danish National Birth Cohort study 1997-2002<sup>1</sup> and from the author's daily work with parents as a general practitioner (GP). Some colleagues suggested a few extra questions in the interview guide. These questions were incorporated before pilot testing. The interview guide addressed the time when the infant was ill, including the parents' concerns and handling of the sick infant.

### *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?

---

<sup>1</sup> Statens Seruminstitut: Sundhed for mor og barn

4. When do you consult the physician with your sick infant?
5. Do you have positive or negative experiences with the physician?
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 with alternative and complementary medicine?
12. Looking back, is there anything you would wish were different?
13. Anything else you want to tell?
14. What did you think of the interview?

A pilot interview was done in February 2002, and a few changes were made.

#### *Development of the questionnaires and diary and the pilot study*

For extended information, see Enclosure F: Development of the questionnaires and diary and the pilot study.

## Data collection

### *Questionnaire and diary*

The data collection months January, February and March were characterized by correspondence with the participating families to obtain a comprehensive diary material<sup>62</sup>. In December 2001 information letters, questionnaires, January diary, one diary example and a stamped envelope were mailed to the participating families. During the following month they received several information letters to encourage them to fill in the diary and the questionnaires. All parents also received a call where verbal information about filling in the diary and the project was provided. In April they were thanked for their participation. In May reminders were sent to 37 who had forgotten to send in the questionnaires and

diary. Late summer telephone calls were made to those who still had not sent in the questionnaires and the diary. Three families could not be reached by phone, so instead they were visited at home.

### *Interview*

Semi-structured interviews, lasting for about one hour, were conducted in the informants' homes during the spring of 2002. The informants chose the place and time for the interview and all the families wanted the interview to take place in their homes. During the interview, they served coffee and cake. Mothers participated in all interviews, fathers in ten. The index infant was often present and in a few cases older siblings too.

Parents were encouraged to talk about their experience with their sick infant. However, they also talked about experiences with their older children. The interviews in which both parents participated were characteristic in the way that the parents took turns telling about their experience and in the way that they supplemented one another. Both the questionnaires and the diary were brought along for the interview and especially the diary was recognized and parents commented on the illness episodes marked in the diary even before the recording of the interview began.

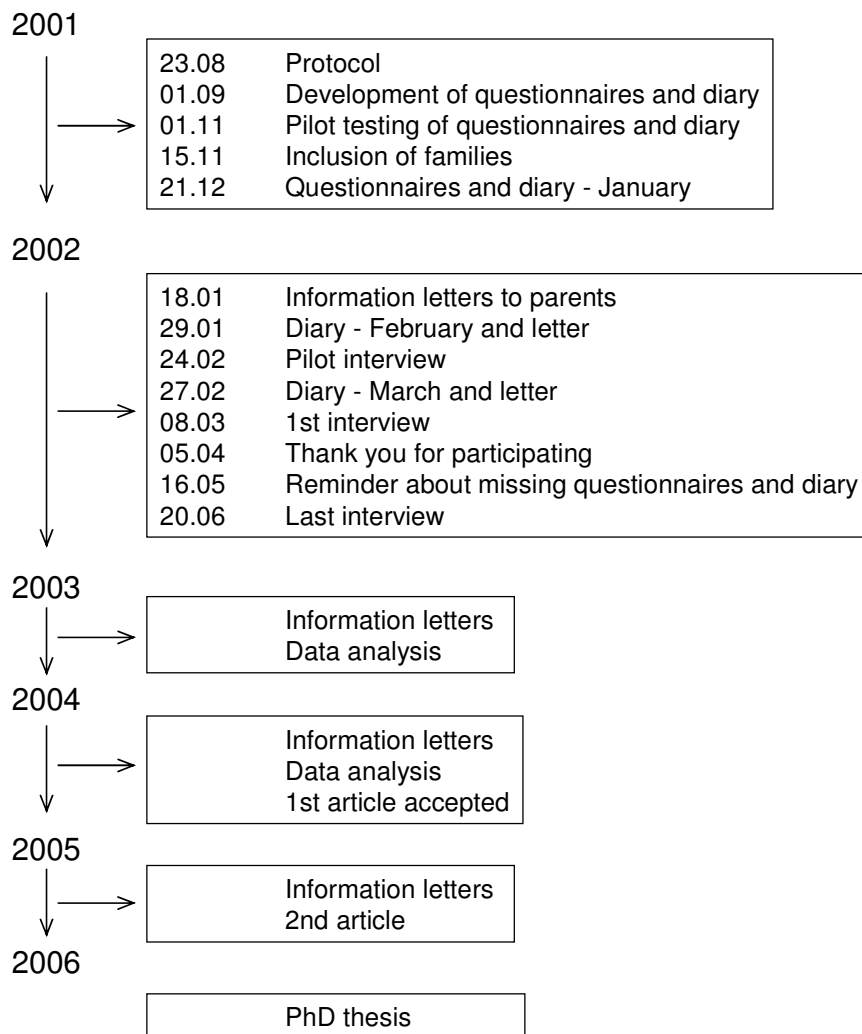
Most parents covered the main points in the interview guide themselves during the interview, except the questions concerning the impact the infant's illness had had on the siblings and their marriage if any or if they had been in contact with alternative therapists.

If the parents asked medical questions, they were gently informed that they would have to wait until after the interview, because it was necessary to hear their story first.

After the interview, notes were made about the interview situation, addressing issues such as who was talking: father, mother or both; how was the atmosphere: hostile, friendly with coffee and so on. A few days after the interview, the interviewed families were phoned to follow up on possible questions from the parents and possible

misunderstandings. The parents were also asked if they had unpleasant feelings about being interviewed <sup>66</sup>.

*Figure 2. Time table of the study*



*Data collection period*

Diary and questionnaire: 21st December 2001 to June 2002 (from each family 3 diaries, 1 questionnaire and some of the families received reminders about missing diaries).

Interviews: took place between 8th March 2002 and 20th June 2002



The data collection procedure was highly successful: the response rate was 96.4% (187 respondents among 194 participants) and 94.3% (183 parents) of the material was complete (viz. filled-in questionnaires and all three diary forms completed). Data on the four families with incomplete data were added to complete the data set.

## Data sources for analysis of the interviewed families

The 20 interviewed families were Danish (except for one family where the father was born in Greece), mediumly to well educated, all married apart from one divorced mother with 6 children, owned their own homes and 16 of the families had more than one child (Table1).

*Table 1: Demographic data on interviewed families*

| <b>Informant No.</b> | <b>Parents Interviewed</b> | <b>City in Denmark</b> | <b>Residence</b> | <b>Occupation<br/>Mother<br/>Father</b>   | <b>Age (years)</b>                | <b>Age of Siblings (years)</b> |
|----------------------|----------------------------|------------------------|------------------|---|-----------------------------------|--------------------------------|
| 000                  | Mother                     | Allerød                | House            | Secretary<br>Office chief                 | Mother 37<br>Father 52            | 6 + 2 adult siblings           |
| 021                  | Mother<br>Father           | Frederikssund          | Apartment        | Draughtsman<br>Cleaner                    | Mother 31<br>Father 48<br>(Greek) | 6, 3                           |
| 024                  | Mother<br>Father           | Espergærde             | House            | Sales support specialist<br>Sales manager | Mother 30<br>Father 36            | No siblings                    |
| 041                  | Mother                     | Veksø                  | House            | Executive secretary<br>Chief adviser      | Mother 35<br>Father 33            | 5                              |
| 045                  | Mother<br>Father           | Veksø                  | Country house    | Head clerk<br>Associate professor         | Mother 34<br>Father 37            | 3                              |
| 063                  | Mother<br>Father           | Skævinge               | House            | Sales assistant<br>Fitter                 | Mother 34<br>Father 35            | 6                              |
| 087                  | Mother                     | Frederiksværk          | House            | School teacher<br>School teacher          | Mother 36<br>Father 38            | 3                              |
| 109                  | Mother                     | Rungsted               | House            | Full-time housewife<br>Lawyer             | Mother 34<br>Father 36            | Two siblings                   |
| 112                  | Mother<br>Father           | Ølstykke               | House            | Educationist, day<br>nursery              | Mother 31<br>Father 34            | 4                              |

|                  |                    |               |           |   |                          |                   |
|------------------|--------------------|---------------|-----------|---|--------------------------|-------------------|
|                  |                    |               |           | Head clerk  |                          |                   |
| 115              | Mother             | Birkerød      | House     | Laboratory assistant<br>Producer – Danish<br>Broadcasting | Mother 28<br>Father 38   | No siblings       |
| 122              | Mother<br>Father   | Hillerød      | House     | Shop assistant<br>Vehicle testing<br>assistant            | Mother 30<br>Father 29   | 3                 |
| 129              | Mother<br>Father   | Ølstykke      | House     | Bio-analyst<br>Service engineer                           | Mother 28<br>Father 29   | 2                 |
| 134/135<br>Twins | Mother             | Nivå          | House     | School secretary<br>Financial manager                     | Mother 31<br>Father 32   | Twin and 3        |
| 136              | Mother             | Stenløse      | House     | Warehouse clerk<br>Spare parts manager                    | Mother 33<br>Father 33   | No siblings       |
| 137              | Mother<br>(Father) | Kokkedal      | Apartment | Bank clerk<br>Confectionoer                               | Mother 34<br>Father 32   | 4                 |
| 139              | Mother<br>Father   | Hillerød      | Farm      | House wife fulltime?<br>Youth club teacher                | Mother, 28<br>Father, 35 | No siblings       |
| 146              | Mother<br>Father   | Slangerup     | House     | Social worker<br>Service manager                          | Mother ,33<br>Father 34  | 7                 |
| 149              | Mother             | Farum         | Apartment | Lost earnings due to<br>disabled infant on<br>welfare?    | Mother ,34<br>Father, 34 | 12, 9, 7, 5,<br>3 |
| 154/155<br>Twins | Mother<br>Father   | Hillerød      | Apartment | Office clerk<br>Taxicab owner                             | Mother 32<br>Father 35   | Twin              |
| 157              | Mother<br>(Father) | Frederikssund | House     | Product manager<br>Corporate controller                   | Mother 30<br>Father 30   | No siblings       |

### *Analysis of the interview*

The interviews were recorded on a digital recorder (Sony discman). The first 5 interviews were transcribed literally by RE. Then RE listened to the recordings again 2 or 3 times and the transcribed text was corrected. The other 15 interviews were transcribed literally by a professional secretary. The transcriptions were controlled 2 or 3 times by RE<sup>66</sup>. All together the interviews ran to approximately 450 pages of A4 text.

The empirical material was inductively and systematically analysed in accordance with Giorgi's phenomenological approach to qualitative data<sup>67;68</sup>. This method of analysis was chosen for several reasons, primarily because phenomenology recognizes the interviewed

person's subjective perspective, and secondly because it emphasizes the importance of the researcher's preconception. The method was modified and described in detail by Malterud<sup>2;69</sup> and included the following procedures: 1) All interviews were collected and read to get an overview; 2) Units of meaning were identified by breaking up the text into smaller parts representing different subjects of conversation; 3) Condensation and structuring of meaning within each coded group; 4) Condensation of the meaning into a new idea. A description of the various steps of analysis from 1 to 4 is given below.

1) The first step of the analysis was to become familiar with the material. All 450 pages were perused to get an overall impression. An overall impression was more important than eye-catching details. An active effort was made to put aside preconceptions and theoretical frames in order to be open and receive the impressions the material offered – to hear the informants' voices.

This step of the analysis led to the following overarching subjects; how could the parents see that the child was becoming ill what did they do – the parents, what worried them, when did they contact the physician, the meeting with the physician, fever, at home with the sick child, parenting, impact on everyday life, etc.

2) The second step of the analysis contained the units of meaning and movement from subjects to codes. During this procedure some text was extracted – that is the units of meaning – which in some way contained information about the overarching subjects that had appeared from the first perusal in step one of the analysis. See table 2.

First, 4 interviews were cut into pieces in the software programme Word in order to single out units of meaning and 41 code groups were created. For instance, fever, cause of the illness, how did parents see that their child was ill, search for information and advice, everyday life in the family, physician etc. The first crude code was made and repeated and joint coding was done in collaboration with the co-writers of paper 1. After having coded 9 interviews and worked with the units of meaning in these interviews, the following superior theme was chosen: "What causes parents to attend a physician with their sick child".

Before recoding the interview, the notes about the family were re-read, the questionnaires and the diary were examined and an effort was made to recall the interview situation at the parents' home. Then all the interviews were recoded and units of meaning where the parents said anything about a situation which might or might not lead to a physician attended call or visit were found and coded. Examples of codes were: fever, crying child, treatment, worsening of symptoms. The same units of meaning could have several codes.

3) The third step of the analysis dealt with abstracting the information represented by each of the code groups. This was done by condensing the contents of the units of meanings. What were the parents talking about when for instance the code was fever. It could be a feeling of fear that the child would die, taking responsibility or that they now were in control of the situations where the child had high fever without calling the physician. That is to say, new sub-groups were emerging. The text was being interpreted on the basis of the researcher's professional standpoint as a general practitioner. A dermatologist might interpret the units of meaning in one way, a sociologist might find a different meaning in the text.

4) In step four of the analysis the text was pieced together again – was recontextualized. First the information from each individual code group and sub-group was recapitulated. On the basis of the condensed text and selected quotations a list of contents was made – a result list – showing what the material told about a selected aspect of the problem complex of the project. After recomposition of the result list a reversion was made to the units of meanings in order to find a few selected quotations that reflected the truest picture of what was said in the text. Nine main concepts about triggering factors were found under the theme: "what causes parents to attend a physician with their sick child". The analysis was inspired by Lazarus & Folkmann's Coping Theory<sup>70-74</sup>, - see also Discussion of Methods.

*Table 2: Example of coding of units of meaning: What triggers a contact to the doctor?*

| Interview of family 115  |            |   |
|--|------------|---|
| Units of meaning   | Code group | Condensation  |
| 150 we were very frightened when suddenly he got 40°C in fever .. so I set off to the emergency department – well I am not sure that many others might have done so – I called the doctor on emergency duty who said that it did sound a little high and so on | fever      | frightened – emotional coping<br>First time = legitimate one's act<br>Compare to others<br>The advice from the doctor on emergency duty not enough to make them cope with the situation |

Coding for the second Paper was done using the computer programme NVivo. Using the long text extracts in Word was very time-consuming, which motivated a change to NVivo which has been specially developed for handling comprehensive text. In order to get to know the programme and be certain that the coding was in accordance with the coding of the first article, I started from scratch by coding units of meanings in 3 interviews. These units of meaning were compared with the cut units of meaning from the first coding and were very similar. There were a little fewer units of meanings (37 against 41) and this was especially because I had merged some units of meanings with statements about the consultation with the physician. Afterwards all the interviews were coded and the following superior theme was chosen: experience with the physician.

Again the notes, questionnaires and the diary were re-read. The interviews were recoded and all the units of meanings where the families "said anything about the meeting with the physician" were found and coded. Examples of codes were: power relationship, praise and criticism, consumer, physicians' answers, learnt from the physician, experienced parents, layman, to get to the physician in time, and expectations to the physician.

In step 3 of the analysis the units of meanings were condensed, and new sub-groups emerged such as: meaning of symptoms, satisfaction/dissatisfaction with the consultations.

Finally the codes and the sub-groups were summarised and described in terms of identifications, meanings and dialogue of signs.

The analysis was inspired by Kleinmann<sup>75;76</sup>, see also the theoretical chapter and Discussion of Methods.

## Ethical considerations

The investigation was approved by the Danish Local Ethics Committee.

The ethical considerations concerned the principle of autonomy and the principle not to do harm.

The study did not involve procedures that could harm the children. The parents merely passed on information about their actions and worries in relation to their sick child. During the pilot test of the project I asked the parents if they would like to participate in the investigation. Most parents wanted to participate, and they particularly stressed that they found the investigation important because, as parents, they wanted to be heard and to be taken more seriously by the physician when they came with their sick children.

Integrity could be an ethical consideration in several situations.

To interview parents in their own home could also be a violation of integrity. However, all parents chose to be interviewed in their home. I did not have any of the families on my list in the practice and had no further contact with them professionally during the study. The interview could have initiated anxiety over the child's health issues as well as parental shortcomings in handling the child's illness. However, the parents were offered the chance to contact RE by telephone on all working days. The researcher (RE) also telephoned the parents within a week of the interviews to follow up on loose ends.

More than 200 parents had to spend time keeping a diary for three months in order to enable the selection of 20 suitable families for interviews. However, as the purpose was to find parents who had a child with recurrent illness as well as parents with other illness

experiences with their child, prevalence calculation required this number of informants. Furthermore, my intention is to analyse the information gathered from the diaries.

## Presentation

For extended information, see Enclosure G

## 4 Theoretical perspective

### Introduction

The present study has an interdisciplinary frame of reference at the intersection between general practice and social science. No theoretical analysis templates were defined at the beginning of the study. Various theories were considered as the general theoretical perspective. Among others Lazarus & Folkmann's coping theory which was used in paper 1 but during the study the choice fell on theories drawn from medical anthropology concerning theories about illness, disease<sup>75-79</sup> and explanatory models (EMs) of specific illness episodes<sup>75-77;80</sup>.

This chapter lays out the theoretical perspective of Kleinman's theories. The biomedical perspective on illness adopted here was expanded by an experiential view claiming that people may experience and interpret illness in very different ways<sup>75;76;78</sup>. Kleinman made me focus on the lay-man perspective as a valuable tool for understanding parental concerns, their actions and sometimes desperation when dealing with the health care system.

### Explanatory models

To understand the communication between physicians and parents, it is fruitful to go beyond the words and explore the context of the experiences with the sick child. Context in this study includes time, place and relations. The context will often hold clues that assist our understanding of the parents' perceptions of their child's illness. The parents' perceptions can be very different from those of the physicians.

The difference between folk beliefs, 'common sense', and popular ideas on the one hand and medical beliefs on the other hand was studied by Kleinman<sup>76;78;81-85</sup>. He was inspired by how people in different cultures and subcultures, e.g. Taiwan, China, and North



America, experienced illness. He was also concerned about the effect of the biomedical orientation of medical teaching during the 1970-1980s and foresaw that failure to include the patients' perspective during the consultation could contribute to communication problems between the patient and the physician. The incorporation of insights gained from this study of parents' perspectives on the management of sick children may provide important insights that can enrich communication.

Exploring the difference between the patients' and the physicians' beliefs, Kleinman sought a practical way to obtain the patients' views on the illness process, prognosis and desired treatment<sup>75</sup>. By using health diaries and interviews, the Explanatory Model (EM) was developed, at the heart of which lies an important conceptual distinction between illness, illness behaviour and disease. The meaning of these terms in the EM will be outlined below.

'Illness' is defined as the perceived changes in body function, appearance, emotional state and the discomfort of unpleasant symptoms (wheezes, abdominal cramps, stuffed sinuses or painful joints). Illness is the main topic of the consultation from the patients' perspective<sup>76;86</sup>. The main challenge in terms of illness is to decide whether action or no action should be taken on the basis of perceived changes in body feelings (sensations). This challenge may be particularly difficult for parents who have to experience these feelings through their children.

'Illness behaviour' is the individual's action or reaction in response to illness under a particular set of circumstances. In the family context, the parents must interpret the child's bodily signs in a common-sense process as being expectable, serious or requiring treatment<sup>76;87;88</sup>. The patient or the family may themselves initiate treatment, for example by changing diet, trying to calm the child, or giving the child over-the-counter medication<sup>76</sup>. Moreover, most decisions regarding when to seek aid and whom to consult are made in the family<sup>76</sup>. Behaviour is rooted in cultural and social systems and norms, and people accordingly exercise culture-specific 'illness behaviour' where patterns of thinking, understanding and actions in response to illness situations are acquired through

socialisation and cultural learning <sup>76;83</sup>. The 'illness behaviour' matches the behaviour and expectations of the family or the social network who have to live with and respond to the patient's symptoms and disability <sup>76;78;81</sup>.

People handle illness differently and this is important both to the physician and society. Hence, Kleinman states that in both western and non-western societies, some 70-90% of all illness is managed solely within the family <sup>5;52;76</sup>.

'Disease' is an impairment of health or a condition of abnormal functioning as ascertained by the physician on the basis of the patient's illness complaints of illness or symptom presentation and the objective findings in the patient. The practitioner recasts the illness in terms of theories of disorder <sup>76;86</sup>. Physicians, in fact, judge 'symptom presentation' rather than 'symptoms' and the physician's professional objectivity is linked to an individual readiness to understand the patients' expressions/stories of their illness <sup>89;90</sup>. When the physician tries to grasp the 'symptom presentation', (s)he is starting a biomedical mapping of the body, while the patient talks about her/him self <sup>89</sup>.

'Explanatory Model' (EMs): 'are the notion about an episode of sickness and its treatment' <sup>75</sup> <sup>2</sup>. Every individual, whether patient or health-care professional, engaged in the clinical process makes his/her own EM, which is the individual's conceptualisation of illness and includes the individual's own personal view of symptoms, patterns, progress and programme actions and treatment. The content of EMs, which seem to explain illness episodes, are founded on 5 concerns: (1) aetiology, (2) time and mode of onset of symptoms, (3) pathophysiology, (4) course of sickness (including both degree of severity and type of sick role - acute, chronic, impaired, etc) and (5) treatment. Later it was found <sup>75</sup> <sup>3</sup> that the difference between the patients' EMs and the practitioners' EMs lay in the answers to these concerns <sup>75</sup>. The practitioners' EMs had answers to most or all of the issues involved, whereas the patients' EMs often had answers to only to a few of these.

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<sup>2</sup> Kleinman 1980, page 105

<sup>3</sup> Kleinman 1980, page 105.

The differences between the patients' and the physicians' EMs in Kleinman's study were elicited by comparing patients' perceptions with those of the traditional biomedically oriented physicians. Kleinman showed that the patients sometimes used the same biomedical explanations as the physicians, but also that their biomedical explanations were often incomplete and sometimes wrong from a physician's biomedical point of view <sup>80</sup>.

In order to achieve mutual understanding between physicians and patients, the physicians must understand the patients' explanations <sup>75</sup>. Patients' EMs show that they typically focus on the most salient aspect, which is the treatment of the illness <sup>75</sup>. Later in the course of a disease, patients usually have no sharp boundaries between the ideas and the experience of an illness. They conceptualise illness in many different ways and these conceptualisations frequently change according to the illness <sup>75;80;91</sup>.

The patients and the families attempt to explain the illness as a kind of understanding/clarification of what is happening and what can be done. Families try to make meaning of the illness in order to cope with the distress it creates. The meaning communicated by illness can amplify or reduce symptoms, exaggerate or lessen disability, impede or facilitate treatment <sup>76</sup>.

Studies of patients with back pain show that almost all respondents integrated the bodily experience. They developed a new understanding and meaning of the illness as they continually developed ideas and concepts about their disease built on the lived experience of everyday activities over a long period rather than on medical information <sup>92-94</sup>. Parents cannot integrate the child's bodily experiences into their own bodies, they have to respond to an interpretation of the child's bodily experiences.

Studies of parents living with a severely disabled child show that meaning is associated with having a medical diagnosis. Knowing the medical diagnosis makes the parents feel confident, and they can then search for coping possibilities <sup>95</sup>.

Cultural and social factors may also facilitate common understanding between the patient and the practitioner by accentuating locally shared illness ideas, for instance that asthma may be a consequence of pollution in the local streets <sup>96-98</sup>. Communication may also be

helped by the fact that most patients present a single problem which the physician often solves, even if the patient does not completely understand the physician's explanation <sup>75</sup>.

Patients do not always dare to talk about their understanding of the illness. Another point to note is that either they do not volunteer their understanding to health professionals or, when they do, they report them as short, single-phrase explanations <sup>77;99</sup>. Many patients fear being ridiculed, criticized or intimidated because their beliefs appear mistaken or nonsensical from the professional medical viewpoint <sup>77</sup>. Patients' fear of being embarrassed and mothers' fear of being labelled as inadequate mothers <sup>60</sup> have been found to be a barrier to seeking medical advice <sup>100;101</sup>. Parents of today are better educated and have access to much more medical information than parents in former times. This may imply that they are more inclined to have a feeling of being a competent parent, but on the other hand, the vast amount of information can make the parents doubt what kind of information is reliable.

Parents of children with chronic illness <sup>102</sup> and recurrent otitis <sup>60;103</sup> experience a lack of understanding and support from health care systems. This is understandable according to Kleinman's theory in the sense that the parents often cannot make meaning of the child's illness. Kleinman explains that the patients' EMs shift towards the practitioners' EMs, because with chronic disease patients want to get more answers to the questions raised by the chronic illness in order to make some sense of the illness. People may ask: What's the reason for this illness? Why did my child catch it? <sup>75;104</sup>. Parents in this study asked this type of questions as well as why exactly their infant fell ill all the time.

Although Kleinman's theory has given important input into the patient-physician relationship over the past twenty years, it is not without controversy. The arbitrary distinction between illness and disease has been criticised because this sharp distinction may invite a division between objective and subjective illness <sup>105</sup>. The objective illness (the professional focus) may leave the patient's subjective experience behind. This could cause alienation of the patient's body, as the patient's experience may be that the physician is only interested in the symptoms that have a biomedical explanation and not in the

consequences of the illness on the patient's emotions and social life <sup>105</sup>. Kleinman did not study parents' EMs in relation to their infants but this study will broaden the adult perspective to include the role of parents' experiences with their sick child.

EM theory has been challenged by Gannik <sup>106</sup>, who found good agreement between Kleinman's EM and her situated illness model in terms of aetiology, prognosis and treatment/intervention. She added to Kleinman's theory the perspective that illness is part of a life story and the understanding that it is rooted in multiple, factual causations, and that the patients have no understanding, or at best, only a vague understanding of what happens in the body. There is no sharp boundary between illness, signs of illness and reaction to illness <sup>92;94;106</sup>. However, Gannik's addition to Kleinman's theory stemmed from observations of adults. No research has shown if this added perspective also applies to illness in children. The present study extends Gannik's results by focusing on how parents incorporate the illness of the recurrently sick child into their own lives. Recurrent child illness entails a new everyday life that is complicated by the fact that the parents have limited understanding of what is going on in the child's body. For example a child with asthmatic bronchitis who starts coughing again may trigger questions about when to increase medication or when to bring the child to the physician.

Even though Kleinman equates the patient and the physician, they are not equal. The relationship is therapeutic, which implies the existence of a power structure in the consultations <sup>107</sup>, this thesis does not elaborate further on the power perspective. Even though Kleinman brings the family into focus he does not explore the power structure. The power imbalance is even more biased when the patient is a child and is unable to represent itself. He does not comment either on the fact that illness is linked to social groups and classes or on the unequal access to health care. Furthermore, if access to health care is limited, parents with resources will be those who actually manage to make contact with the physician <sup>108</sup>.

Kleinman's EM has clearly brought the patient's perspective into the consultation and has augmented our understanding of the importance of taking this perspective seriously when organizing strategies for clinical care <sup>76;80</sup>. But the theory falls short of describing the communicative interaction in the consultation room with a sick child. Kleinman's work was not constructed to shed light on communication; rather it focused on how a few direct aspects could elicit the patient's perspective <sup>80</sup>. It was therefore a forerunner of the patient-centred communication research of the 1990s <sup>109-111</sup>. The goal of patient-centred communication <sup>112</sup> is to help physicians to provide care that is in accordance with the patient's values, needs and preferences and to allow the patients to provide input and to participate in decisions regarding their health and health care. Patient-centred communication supplements Kleinman by including important elements such as socio-economic factors, emotional distress, insurance, waiting times, trust and personality (just to mention a few) <sup>112</sup>. This may also be important for parents with sick children.

## 5 Results

This section includes a brief presentation of the results in the two Papers.

### I. Trigger factors inducing parents to call upon the physician for advice

The parents described how they seriously considered whether to consult a physician or not. Their reasons for consulting the physicians were based on logical reasoning and emotional reactions while caring for their sick children. The parents were in need of advice, treatment and support to manage the child's illness. Supported by Lazarus & Folkmann's Coping Theory, we identified nine trigger factors associated with physician contacts. The first four triggering factors are in situations where the parents act because they are in need for advice. This concerns parents' need for evaluation of the severity of the child's symptoms, the parent's perceptions of need for treatment or knowledge of symptoms. In trigger factor 5 and 6 the action is based on social relations. These concern family and friends who are worried about the child and recommend that the parents should contact the physician. They also concern the need for advice to help the family to cope with children who fall ill all the time. The last three triggering factors are based on parents' emotional reactions. They concern families who panic and need the physician's advice to be calmed down, mothers or fathers whose intuition tell them that something is terribly wrong and families who are emotionally affected by their own stressed situations - not really because they are worried about the child.

1. Parents' need to re-evaluate the situation: Symptoms lasting several days and the parents start to wonder if they have overlooked illness that needs treatment by the physician.

2. Parents' ideas about symptoms: Parents want expert evaluations, do not want to lose time if treatment is necessary. Think it is possible to catch and stop illness in the beginning.

3. Parents facing previously unknown illness symptoms: Bleeding from the child's ear; what to do?
4. Parents with previous illness experience: Parents know these symptoms need treatment and want to start treatment.
5. Parents feel responsibility towards other people looking after the child: Day-care mother recommends that parents should call the physician. The parents think the consultation is unnecessary.
6. Need to reorganize everyday life: Symptoms and illness continuing for weeks and months and the parents' working life and the families' social lives coming under great pressure.
7. Parents who panic: Parents become very emotionally upset every time something with illness turns up.
8. Parents who are afraid because of the child's medical conditions: Children in need of intensive medical care; referral to hospital.
9. Reaching their limit: Parents cannot handle one more night without sleep due to a crying baby.

The parents said they were very emotionally affected the first time the children were ill (trigger factor 7) and that their knowledge about symptoms was very limited (trigger factors 2 and 3) and this was the reason why they contacted the physician. As they gained more experience in handling a sick child they contacted the physician mainly in situations like trigger factor 1, 4 and of course 8. The experienced parents said that sometimes their experience had been hard-earned – too much unnecessary worry. They wished they had got better information about symptoms and illness in children.



## II. Uncover parents' experience of their child's illness signs

- With focus on how their interpretation influenced their understanding of the communication in the consultation.

The parents' main concern was whether observed behavioural changes in their child were signs of illness; specifically what these signs meant and how serious they were. They described how they reflected on how difficult it was to differentiate between normal behaviour and early signs of illness and they felt the lack of a hard-and-fast boundary. If the signs continued or were supplemented with other signs, they started wondering if something was wrong. They described the arrival of fever as a kind of relief, because they all recognised fever as a specific sign of illness. When the child became ill a number of acts and reflections were set in the train. Often, the parents searched for information about symptoms and illness in books, from family and friends or on the internet. A number of practical problems also needed a solution: who should look after the sick child? Parents told how they currently appraised the child's symptoms and that it was very difficult to judge the seriousness of the symptoms and whether a visit to the physician was necessary.

The parents' interpretation of the child's illness influenced the sense they made of communication with the physician. It appeared from the interview that the parents experienced problems in the consultation with the physician. They questioned the physician's expertise if their concern was at odds with the physician's interpretation and response to the child's illness; in particular if the physician said that the 'signs will disappear' , 'it's nothing' or 'it's a virus'. They also failed to understand the physician's rationale and conclusion about the nature of the observed signs and the body's self healing. Lastly the parents misunderstood the commonly used medical vocabulary used by themselves and by the physician.

The communication gap seemed to widen if the signs had been going on for a long period or if the children did not seem to thrive, in which case the parents seemed to be really confused and frustrated. The parents felt that the physician did not use the signs they had observed to figure out the cause of the disease and treat the children.

The parents' evaluation of the physician/consultation was strongly influenced by the parents' own conception of the child's symptoms/illness and by the physician's explanations and actions. So, the good/bad meetings between child – parents – physicians may have an impact on how parents cope with having a sick child and their future use of health services.

## 6 Discussion of methods

This study starts with describing what parents say about various experiences they have had with their sick child. When parents suddenly have to deal with a child who is ill to a greater or lesser degree, it is their knowledge, feelings and a possible powerlessness that are touched on. Emphasis has been placed on describing special situations which may elucidate how parents think and act, and situations which in their opinion could improve the consultation process with sick children. A qualitative interview design was therefore chosen because the interview is particularly suitable for exploring people's experience and self-knowledge and for clarifying and further developing people's own perspective on their lives<sup>66</sup>.

The interview data were obtained through a semi-structured interview using questions that had been prepared beforehand and which raised issues that explored parents' responses, their general reflections as prompted during the dialogue.

Focus group interviews, interview after the consultations or questionnaires could have been chosen as designs. A questionnaire might not have revealed the ironic comments and the sense of humour shown by the parents expressed by saying that they did get through the experience – often put like: "but as you see the kid survived". Methods such as focus groups might have unveiled more detail about the social daily life with sick children while interviews after the consultation might have given material with more focus on sickness.

Originally, it was estimated that the number of 20 informants would produce a manageable amount of material both with regard to variation, presumed number of transcribed pages, and the time factor. This was shown to be correct when data saturation was achieved prior to the 20 interviews.

The choice of including a cohort for selection of a group of 20 informants rather than simple continuous inclusion of, for example, the first visiting 20 families with young children from a single practice could seem a waste of time. It was rooted in a wish to uncover variations of symptoms and illness frequencies in young infants (see enclosure

diary) and how ill the parents stated the child to be. As already mentioned, it made it possible to make a strategic selection.

The 20 informants were extracted from a birth cohort of whom only 50 % participated. It is reasonable to presume that there may be a selection bias as the participating families were selected from a well-motivated study group. The variations according to a cohort were smaller than expected. The selection bias might have been reduced by including families from two very different counties, one in a socially disadvantage area.

Systematic text condensation was chosen as the method of analysis because the wish was to analyze descriptions. Well-reputed systematic text condensation methods are Giorgi's phenomenological method<sup>67</sup> and Grounded Theory<sup>113</sup>. Kirsti Malterud<sup>2:69</sup> has modified Giorgi's method, and the choice fell on her method because it reduces "Units of meanings" to passages dealing with only the subject that is analyzed, whereas in Giorgi's method the entire interview text has to be turned into "Units of meanings".

The choice of analysis method was also inspired by Kvale's interpretation of hermeneutics and phenomenology<sup>66</sup>. Hermeneutics<sup>68</sup> investigates and explains interpretations and preconceptions (originally interpretation of the bible). Phenomenology contributes with recognizing the world as experienced by the subject: things as they are for some and not the things they are in themselves. This study deals with the understanding of parents' actions from their own subjective perspective because each individual's universe of meaning is decisive for what they actually do.

The phenomenological framework was unfolded in an attempt to be as faithful to the informant as possible, trying to recall the interview situation, the person, the child and the room by reading the interview field notes, the diaries and the questionnaires before coding each interview.

The analysis method of this study is inductive and therefore no theoretical framework had been laid down in advance for this project. The material has been allowed to speak for itself while theories have been sought that would help to unfold and explore the empirical material. This approach means that the study has been influenced by many different theories.

The preconception was influenced by the medical history of general practice <sup>108;114</sup>, studies of health care service evaluation <sup>115;116</sup> supplemented with a patient-centred medicine <sup>101;109</sup>. For some time, coping theories <sup>70-72;117</sup> were the theoretical framework, but during the review of an article it became clear that many theoretical schools interpreted coping in different ways. According to Lazarus and Folkman, coping is an act against a stressful or threatening event, and they operate with Emotional-focused and Problem-focused coping and with appraisal. Others, in particular psychologists, conceive coping as a cognitive process and they do not think that coping can be split into an Emotional - and Problem-focused coping. Coping is also a commonly used everyday word in English for which there is no exact Danish translation, but an approximate translation is "mestre/magte/klare" (master) or "at komme overens med en situation" (to come to terms with a situation). The use of coping in this study reflects the English everyday word. Coping theory was the basis for the analysis work in paper 1. In the search processes looking for situations where the physician could have had an opportunity to support parents in handling a difficult situation – empowering the parents - the theoretical framework of Kleinman <sup>75-78;83;86;91-94;104;118</sup> was used. His theory was based on a well-known medical construction around aetiology, pathophysiology and treatment. Furthermore, because he considers the layman as an equal actor in the physician-patient relationship his theories were an obvious choice as a framework for this study.

The theoretical framework with Kleinman's explanatory models has not been fully utilized in this study. The design of the study limited it because only the parents were interviewed, reflecting only the parents' subjective appraisal of the professional perspective. The physician was not heard and therefore it was not possible to counterbalance various 'explanatory models'.

## Reflexivity

Any research and the ensuing knowledge produced is inextricably entwined with the researcher's presuppositions and the positions adopted while collecting data <sup>69;119</sup>. A reflexive research approach, therefore, becomes particularly important <sup>1;2</sup>. According to Malterud, Crabtree and Kvale, reflexivity refers to self-reflection and self-criticism. It is based on the premise that the engaged field researcher is an active part of the setting, forms relationships and makes interpretations; this includes reflection on how the project influences the researcher, how the researcher influences the project and what metapositions<sup>4</sup> are established <sup>63;66;69</sup>.

My preconception about the possibility of communication gaps was confirmed during the interview where the parents mentioned that they had found it confusing to receive very different information from different physicians, but it was surprising to hear that the parents questioned our professionalism if they did not understand the physician's explanation.

The parents confirmed the important role of the physician as a provider of information about illness, treatment and health, and it was interesting to discover how capable the parents became in handling sick children and how this reduced their need for visiting the physician. The parents supported my preconceived view that they would seek professional medical help when they needed information and support. The diaries showed how few contacts they actually had with the physician during the infant's many illness periods.

During the interview situation the parents asked about the connection between the reason they had been chosen for the interview and the infant's diaries. After clearing up this issue and putting their diaries on the table, the ice seemed to be broken and a nice friendly dialogue took place during which the parents commented <sup>120-122</sup> on the illness episodes mentioned in their diaries. The fact that they had produced the diaries testified to their ownership of the process and was instrumental in reducing the power distance between

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<sup>4</sup> i.e. strategies for creating adequate distance from a study setting in which the researcher is personally involved

informant and the interviewer. Visiting the families in their homes underlines the importance of the parents' private actions and perceptions when caring for the sick child<sup>123</sup>.

Parents were aware that the investigator was a physician. It was considered important not to interrupt their story and not to allow the focus to shift to the medical interviewer<sup>124</sup>. It was difficult to avoid switching from the role of neutral observer into the role of the professional, correcting misunderstandings and providing knowledge where such knowledge was clearly needed. The agreements that medical questions and answers should wait until after the interview helped, so the parents were not interrupted. The parents' use of irony and jokes about my colleagues when telling their stories could indicate that they did not pay much attention to my profession as irony is mostly used among friends. The atmosphere during the interview supported that, but the opposite could be the case too, because irony can also be used to keep a distance. The parents may also have been influenced by the official nature of the study and may have feared that incriminating information would reach the social service authorities, which could mean that they could hold back some information. The interviewer's position as a physician could also have influenced the interviews by enforcing an agenda that gave priority to illness at the expense of parents' feelings about illness and its effect on their marriage and siblings, if any. The interviewer therefore actively raised these subjects during the interview. However, the parents did talk about how the illness episodes influenced their work situation: for example how they had to decide who should stay at home to take care of the sick child.

## Validity

The internal validity of a study reflects the degree to which it investigates what it is meant to investigate, and external validity explores the contexts in which the findings can be applied<sup>66;69</sup>.

### *Internal validity*

The present study aimed to capture the breadth of parental experience in coping with sick children and their experiences with the health services; an aim that guided the decision to include cases spanning a wide range of experiences, which was possible on the basis of diary and questionnaire. In my efforts to get the most varied reflections possible about sick children and consulting a physician with them, two families were selected whose children had almost never been ill.

Methodologically, diary information supplemented the strategic selection<sup>5</sup> of interview families in a highly focused way that facilitated finding suitable interview families much earlier than would have been possible with another design.

The validity of the diary information and the families' agreement to be interviewed may have been facilitated by the fact that the investigator (RE) spoke to all of the informants on the phone about how the diary should be filled in.

The methodological process was continuously validated by senior researchers in family medicine, and design issues were brought up during study group sessions 'Metodeforum' which triggered valuable discussions about alternative perspectives and meta positions. Irrespective of what research design is chosen, there will always be limitations with regard to the transferability of study findings<sup>66;69</sup>.

Many families chose a time for the interview during the late afternoon, early evening or during the week-end, which made it possible for both parents to participate in 50% of the interviews. The interview setting, the family's home, may also have helped to create an atmosphere where the parents felt more relaxed. The confidential setting also provided an opportunity for the interviewer to make observations which included the interaction between the family members, because the project infant, the siblings and the father were also often at home.

The parents recalled experience from the illness cases they had recorded in the diaries and it seemed to help them to get started on their story and to assist their memory<sup>65</sup>. Investigation of people's memories shows that people quickly forget details.<sup>125</sup> However, for some informants, the episodes came together in a coherent large story of an illness

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<sup>5</sup> Families from the stack= many illness episodes.



that had become a central organizing theme in the family's life, and it was described as a story<sup>81;126</sup>. The interview where both parents participated may have facilitated the validity of the information as it seemed that they helped each other to tell the story, and they put into perspective different experiences concerning the illness episode.

Parents' stories about their experience of visits to the physicians could be at odds with the physicians' stories about the same illness episodes. Several studies have mentioned this duality<sup>70;75</sup> and this study explores the shared event from the parents' points of view. The families could have been interviewed more than once and this would probably have given new information about every-day life with sick children.

### *External validity*

Although the study included different families and children with different experience of diseases, there is still much similarity in the stories, both in terms of parents' worries and experience in dealing with sick children and in their experience with the health care system. The parents narrated how their response to similar symptoms/illnesses changed in response to the accumulation of experience in coping with sick children and to the changing circumstances of the illnesses.

The parents' educational level may have influenced the data supplied because of the richness of the vocabulary and reflections on both the child's illness and the contact with the health care system. The data thus may not be valid for parents from low socioeconomic groups. The ironic distance expressed by some of the parents in the study to the physician's professional knowledge may also have been influenced by the parents' education.

The parents' experience and understanding of illness signs may be seen as representative for middle-class families in Denmark. The parents coupled the concrete illness experience with the participating child to their experience with older siblings which made the investigation applicable to a wider age group. The adoption of a user perspective on illness experience adds new insights to our professional knowledge pool and shows that patient experience may cut across different diagnoses. The Danish health system where

families have their own family physician and the physician often knows the child and the family well, differs from the systems seen in some other countries. In the Danish system, the parents also know the particular practitioner, which may instil confidence in the relationship, but it could also serve to raise parents' demands on the physician and the health care system. The close, long-term nature of the patient-physician relationship within the Danish context makes the Danish health care system particularly well-suited for studies of physician/patient interaction.

However, it could also be expected that parents' dissatisfaction with health services with regard to recurring illness is transferable to other health services such as paediatric wards.

## 7 Summary of results

### Signs of illness

The parents described their experience with children who fell ill as a journey through stages characterized by different signals and symptoms.

1) At first they noticed a change in the child's behaviour, e.g. the child seemed to whimper a lot. Then they observed more visible bodily signs such as tiredness or reluctance to eat. They described this particular stage as somewhere in between the normal and the abnormal: the parents' interpretation of the child was that the child did not feel well; on the other hand, the condition was not serious enough to be characterized as an illness. If the signs continued and symptoms such as cough or fever appeared, the parents concluded that the child had actually fallen ill (Paper 2)

2) The next stage concerned classification of the illness. At this stage the parents' attention to the child's needs makes them try to decode their child's bodily experience, recognise and respond to it. They try to make the child feel better by undressing it, giving it liquid, comforting it, and they say that they often give the child medication. At this stage, the parents seek information through family and friends as well as through books and the internet. They constantly observe the child's symptoms and appraise the severity level of the illness.

If the child does not get better or the parents are deeply emotionally involved, they seek a physician now (Paper 2).

3) The parents consider consulting a physician. Generally, the following four factors can be seen as different factors which have a greater or lesser impact on that decision: A) their awareness of the fact that their decision was based on their personal ability to discover and interpret the child's signs and symptoms, and some parents did not always rely on their own ability to judge the nature of the illness; B) their awareness of the

importance of consulting the physician just in time, neither too early, making inappropriate visits, nor too late, fearing to overlook disease that needs treatment; C) their emotional response where they needed the expert to either confirm or dismiss their worry; D) their awareness of inappropriate visits when consulting on behalf of another person's worry (Paper 1).

Family 109. . . . running a fever of 40°C degrees 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. . .

The parents described how the child's distress affected them emotionally and how this undoubtedly took them by surprise; this was especially first-time parents. Parents with more than one child stated that their emotions had become less overwhelming. Parents also said that they shared the care of their sick child and stressed how more emotionally stressful it was to be at home alone with the sick child.

Most of the parents who hesitated before consulting the physician, although they knew that the child had fallen ill, tended to have experience from illness among older siblings. They seemed more confident when it came to the interpretation of the child's signs and symptoms. When they consulted the physician they did so because they had come to the conclusion that it was useful or necessary at that particular point to have the child examined by an expert.

## Parents' experience from the consultation

The parents described their experience with the physician in explicit terms, both about good and bad experiences. Below are only a few somewhat negative experiences which have been taken to an extreme in order to promote the reflection.

### 1) Parents in defence

The communication in the consultation sometimes gave the parents a feeling that they had to defend their decision to consult a physician. Some described situations where they felt that the physician found them to be 'overprotective parents', implying that the consultation was based not on sound judgement, but on an irrational feeling. Such an experience made the parents stress their responsibility for the child as indispensable. They stated that they preferred to be "safe rather than sorry" or that it was not their intention "to disturb the physician" (Paper 2).

### 2) Communication gap

Consultations could also result in factual misunderstandings. Some parents referred to medical terms introduced by the physicians and media in a way that showed that they could have misunderstood their factual meaning, e.g. the nature of a virus. It may be argued that the parents had interpreted the terms from a layman's perspective and if the physician had been aware of this, a clash between the parents' and the physician's comprehension of a medical term could have been avoided (Paper 2).

### 3) Lack of trust

When the parents were not able to make their interpretation of the child's illness fit with the physician's explanation it sometimes made the parents go on the offensive. Some made rather disrespectful jokes about the physician, telling stories about how s(he) did not bother to do his/her job properly or that s(he) was not clever enough to identify the illness of the child (Paper 2).

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 colours there

#### 4) Recurrent illness episodes

Critical remarks or lack of trust concerning the qualifications of the physician were made in relation to children with recurring illness episodes.

The parents described several frustrations:

- they did not think that the physician took the child's recurring illness seriously
- the physician had not been able to explain why the child had recurring illnesses
- the physician was not able to offer an efficient treatment

The parents concluded that the physician's incompetence had negative consequences both for the child's health and for the families' well-being (Paper 2).

## 8 Discussion of results

The results of this study raise several issues for discussion, but the following themes have been singled out for special attention:

- The process where the parents decide to consult a physician
- The meeting between the parents and the physician

On the meta-level the discussion will focus on the encounter between the explanatory models of the parents and those of the physicians as seen from the parents' perspective. The discussion will thus present reflections on the meeting between the parents' perspective and the physician's biomedical perspective.

### The decision-making process

When a child falls ill, the parents' ability to respond to and take responsibility for the child is challenged. They try to read the signs in an attempt to categorize and explain the illness<sup>17</sup> making a common sense<sup>78;81-85</sup> reflection. If they are unable to handle the illness themselves<sup>18;127-131</sup>, medical advice by a physician may be considered. People's common sense actions in relation to illness are very relevant as people seek information, try self-treatment or visit a physician. This indicates that parents are good at observation if they get the necessary information and this could be used to enhance their ability to interpret signs of illness.

#### *Interpretation*

The waxing and waning of illness signs make it difficult to decide whether or not to consult a physician. On the other hand parents' attention to the child's needs makes them very experienced in decoding their child's bodily experience and in recognising and

responding to its illness. A medical focus relying exclusively on symptoms presented by the child patient coupled with the failure to include the parents' perceptions of the sick child, may narrow the physician's diagnostic procedure. The physician also loses the opportunity to help insecure parents to cope better with the child's illness and to empower the parents from their own standpoint. This standpoint could be different for first-time parents, parents who have grown up in another culture than that of the physician, parents of children with chronic diseases and parents of infection-prone children with recurrent frequent episode of infections.

When parents decide to consult (or not to consult) a physician, they have to relate to a bodily experience that is not their own: Kleinman<sup>76</sup> describes illness as a concrete bodily experience that one has learned to relate to. But a child at the age of approximately 12 months has not yet learned to express their bodily experiences. So it is up to the parents to interpret and respond to the child's signs and symptoms. The child's lack of verbal language complicates this interpretation. Kleinman did not discuss situations where the illness experience is based on a more parental interpretation of signs and symptoms instead of a concrete bodily experience. Parents told about how the growing knowledge of the children, and later on the child's ability to communicate, made it much easier to interpret the child's bodily experiences when ill.

Parents' interpretation of illness is also shaped by their emotional response to the sick child. Especially first-time parents seem to be very affected and respond to the child's illness emotionally<sup>61</sup>. Some parents described this experience as a loss of control and discussed whether it was appropriate or not in the given situation. Parents said that their emotional response changed when they had learned how a child falls ill and recovers. When illness appeared, normality disappeared in the sense that the child's behaviour changed<sup>132</sup>. But the parents learned that the change was not static and this influenced their emotional response to the child's illness and they expressed it like 'children fall ill now and then'.

Kleinman made no comments on the effect that emotions have on illness interpretations and explanations and on laymen's emotional decisions when confronted with illness. Kleinman invited the patients to express their perception of the illness in the consultation



which may indicate that he thought that the consultation could be a forum for articulation of emotions <sup>75</sup>. The results of the present study seem to expand Kleinman's hypothesis because it demonstrated that emotions did, indeed, affect parents' experience and explanations of their child's illness.

### *Intuition*

Most parents did not consider their emotions to be a sound co-interpreter of the child's signs and symptoms. This could seem paradoxical because parents have learned how emotions seem to be a very important guide to action. A child could indeed be saved by parental emotions that tell them "something is terribly wrong – I can feel it – I am sure about it" <sup>133</sup> and bring the child to a physician or a hospital. These could be children severely ill with meningitis, pyelonephritis or heart malformation. Thus, such an emotional reaction could be a life saver. Physicians appreciate that kind of emotional reaction because they have experienced that mothers (parents) are often right and capable of recognizing the severity of the symptoms and do not fail to seek medical help <sup>40;51;134;135</sup>. However, it seemed that the physicians did not let the parents know that seeking help on the basis of an emotional reflex was, indeed, a very sensible act. Emotional reactions seem to be a very efficient way to learn about your child's illness reaction.

### The meeting in the consultation room

The present study reveals that only a few of the meetings between parents and physicians were, in fact, unsuccessful from the parents' point of view. However, it was interesting to study the less successful meetings because they dealt with problems where physicians and parents may have communicated badly. Two such problems discussed are fever and recurrent episodes of an illness, mostly respiratory tract infections.

### *The contradictions in fever*

Several parents characterize the meeting as less successful when they consult the physician because the child has a fever. To be afraid of fever is understandable because a child with fever looks very ill and holding a hot, feverish child in your arms may be frightening. It is like a boiling kettle. Furthermore, parents consider fever to be a risk for the child e.g. believe that moderate fever (a temperature of 40°C or less) may cause serious neurological side-effects<sup>45;131</sup>. This impression is backed by the physician's (as well as other personnel giving advice to parents) recommendation of medication to reduce the fever<sup>136</sup>. The parents are therefore unable to understand the physician when (s)he sometimes describes their concern about fever as being too emotional or irrational<sup>42;47;137</sup>. Seen from the parents' perspective, it is a contradiction in terms and they fail to understand this message and accordingly they feel insecure. It seems that by prescribing fever-reducing medicine, the physicians introduce a common sense attitude that fever is dangerous and they thus make fever a pathological condition.

### *The frustrations upon recurring episodes of illness*

Several parents also find that consultations motivated by the recurrent illness episodes of their child are unsatisfactory<sup>102;103;138</sup>. Seen from their perspective, the physician does not invest enough effort in his or her job as s(he) does not explain why the child has recurring illness. The impression is that the parents demand an explanation that the physician does not or perhaps cannot give them. The results of the present study indicate that the parents are frustrated because the explanations they get from the physician are not sufficiently detailed. They interpret sentences like 'it is just a fever', 'it is a virus' or 'it will pass' as dismissive answers – a rejection of their interpretation of the illness and its negative consequences - lack of sleep, absence from work, etc.<sup>139</sup> - for the whole family. According to Kleinman, parents' frustrations can be rooted in the physician's inability to satisfy the layman's need for short, single-phrased explanations because this is not the physician's own way of explaining and understanding complex medical issues such as fever, resistant bacteria, antibiotics, and the relationship between the immune system and infections.

However, this hypothesis may be challenged by the results of the present study: when the

child falls ill again and again it seems that some parents need more than a short, single-phrase explanation. They experience a need for and therefore ask for a more detailed explanation from the physician to make meaning of the situation. The results of this study indicate that it becomes easier for the parents to live with the child's illness and the effects this illness has on the family when they have a better understanding of the illness processes, e.g. of the role of the immune system<sup>72;76;95</sup> now and in the future. We may also hypothesize that the parents' dissatisfaction with the limited explanations they get may be rooted not in lack of communication, but in an actual lack of biomedical knowledge about the nature of recurrent illness. Maybe this lack of biomedical knowledge about the nature of recurrent illness makes the physicians' explanations somewhat limited and hence leaves the parents dissatisfied.

#### *A meeting that does not take place*

As already mentioned, it is thought-provoking that the unsuccessful meetings between the parents and the physician seem to be related to relatively ordinary cases such as fever and recurrent illness. The results of the present study invite further examination or discussion about the less successful meetings where the explanatory models of the parents and the physicians fail to meet. Parents experience one-way communication where the physician was neither listening to nor acknowledging their story about the child's signs and symptoms.

The meeting in the consultation room is described by a relatively large number of parents couched in ironic or sarcastic terms. Irony and even sarcasm cannot in themselves be categorized as negative, but in the context of the parent-physician encounter they can be interpreted as symptoms of a lack of success.

Irony and jokes can be seen as a reflection of the asymmetry in the consultation in the sense that the parents try to reduce the physicians' dominant position by making jokes about them<sup>84;101;109;112;140-147</sup>.

The parents' use of irony and jokes can also be seen as a defensive reaction to a consultation where they felt that the physician was not able to explore and understand their reasons for visiting. That could give a feeling that the physician neither

acknowledged nor appreciated parental concern for their child. It is not 'just' a virus seen from parent's perspective.

The feeling of unpleasantness and embarrassment is understandable because parents' knowledge about illness and anatomy is limited <sup>148;149</sup> as is their understanding of common medical terms such as fever, antibiotic, immune system and virus <sup>150-155</sup>. Kleinman and others state that patients do not like to reveal their beliefs in formal health care settings as they fear being ridiculed, criticized, or intimidated because they are afraid that their beliefs will appear mistaken or nonsensical from a medical professional point of view.

### *Lack of acknowledgement*

The lack of acknowledgement seemed to be a central theme for the parents who experienced less successful meetings with the physician. This is in accordance with other studies where patients wish to be 'seen' or 'believed' <sup>156</sup>. Parents expected the physician to acknowledge their way of experiencing and explaining the situation just as they expected to be recognized as parents who took responsibility. Parents seem to be frustrated when they experienced that the physician saw them as parents who fussed. In these cases, it seemed as though the physician gave the parents a feeling of incompetence or powerlessness <sup>157;158</sup>. Parents pointed out that the physicians have a very good opportunity to make them feel more comfortable, and some parents said that they would like to be trained in illness managing.

### *The premises of the consultation*

One could argue that the parents' frustrations are not a medical problem that concerns their child's illness that the purpose of the consultation is the examination of the child and that the physician can do that, no matter how the parents experience the situation. On the other hand, it could also be argued that a successful meeting between the parents and the physician improves the premises of the consultation, including the medical assessment and possible treatment of the child. A successful meeting between the parents and the physician can probably also reduce the number of times when parents misunderstand the medical information given by the physician and such misunderstandings may cause serious mistakes in the treatment the child receives at home.

*Two explanatory models in the same boat*

The interpretation of the signs and symptoms in young children is complex, not only for the parents but also for the physician. Just as parents tend to consult a physician when in doubt, the physician tends to consult another specialist if (s)he is in doubt <sup>159</sup>. Despite the difference between the explanatory models of the parents and those of the physician, they may both need second opinions. They are in the same boat facing the same challenge when interpreting a young child's signs and symptoms. The child would therefore probably benefit if they, parents and physician, worked together by sharing perspectives which would include the parents' explanatory models. Physicians' explanatory models must also be understood by parents.

## 9 Conclusion

This PhD thesis about Danish, well-educated, middle-class parents concludes that parents have a good (or a fair) reason when they bring their children to the doctor and that the lay people perspective they represent may be useful.

The parents' main concern was how to act suitably and responsibly in the face of their child's illness and the physicians should be aware that parents have to make decisions based on behavioural changes or minimal body signs.

*The parents' considerations about when the child is ill and when to consult a physician:*

- Parents are very sensitive to identifying signs and symptoms of illness in their children
- Parents appraise and reappraise signs and symptoms constantly
- Parents find it difficult to estimate the severity of the signs
- Parents can emotionally feel the children's bodily pain
- Parents' reasons for consulting the physicians are based on the duration or the exacerbation of the child's signs and illness
- Parents are eager to consult the physician just in time, i.e. neither too early nor too late

The parents tried to handle the situations by themselves and when visiting the physician they appreciated the physician's information and tried to learn from it in order to be able to deal with it themselves the next time without a physician.

*The parents' experiences when consulting a physician*

- Parents experienced that the physician did not acknowledge their sensitivity and 'common sense' response to the child's signs of illness
- They felt judged as incompetent by the physician if they visited with symptoms that the physician considered minor or emotional

- They experienced that their observations and anamneses of the child's illness episode(s) were not taken seriously and rejected with phrases such as 'it will disappear' or 'it is a virus'
- They experienced that the physician was not able to figure out why their children continued to suffer from recurrent illness. The parents felt the lack of a specific and concrete diagnosis and effective treatment of their children

*The results also indicate that*

- Parents sometimes misunderstood factual information given by the physician

The physician's lack of acknowledgment of the parents can have serious consequences because parents may come to question the physician's expertise and doubt that the physician has done enough to make the child healthy again. Physicians should be aware that parents need illness-specific knowledge and that the parents (due to the power gradient in consultations) can be anxious not to appear stupid or to cause inconvenience. The quality of consultations with parents of sick children could be improved if physicians bear this in mind.

## 10 Implications for clinical work

Thousands of Danish parents daily have a consultation with their physician that is characterized by high professional quality and adequate communication. However, parents in this study also recounted instances of physician-parent communication that fell short of expectations.

The decision to seek medical advice is characterized by a high degree of complexity and a parental need to be acknowledged<sup>158;160</sup>. Physicians should therefore avoid giving the parents a feeling that their initiative is inappropriate. Parents' emotions and responsibility for their sick children should be appreciated instead of being denigrated. Parents should be acknowledged as an important source of illness information<sup>45;161</sup>.

Never insinuate that parents do not have a good reason when visiting with small children. If the reason does not seem obvious – find it!

The implication for encounters between parents and physicians is to be aware of:

- parent's sensitivity in recognising and responding to signs and symptoms in their sick children
- parent's emotions and thoughts about the child's symptoms
- possible misunderstandings of medical expressions such as 'it is just a virus'
- the difference between first-time parents and experienced parents

The physicians could try:

- to explore the parent's illness experiences when they try to communicate symptom presentations from the child's body
- to explore the context around the sick children and the family
- to give information according to the child's symptoms and arrange agreements about treatment/no treatment



- to contribute to the parent's own attempt to cope with the situation

Some practical implications with regard to children with recurrent illness from this and other studies:

- parents of children with recurrent illness should receive extra attention and carefully planned information.

These parents experienced that the physicians did not take the child's illness seriously, due to gaps in communication, as found in this study. Parents lack the opportunity to make meaning of the illness, because as laymen they lack significant medical knowledge<sup>149</sup>. The physician could invite such parents for a talk about the illness<sup>157</sup> and their perceptions and emotions. The significance of not knowing the reasons for recurrent illness and the impact on family life should also be discussed as well as the availability of resources.

Such an approach will give the physician an opportunity perhaps to prevent common parental misperceptions like "something is wrong with the child's immune system" and it may shift the focus from what the physician thinks the parents want, e.g. to have a prescription for antibiotics,<sup>161;162</sup> to their wish for information.

To prevent misunderstanding of the medical information given, the physician could work with a handy standard presentation of issues such as fever and virus.

However, the content of such information should first be discussed among physicians.

## 11 Implications for future research

Based on the results of the present study, it is suggested that further research explores children suffering from recurrent illness. A study of the causality/aetiology of why these children are prone to illness could add important new information to the existing knowledge pool about illness among young children.

There seem to be problems related to 'everyday lives' with children with recurrent illness such as problems with siblings, married and working life, which could provide some clues for future research. Questions could include the extent to which physicians *de facto* need more time for consultations with the recurrently sick children where the information about fever, recurrent illness, virus, and immunity could be discussed in more detail. Research on the lives of families with small children in this post-modern era is currently in progress, but the protocol <sup>163</sup> lacks focus on the sick child and the health care system.

Research into the kind of information that parents need as critical and reflexive users of primary health care is also lacking <sup>164-166</sup>. The explanatory models of the present-day general practitioner could be worth studying too.

The literature reviewed during this study indicates some interesting subjects for research on children. Triad communications studies<sup>53</sup> exploring what kinds of communication skills the physician needs <sup>167</sup> to improve the involvement of the child in the communication and how it can be done would also seem to be warranted. Modern sociology states that children's bodies (even children 2-5 years old) are the critical site of their own experience <sup>168;169</sup>. From that point of view, the child's experience of embodied distress when ill can have a negative impact on its later bodily well-being. In that light the physician should therefore explore and direct information towards the child as well as towards the parents. A trial communications study could explore the power structure in such a consultation.

## 12 English summary

### What makes parents consult a physician?

#### Parents' experience with their sick child

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*This PhD study aims to heighten our understanding of parents' experience with their sick child and to explore their reasons for visiting a physician as a first step to improving the quality of these consultations.*

#### *Introduction*

Pre-school children have many consultations in primary care. Some of these could be questioned from the physician's point of view as the child has only minor diseases. Parents manage to take care of the majority of their child's illness episodes and only 20% of all episodes actually require the attention of a physician, so the question is what makes parents consult a physician.

Studies show that some parents seem to feel insecure about how to handle the child's illness and they could be irresolute and frustrated. How could these reactions be understood from a physician's point of view? Could a better understanding of the parents' experience and interpretation of their child's illness provide knowledge that could be used in practice to improve the consultation?

The primary aims of the study were:

- 1 To investigate and uncover parents' experience with and understanding of the child's illness
- 2 To investigate the reasons triggering the decision to see a physician
- 3 To discuss possible misunderstandings in the communication between parents and the physician

### *Methods*

A qualitative interview study, comprising 20 semi-structured interviews with parents, was conducted. The parents were asked to talk about an incident of their own choice when their infant was ill. The study was carried out on 0-12-month-old infants and their families living in Denmark. The families were strategically selected among a birth cohort of 194 infants born in February 2001 and followed prospectively by diary. The 20 families were selected on the basis of the diary and a questionnaire to cover a wide range of infant illness experiences: several illness episodes with/without visits to physicians; cases of pneumonia or acute otitis media; use of prescribed medicine; parental infant-caring problems; early infancy sickness; parental illness-experience from older siblings; healthy without older siblings; no significant episodes of disease but parental anxiousness

The empirical material was systematically analysed according to Giorgi's phenomenological approach to qualitative data.

### *Results*

The parents' main concern was whether observed small behavioural changes and minimal body signs in their child were signs of illness; specifically what these signs meant and how serious they were.

Nine trigger factors associated with physician contacts were identified. Parents' answers demonstrated how their emotional feelings and logical reasoning while caring for a sick child led them to consult the physician. The main reason for consultation was protracted or aggravated symptoms in the child. Parents initially tried to handle the situation, but when unsuccessful, they sought information and advice by consulting a physician.

The parents questioned the physician's expertise if their concern was at odds with the physician's interpretation and response, in particular if the physician said: 'it is nothing' or 'it is a virus'. They failed to understand the physicians' rationale and conclusions about the nature of the observed signs.

### *Conclusion*

Parents consult a physician if their interpretation of the child's illness makes them afraid or insecure about how to care for their sick child. They seriously consider whether or not to consult a physician. However, they have to make decisions about a possible illness through observation of behavioural changes or minimal body signs, a condition the physician must learn to appreciate. Parents were distressed when the physician minimized or dismissed their observations and reasons for visiting. If parents misunderstood the physician's interpretation and response to their children's recurrent illness they questioned the physician's expertise. The quality of consultations with parents of sick children may be improved if physicians bear this in mind.

## 13 Dansk resume

### Hvad får forældre til at kontakte lægen?

#### Forældres erfaring med syge småbørn

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Det overordnede formål med dette ph.d.-studie er at forstå, i hvilke situationer forældre til syge småbørn har behov for at kontakte lægen, ud fra et ønsket om at forbedre kvaliteten af disse konsultationer.

#### *Introduktion*

Småbørn udgør den patientgruppe, som har det højeste antal konsultationer i almen praksis. Den praktiserende læges vurdering af barnet er ofte, at barnet lider af en ufarlig sygdom, der vil gå over af sig selv. Dette rejser spørgsmålet: Hvorfor henvender forældrene sig lige nu, når vi ved, at de i andre situationer klarer barnets sygdom uden lægens hjælp? Kun ca. 20 % af alle perioder med sygdomstegn hos småbørn fører til lægekonsultation.

Nogle forældre virker usikre på, hvordan de skal håndtere barnets sygdom, og de kan virke tvivlrådige og frustrerede. Hvordan skal den praktiserende læge tolke den utilfredshed, de giver udtryk for? Kunne samtale i konsultationen omkring det syge barn forbedres, hvis lægen fik indblik i, hvordan forældrene tænker og handler, når deres barn er sygt?

Det primære formål med dette studie er:

- 1 At undersøge og afdække forældres oplevelser og forståelse af barnets sygdom
- 2 At undersøge i hvilke situationer forældre beslutter, at nu skal lægen se på barnet
- 3 At diskutere mulige misforståelser i kommunikationen mellem forældrene og lægen

### *Metode*

Kvalitative semi-strukturerede interviews med 20 forældre. Forældrene fortalte om oplevelser, de har haft med barnet og sundhedsvæsenet, når barnet har været sygt. I studiet deltog børn mellem 0-12 måneder og deres familier, alle bosat i Danmark. De 20 familier var strategisk udvalgt ud af en fødselskohorte omfattende 194 børn, alle født i februar 2001. Børnene i kohorten blev fulgt prospektivt med en dagbog. Forældrene blev udvalgt på basis af dagbøgerne ud fra det princip, at de skulle dække en bred vifte af sygdomserfaringer med småbørn: mange sygdomsepisoder med/uden konsultation hos lægen; episoder med lungebetændelse eller mellemørebetændelse; brug af receptpligtig medicin; pasningsproblemer under sygdom; sygdom som helt spæd; forældre som har sygdomserfaring fra ældre søskende; rask barn uden søskende; ingen nævneværdig sygdom hos barnet men alligevel bekymring hos forældrene.

Det empiriske materiale blev systematisk analyseret efter Giorgis fænomenologiske analysemetode til kvalitative data.

### *Resultater*

Når forældrene observerede, at deres barns adfærd ændrede sig, var deres hovedbekymring, om barnet var ved at blive sygt. Især bekymrede forældrene sig om de sygdomstegn, barnet udviste, hvad kunne de betyde, og hvor alvorlige var de?

I forbindelse med udløsende årsager til lægekontakt blev der identificeret 9 triggerfaktorer. Forældrenes fortællinger viste, hvorledes deres følelser og logiske ønske om afklaring omkring barnets sygdomstegn fik dem til at kontakte lægen. Hovedårsagerne til lægekontakterne var varighed eller forværring af barnets symptomer. Forældrene forsøgte at klare situationen selv, men hvis det ikke lykkedes for dem at få barnet til at have det bedre, opsøgte de information og råd hos lægen.

Forældrene tvivlede på lægens professionalisme, hvis de ikke kunne få deres oplevelser og forståelse af barnets sygdom til at stemme overens med lægens forklaringer og behandling. Især tvivlede de på lægens fagkundskab, hvis lægen slog barnets symptomer

hen med ordene 'det vil gå væk af sig selv', 'det er ingenting' eller 'det er en virus'. Forældrene formåede ikke at forstå lægens ræsonnement og konklusion på barnets almindelige sygdomstegn.

### *Konklusion og perspektivering*

Forældre opsøger lægen, når de føler sig overbebyrdede, bange og føler sig ude af stand til på forsvarlig vis at tage sig af det syge barn. De overvejer seriøst, om lægekontakt nu også er nødvendig i den pågældende situation. Imidlertid er forældre nødt til at træffe en beslutning omkring mulig sygdom hos barnet på basis af observation af barnets adfærdsændringer og mindre symptomer, en situation lægen er nødt til at anerkende. Forældrene føler sig afvist af lægen, hvis lægen ikke anerkender deres observationer af barnet og deres grund til at henvende sig. Forældrene betvivlede lægens faglighed hvis de misforstod lægens opfattelse og respons på barnets hyppige sygdomstilfælde. Hvis lægen har det for øje, er det muligt at forbedre kvaliteten af barn – forældre – læge konsultationer.



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## **15 Enclosures**

*Enclosure A: Literature search*

*Enclosure B: Diary*

*Enclosure C: Questionnaires*

*Enclosure D: Dropouts and questionnaires to the non-participating families*

*Enclosure E: Families chosen for interview*

*Enclosure F: Development of the questionnaires and diary and the pilot study*

*Enclosure G: Presentation*

*Enclosure H: Paper 1*

*Enclosure I: Paper 2*



## Enclosure A: Literature search

The first search for literature in this project was carried out in May 2001, with the assistance of a librarian from the Royal Library. The purpose of the project was a little different at that time. The focus of the project was families with children who had ear infections.

Searches were made in PubMed with combinations of the following words: Parents, medical records, diary, behaviour, child, preschool, all children 0-18, otitis media/epidemiology, epidemiological methods. Result: 819 titles, of which 69 were usable abstracts/articles.

After this a search was conducted in Win SPIRS, the article base, Clinical and Cochrane.

Then a librarian at Denmark's pedagogical library searched with several combinations in PsycInfo with the following words: Children, morbidity, illness threat, psychosocial conditions, parents' care, primary health care and child health care. Result: 135 articles of which 16 were usable abstracts/articles.

Despite the comprehensive search the result was rather meagre. It was particularly difficult to find articles where parents were the research focus. This resulted in an extension of the inclusion criteria for acceptance of the articles; if they dealt with parents and sick children, they were accepted.

During the following years search continued in PubMed with words such as parents, diagnosis, fever treatment. On-going search in relevant scientific papers was carried out as well. Additional literature by certain authors was searched for, and finally, colleagues and academic advisors recommended good articles to read or certain authors. In particular the academic advisors' literature recommendations were decisive for the choice of method literature and theory literature. Other very useful literature was found by perusing the literature lists of found articles.





# Enclosure B: Diary

| KALENDER NOVEMBER  |  | Dato                    | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29           | 30 |     |  |
|--|--|-------------------------|----|----|----|----|----|----|----|----|----|----|----|----|--------------|----|-----|--|
| <p>Rask: Sæt 0 ved alle dage, hvor dit barn er rask</p> <p>Sæt X ved alle de dage, hvor dit barn er sygt.<br/>           Ved antallet af X på de enkelte dage skal fremgå, hvor sygt du mener, at barnet er:<br/>           (X): ikke rigtig syg; ej heller rigtig rask<br/>           X: syg<br/>           XX: meget syg<br/>           XXX: alvorligt syg</p> |  |                         | 0  | 0  | 0  | 0  | 0  | 0  | 0  | 0  | 0  | 0  |    | X  | XX           | X  | (X) |  |
| <p>Sæt X ved alle de dage, dit barn har et eller flere af disse symptomer, også selv om du ikke har krydset i feltet 'syg' ovenover</p>  |  | Græder mere             |    | X  | X  |    |    |    |    |    |    |    | X  |    |              |    |     |  |
|  |  | Forkølet/snottet        |    | X  | X  | X  | X  |    |    |    |    |    |    |    |              |    |     |  |
|  |  | Spiser ikke som vanligt |    | X  |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
|  |  | Sover dårligt           |    | X  | X  | X  | X  |    |    |    |    |    |    |    |              |    |     |  |
|  |  | Påvirket vejrtrækning   |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
|  |  | Feber                   |    |    |    |    |    |    |    |    |    |    |    | X  | X            | X  | X   |  |
|  |  | Hoster                  |    |    | X  | X  | X  |    |    |    |    |    |    | X  | X            | X  |     |  |
|  |  | Kaster op               |    |    |    |    |    |    |    |    |    |    |    | X  | X            |    |     |  |
|  |  | Tynd afføring           |    |    |    |    |    |    |    |    |    |    |    |    | X            | X  | X   |  |
|  |  | Ondt i ørerne           |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
|  |  | Andet, skriv hvad       |    |    |    |    |    |    |    |    |    |    |    |    | Ondt i maven | X  |     |  |
|  |  | Ringet til egen læge    |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
|  |  | Besøg hos egen læge     |    |    |    |    |    |    |    |    |    |    |    |    |              | X  |     |  |
|  |  | Ringet til vagtlægen    |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
|  |  | Besøg hos vagtlægen     |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
| Vagtlægen kom hjem til os  |  |                         |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
| Besøgt speciallæge   |  |                         |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
| Besøgt sygehus   |  |                         |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
| Skriv, hvad lægen sagde, at barnet fejlede   |  |                         |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
| Panodil el. lign.  |  |                         |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
| Penicilin el. lign.  |  |                         |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
| Luftvejs/hoste medicin   |  |                         |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
| Andet, skriv navnet  |  |                         |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
| <p>Sæt X ved de dage, hvor du har været bekymret for barnet</p>  |  |                         |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |
| <p>Sæt X ved de dage, hvor du har haft problemer med at få passet dit syge barn</p>  |  |                         |    |    |    |    |    |    |    |    |    |    |    |    |              |    |     |  |

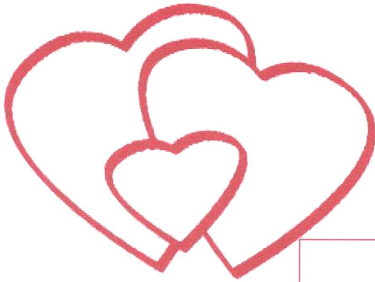
**EKSEMPEL**

Virus infektion

Ondt i maven



## Enclosure C: Questionnaires



### Spørgeskema til undersøgelsen "Forældre til småbørn, der ofte er syge"

#### **Vejledning:**

- Sæt venligst kryds ved hvert spørgsmål, ud for det svar, som passer bedst.
- Hvis du bor alene med barnet, behøver du ikke nødvendigvis at udfylde de spørgsmål, som er rettet til begge forældre.
- Hvor der står mor og far, menes barnets biologiske mor og far.
- Hvis du går i stå ved besvarelsen af et enkelt spørgsmål, så gå hellere videre til næste, frem for helt at opgive at udfylde skemaet.

## Det første spørgsmål handler om pasning af jeres barn

### 1. Hvor bliver barnet passet om dagen

Kun et svar

- I vuggestue .....
- I dagpleje .....
- I hjemmet .....
- I anden form for institution .....

### 2. Hvis barnet bliver passet uden for hjemmet

Hvor gammel var barnet da det startede ..... Måneder gammel

Hvordan er barnets trivsel i pasningen .....  God  Nogenlunde  Dårlig

## De følgende spørgsmål drejer sig om jeres barns helbredstilstand

### 3. Får barnet medicin regelmæssigt eller ved særlige symptomer

(Vitaminpiller medregnes ikke)

Ja .....

Hvis ja, skriv hvilken .....

Nej .....

### 4. Hvor mange gange har barnet i alt siden fødslen været syg indtil nu

Skriv antal

(Hvis 0 har barnet aldrig været syg)

\_\_\_\_\_

**5. Har barnet haft en eller flere af følgende symptomer.**

(Tidsperiode : fra fødslen af og indtil nu).

Gerne flere svar

- Feber .....
- Hoste .....
- Kastet op .....
- Tynd afføring .....
- Hududslet .....
- Hvæsen og / eller piben fra brystet .....
- Øresmerter .....
- Forkølelse, snottethed, løbende næse .....
- Betændelse i øjnene .....
- Urolig søvn .....
- Overfølsomhed/allergisk reaktion .....
- Andet, skriv hvad \_\_\_\_\_

**6. Får barnet naturmedicin regelmæssigt eller ved særlige symptomer**

Ja .....

Hvis ja, skriv hvilken \_\_\_\_\_

Nej .....

**7. Hvor mange gange har barnet i alt siden fødslen fået penicillinbehandling**

Skriv antal

(Hvis 0 har barnet aldrig fået penicillinbehandling)

\_\_\_\_\_

**8. Har barnet haft en eller flere af følgende sygdomme**

Gerne flere svar

(Tidsperiode : fra fødslen af og indtil nu).

- Forkølelse .....
- Lungebetændelse .....
- Mellemørebetændelse .....
- Astmatisk bronchitis .....
- Feberkrampe .....
- Eksem .....
- Maveinfektion (diarre og/eller opkastninger) .....
- Anden, skriv venligst \_\_\_\_\_

**9. Hvor mange gange har barnet på grund af sygdom været til behandling hos følgende**

Antal gange

(Skriv 0 hvis barnet ikke har været til behandling hos pågældende behandler)

- Praktiserende læge ..... \_\_\_\_\_
- Praktiserende speciallæge ..... \_\_\_\_\_
- Vagtlæge ..... \_\_\_\_\_
- Indlagt på børneafdeling ..... \_\_\_\_\_
- Zoneterapeut ..... \_\_\_\_\_
- Andre behandlere uden for det almindelige sundhedsvæsen ..... \_\_\_\_\_

**10. Har barnet søskende, som ofte har været syge**

- Ja .....
- Nej .....

**11. Hvordan vurderer I jeres barns almindelige helbredstilstand**

Kun et svar

- Virkelig .....
- God .....
- Nogenlunde .....
- Dårlig .....
- Meget dårlig .....

Næste spørgsmål er om jeres bolig

**12. Hvordan bor I**

Kun et svar

- I etageejendom .....
- I kæde-, gård- eller rækkehus .....
- I fritliggende enfamiliehus .....
- I to, tre- eller firefamiliehus .....
- På landejendom .....
- Andet, skriv hvordan I bor \_\_\_\_\_

De følgende spørgsmål handler om jeres familie

**13. Alder på forældrene**

- Mor .....  Skriv alder
- Far .....  Skriv alder



**14. Hvem bor barnet sammen med**

Kun et svar

Barnet bor sammen med begge forældre .....

Barnet bor fortrinsvis sammen med moderen .....

Barnet bor fortrinsvis sammen med faderen .....

Barnet bor lige meget sammen med moderen og faderen .....

Anden boform, skriv \_\_\_\_\_

**15. Antal hjemmeboende søskende, som bor sammen med barnet**

Ingen hjemmeboende søskende .....

|                          | Alder | Dreng                    | Pige                     |
|--------------------------|-------|--------------------------|--------------------------|
| Ældste bror/søster ..... | _____ | <input type="checkbox"/> | <input type="checkbox"/> |

|                              |       |                          |                          |
|------------------------------|-------|--------------------------|--------------------------|
| Næstældste bror/søster ..... | _____ | <input type="checkbox"/> | <input type="checkbox"/> |
|------------------------------|-------|--------------------------|--------------------------|

|                             |       |                          |                          |
|-----------------------------|-------|--------------------------|--------------------------|
| 3. ældste bror/søster ..... | _____ | <input type="checkbox"/> | <input type="checkbox"/> |
|-----------------------------|-------|--------------------------|--------------------------|

4 eller flere ældre søskende , skriv her køn og alder \_\_\_\_\_

**16.**

Angiv her en eventuel E-mail adresse som jeg må bruge, når jeg får brug for at kontakte jer i forbindelse med undersøgelsen \_\_\_\_\_

## Til sidst nogle spørgsmål om beskæftigelse og uddannelse

### 17. Hvilken grundskole har I

|  | Mor<br>Gerne flere svar  | Far<br>Gerne flere svar  |
|--|--------------------------|--------------------------|
| 9-10 års skolegang .....                       | <input type="checkbox"/> | <input type="checkbox"/> |
| Student-, HF- eksamen ( inkl. HHX, +HTX) ..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Andet (herunder udenlandsk skole) .....        | <input type="checkbox"/> | <input type="checkbox"/> |

### 18. Har I fuldført en erhvervsuddannelse

|  | Mor<br>Gerne flere svar  | Far<br>Gerne flere svar  |
|--|--------------------------|--------------------------|
| Ja, specialarbejder .....  | <input type="checkbox"/> | <input type="checkbox"/> |
| Ja, basisår i EFG-uddannelse eller handelsskolernes grunduddannelse (HG) ..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Ja, lærlinge-, EFG- eller HG-uddannelse .....                                  | <input type="checkbox"/> | <input type="checkbox"/> |
| Ja, anden faglig uddannelse .....  | <input type="checkbox"/> | <input type="checkbox"/> |
| Ja, kort videregående uddannelse, under 3 år .....                             | <input type="checkbox"/> | <input type="checkbox"/> |
| Ja, mellemlang videregående uddannelse, 3-4 år .....                           | <input type="checkbox"/> | <input type="checkbox"/> |
| Ja, lang videregående uddannelse, over 4 år .....                              | <input type="checkbox"/> | <input type="checkbox"/> |
| Ja, anden uddannelse   |                          |                          |
| Skriv hvilken (mor) _____  |                          |                          |
| (far) _____  |                          |                          |
| Nej, er i gang med en uddannelse .....   | <input type="checkbox"/> | <input type="checkbox"/> |
| Nej, ingen uddannelse .....  | <input type="checkbox"/> | <input type="checkbox"/> |

**19. Jeres erhvervmæssige situation i øjeblikket**Mor  
Gerne flere svar

Far

Gerne flere svar

- |                                     |                          |                          |
|-------------------------------------|--------------------------|--------------------------|
| Selvstændig erhvervsdrivende .....  | <input type="checkbox"/> | <input type="checkbox"/> |
| Funktionær eller tjenestemand ..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Faglært arbejder .....              | <input type="checkbox"/> | <input type="checkbox"/> |
| Specialarbejder .....               | <input type="checkbox"/> | <input type="checkbox"/> |
| Ikke-faglært arbejder .....         | <input type="checkbox"/> | <input type="checkbox"/> |
| Førtidspensionist .....             | <input type="checkbox"/> | <input type="checkbox"/> |
| Arbejdssøgende .....                | <input type="checkbox"/> | <input type="checkbox"/> |
| På bistandshjælp .....              | <input type="checkbox"/> | <input type="checkbox"/> |
| På sygedagpenge .....               | <input type="checkbox"/> | <input type="checkbox"/> |
| Studerende eller i lære .....       | <input type="checkbox"/> | <input type="checkbox"/> |
| Forældreorlov .....                 | <input type="checkbox"/> | <input type="checkbox"/> |
| Andet, skriv _____                  |                          |                          |

**20. Skriv med jeres egne ord, hvad jeres stillingsbetegnelse er**

(Nøjagtig angivelse: F.eks. butiksejer, ikke blot arbejder i butik, tømrersvend, ikke blot tømrer, kontorchef hos DSB, ikke bare kontorchef)

Mor \_\_\_\_\_

Far \_\_\_\_\_

**21. Spørgeskemaet er udfyldt af**

Kun et svar

- |                          |                          |
|--------------------------|--------------------------|
| Mor .....                | <input type="checkbox"/> |
| Far .....                | <input type="checkbox"/> |
| Begge i fællesskab ..... | <input type="checkbox"/> |
| Andre voksne, hvem _____ | <input type="checkbox"/> |

I er nu igennem alle spørgsmålene, og jeg vil bede jer om at se spørgeskemaet igennem for at sikre, at I ikke er kommet til at springe nogle sider over. I er meget velkomne til at skrive kommentarer på denne side.

**Mange tak for hjælpen**



## Enclosure D: Dropouts and questionnaires to the non-participating families

Dropouts: Seven infants and their families did not complete the data collection: Four families did not return the study diary, one family did not read or speak Danish, one family moved from Denmark and one father of an infant died during the data collection period.

Non-participating families: 117 parents did not respond to the letter. Two families left Frederiksborg County during the recruitment period; 76 parents did answer the invitation letter, but did not want to participate in the study. They answered a questionnaire addressing their reasons for not participating.

Answers to questions addressed to the non-participating families were distributed as follows:

1. As I am/ We still are very 'new' parents, we do not have the time or energy to participate: 32
2. I / We do not find the investigation relevant to us: 10
3. I / We have difficulty in reading Danish: 3
4. I / We already participate in a lot of investigations: 20
5. I / We do not think that we have anything with which we can contribute: 14
6. I / We do not participate in investigations: 16
7. No comments: 11

The questionnaire was answered by 76 persons. The parents were supposed to set a cross in one question but in 16 cases the parents ticked off several questions; twelve parents ticked off 2 questions; two ticked off 3 questions; one answered 4 questions; and one parent all 6 questions.

### Discussion

The majority of the parents answered that they lacked time, which is understandable as most had just had their first baby. The reason for the high response rate to question 2

"not relevant to us" and question 5 "nothing with which we can contribute" might lie in the unfortunate wording of the information letter. During the subsequent telephone call to the participating parents, it became clear that the participants had been in doubt whether the investigator wanted only the participation of parents of infants who had often been ill.

## Enclosure E: Families chosen for possible interview

Participating families fell into the categories below. All the participating families got an identification number and the identification numbers of interviewed families are highlighted:

*Table 3*

| <i>Participating families</i>   | <i>Identification numbers</i>                          |
|---|--|
| Infants with several illness episodes with/without physician-attended visits: | 087, 109, 149, 020, 156, 021, 091, 069, 154, 137, 141. |
| Infants with an episode of pneumonia or acute otitis media:                   | 041, 144, 129, 122, 045, 157.                          |
| Parents with illness experience from older siblings:                          | 192, 134+135 (twins), 149.                             |
| Infants without significant episodes of disease but with anxious parents:     | 017, 078, 014, 024, 136, 115.                          |
| Healthy infant without older siblings:  | 194, 057, 079, 090, 022, 139.                          |
| Infants who were prescribed medicine:   | 080, 063, 081, 185, 112.                               |
| Infants whose parents had infant-caring problems:                             | 065, 021, 154, 155.                                    |
| Illness episode as newborn:   | 072, 025.  |
| Large age difference between the parents:                                     | 191, 163, 030, 107, 123, 142.                          |
| Immigrant:  | 169, 098, 113, 165.                                    |



## Enclosure F: Development of the questionnaires and diary and the pilot study

The questionnaire was developed in collaboration with two co-writers on the basis of questionnaires used by the Danish Institute for Clinical Epidemiology<sup>6</sup>. This questionnaire contains a number of questions and it had to be decided which questions should be reused.

The questionnaire raised issues concerning nurseries, the infant's state of health, the family and its residence, brothers and sisters, parents' education, vocational training/education and work.

The diary was developed by RE and inspired by the work done on a questionnaire used for another study (not published). The diary was a one-month calendar with 14 days on each page. The diary was meant to be kept on a daily basis, with parents ticking off a number of questions each day addressing the following issues concerning the infant: healthy or ill, symptoms of illness, physician visit, medication given, days of parental worries, and problems with infant care.

The questionnaires and the diary were tested by a group of parents in a general group practice in Allerød, a city in Frederiksborg County, in November 2001, and they seemed to function well.

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<sup>6</sup> DIKE: Dansk Institut for Klinisk Epidemiologi.

## Enclosure G: Presentation

### *Information to the parents*

The families were informed about the project several times during the study period. Correspondence was most intensive during the data collection months, but they also received information letters about project progress during the subsequent years. Also, a journalist interview with RE was printed in a health magazine distributed to all Danish households. Finally, interviewed families received the first published Paper and the rest of the participating families got a reference to the Paper.

### *Presentation of results*

The study has already been presented on several occasions.

The scientific discourse community: One Paper has been published in *Scand J Prim Health Care* and another Paper has been submitted to *Family Practice*. The study has also been presented at the following conferences: Wonca Florence 2006; poster, Nordic Conference of General Medicine in Trondheim and Stockholm 2005; poster, SFAM's Höstmöte (autumn meeting) in Lund 2004; oral presentation and at Wonca, Amsterdam 2004; oral presentation.

The politicians: The study has been presented as oral presentations both in 2004 and 2005 at a special research meeting with the mayors of several counties, the vice-chancellor of the University of Copenhagen, the manager of the university hospitals in Copenhagen and the main county hospital of Frederiksborg county.

The parents: All the participating parents will receive the Danish resumé of the PhD thesis and an offer to receive the entire PhD thesis. Some parents have already asked for the thesis and they will receive it when it has been published.



## Enclosure H: Paper 1:

Ertmann Ruth K, Söderström Margareta, Reventlow Susanne. Parents' motivation for seeing a physician. *Scand J Prim Health Care* 2005; 23:154-8.

















## Enclosure I: Paper 2:

Ertmann Ruth K, Reventlow Susanne, Söderström Margareta. Parents' situated experience and knowledge of their child's illness signs – a key to better doctor-patient communication. *Submitted.*



Family Practice

Parents' situated experience and knowledge of their child's illness signs– a key to better doctor-patient communication

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## **Abstract:**

**Background.** Parents with ill children are frequent visitors in primary care. Absence of explicit signs of illness may occasion misunderstandings in doctor-parent communication.

**Objective.** To uncover parents' situated experience and knowledge of their child's illness signs and to discuss possible misunderstandings in parent-physician communication.

**Methods.** Qualitative interviews with 20 families strategically selected from a birth cohort from the Frederiksborg County. The cohort counted 194 of 389 children who were followed prospectively from the age of 9 to 12 months by diary (January-April), and retrospectively from birth to the age of 9 months by questionnaire.

**Results.** The parents' main concern was whether observed behavioural changes in their child were signs of illness; specifically what these signs meant and how serious they were. The parents questioned the physician's expertise if their concern was at odds with the physician's interpretation and response, in particular if the physician said that the 'signs will disappear' , 'it's nothing' or 'it's virus'.

They failed to understand the physicians' rationale and conclusions about the nature of the observed signs.

**Conclusions.** Parents are aware of the importance of their ability to discover and interpret signs and symptoms of their child correctly and they express a certain kind of distress when physicians minimize or dismiss their observations. Parents misunderstand commonly used medical vocabulary used by themselves and by the physician.

**Key Words:** general practice, parents' perspective, lay people, illness definition.

## Introduction

Conceptions of sickness and health are socially constructed as are the explanatory models to which people resort to explain illness and poor health and to identify appropriate treatment<sup>1;2</sup>. The process of defining oneself as being ill is integrated into these conceptions and varies among individuals, families, cultural groups and social classes. The process includes subjective experience such as observation of changes in body function and appearance, emotional states and unpleasant symptoms like pain<sup>3</sup>. Another perspective on illness is that illness is framed by peoples' everyday living as<sup>7</sup> situated knowledge<sup>4;5</sup>. How these processes of defining illness work when the sick person is a child remains a poorly investigated area.

Parents must necessarily rely on the child's signs which are filtered through the parent's mind. When communicating their interpretation of the child's signs to a physician, the parent's situated knowledge may clash with the physician's biomedical focus<sup>3</sup>. Patients and physicians live in different conceptual worlds and often have little knowledge of the extent to which their conceptions differ, or why they differ<sup>6-9</sup>. However, to understand parents' dissatisfaction, we must move beyond the level of the dialogue<sup>10</sup>. The aim of this study is to uncover parents' situated knowledge of their child's illness signs and to discuss possible misunderstandings in parent-physician communication.

## Methods

This study is based on interviews with 20 families strategically selected from a birth cohort within the Frederiksborg County (Fig. 1). The cohort included 194 of the 389 children born between 1 and 28 February 2001. The cohort was followed prospectively from the age of 9 to 12 months by diary (January-April), and retrospectively from birth to the age of 9 months by questionnaire. The families were selected on the basis of diary information. The selection procedure covered the following steps: first, all the diaries and the questionnaires were read and split into a group with children having had several illness episodes and another group with children with no or few illness episodes. The first group

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<sup>7</sup> Situated knowledge can be explain as e.g. parents who used to manage the care for their fever child at home wanted a physician's examination when for instance they were on holiday and thus in different settings far from home.



of diaries was re-read and families were selected that seemed to cover a wide range of experience:

- Children with several illness episodes with/without physician-attended visits.
- Children with an episode of pneumonia or acute otitis media.
- Parents with illness experience from older siblings.
- Children without significant episodes of disease, but with anxious parents.
- Healthy children without older siblings.
- Children who were prescribed medicine.
- Children whose parents had child-caring problems.
- Illness episode as newborn.

Several families from each group were identified. They were chosen at random and phoned by the author. If a family did not answer the telephone, the next family in the same pile was phoned. Semi-structured approximately 60-min interviews were conducted in the informants' homes during the spring of 2002. The interview guide was tested in a pilot interview and we found no reason to change it (Table 1). Parents were encouraged to talk openly about their experience with their ill child. Most covered the main points in the interview guide themselves. Mothers participated in all interviews, fathers in ten. Interviews were taped and transcribed verbatim.

The texts were systematically analysed according to Giorgi's phenomenological approach as described by Kvale <sup>11</sup>: 1) All interviews were collected and read to obtain an overview; 2) units of meaning were identified (all sentences where the parents mention the physician) and coded according to the parent's experiences with the physician; 3) condensation and structuring of meaning within each coded group was performed; 4) the contents of situations/elements where the informants told about experience of satisfaction/dissatisfaction with the consultations were summarized into dilemmas around signs of illness (how dangerous is fever), inspired by the explanatory models of Kleinmann, Helmann and situated knowledge of Gannik <sup>2-4</sup>. In general, parents expressed satisfaction with the physician examination, information and treatment. Negative statements were chosen for further analysis in order to allow analysis of communication problems and doctor-parent disagreement of opinion. The interview focused on the parents' experience with the physicians, and data do not reflect precisely what the

physician told the parents. The study abided by the principles of the Helsinki-declaration and was approved by the local ethical committee.

## **Results**

The results centred on the dilemma faced by the parents when they perceived a discrepancy between their understanding and interpretation of signs of illness in their child and the physician's handling of these signs

### *Signs identification and meaning*

Concern over possible illness was a central concern in the parents' account of their child's signs. Parents described that they noticed unusual behaving: the child was moody, just wanting to hang on the parent's shoulder, did not eat as much as usual, seemed to be apathetic or was crying inexplicably (Table 2). They considered these behavioural changes could be signs of illness or if the child had just become overtired. If the signs persisted or additional signs emerged, they started to wonder if something was wrong and if their child might be ill and they considered what to do (Family 063).

Parents often found it difficult to determine if a sign was, indeed, a sign of a problem. Some parents told they that had trouble interpreting the signs (Family 122a); in particular, it could be difficult to estimate their seriousness. Fever was recognized by all as a sign of illness, but precise interpretation of the significance of the fever remained an issue. High fever, > 39 C, frightened the parents, producing images of both fever cramps and meningitis. But, on the other hand, they also told that they grew with the challenges of coping with an inconsolable child and handling its signs (Family 045a).

Parents found it difficult to determine if and when signs of illness required a professional opinion. Some parents reacted quickly to signs, just making an appointment with the physician. Parents either failed to see why they should wait (Family 024a), or they reflected carefully on the signs and concluded that they wanted to nip the illness in the bud, having the child eligible for an early treatment (Family 021a). Other parents wanted to know what was the matter with their child. They found that it was easier to care for

their ill child if the signs were explained to them or they got a diagnosis. If medication was prescribed, they felt that they had a feeling of power over both the symptoms and the healing process. Parents prioritized quick recovery in order to get the family back to its normal routines, which included that they could return to work.

They also occasionally merely wanted the physician to take action, even if no effect was achieved, simply because action was preferred to inaction (Family 122b). On the other hand, the prescription of antibiotics was accompanied by parental reflections. Parents described antibiotics as a two-edged sword: on the one hand, they welcomed antibiotics because they expected that the child would recover more quickly; but, on the other hand, they were afraid that antibiotics would be harmful to the child, especially if the child received antibiotics too often. (Family 087)

Experienced parents<sup>8</sup> were more relaxed about signs. They had often waited for several days, observing the signs before physician attendance. These parents reported that they often had a reasonable bid for a diagnosis (Family 021b). In such situations, the child was often prescribed medicine and the parents made the appointment for a discussion of the situation and to be confirmed in their observations of the signs and their conclusions. In these situations, the parents were quite satisfied with the dialogue with the physician. Some also told that it became a kind of game to them to figure out the meaning of the signs of the illness. Sometimes they had formulated a preliminary hypothesis about the cause of their child's signs.

However, even experienced parents reported being in doubt about how to balance the duration of the signs and their perception of their level or seriousness against the urgency of contacting a physician to ascertain the real importance of the signs (Family 109).

The parents emphasized that it lay squarely within their responsibility to decide what was the right thing to do and when it was time to contact the physician, even if it was difficult. Parents of children with recurrent symptoms reported asking numerous questions to improve their coping ability and mentioned that it was most frustrating to get no answer (Family 045b).

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<sup>8</sup> Experienced parents: parents who have older children.

### *Signs – the centre of the doctor-parent dialogue*

The parents displayed varying degrees of difficulty in interpreting and understanding the signs and the physician's response in the light of their presentation of these signs.

This difficulty was apparent in the manner in which the parents reported their conversation with the physician; a manner that testified to their difficulty in understanding and accepting the physician's thoughts and actions and in understanding the terminology used by the physician to explain the meaning of the signs and illness

Disagreement with the physician's way of handling the child's signs of illness produced a conflict irrespective of the child's symptoms, e.g. gastric pain, recurrent colds or prolonged loose stools. The parents described how they felt that the physician did not take these signs seriously, which produced a feeling that (s)he did not value their observations.

They were particularly worried when the physician just said that "the signs will disappear" or that "the signs are nothing" (Family 146). Parents' response to physicians producing such utterances depended on the context in which the utterance was produced. In the worst case the parents thought that the physician could not find out what was wrong with the child, and as a consequence they had to find another physician. If the physician said that the signs were yet too few or ambiguous, parents felt that they were causing the physician inconvenience and they took responsibility for this (Family 134)

If the physician prescribed medication in the absence of a clear explanation, the parents became confused about the physician's working principles (Family 024b). They explained that they failed to understand why the physician did not include the reported signs in an attempt to ascertain the cause of the disease and make a diagnosis. They experienced that the physician was merely treating a symptom without caring about its cause

Another remark was that the parents failed to understand how the physician could order paracetamol without examining the child. They explained that they expected paracetamol to eliminate the signs of illness, signs the physician should see in order to arrive at a diagnosis (Family 034). If signs of a possible illness were persistent or the child did not seem to thrive or continued to have signs according to the parents, they began to think that something was wrong with the child's immune system. In those consultations, they explained that they felt like fighting with their backs to the wall, and a way out could be to

force changes in the treatment or a referral to another specialist or to the children's hospital (Family 154a).

The parents had trouble understanding the word and the explanation "virus". In this investigation they were asked directly about the meaning of this particular word and some of the parents responded to the question, saying; "something nothing could be done about", "something like bacteria, but not dangerous". The parents told that they questioned the physician's expertise when the sign was dismissed and simply called a virus. They described that they felt lost, doubting that everything could be a virus, and that 'the virus explanation', in their view, appeared to be a nice, convenient explanation (Family 154b). The experienced parents told that they could accept the virus explanation, provided they had a good dialogue with the physician, which included that they had the feeling that the physician was listening to their observations of the child's signs (Family 122c).

### **Box 1. Signs**

**Family 063:** "you just know when your child is really sick; that she is not just whimpering; that she is not just a cry-baby; that it is not an unreasonable snivelling; you do feel and can see that she is not well; reaches for her ears and hangs her head; and if she can just sit and lean on me, just lean on me then she is sick; then it is not only because; if nothing else interests her, then she is sick"

**Family 122a:** "was it something or was it not "

**Family 045a:** "the limit is moving all the time....; 39 at that time we thought she was very sick, and at last she had 41,8 you know, so at that point we found out that's when you are really sick "

**Family 024a:** "why should I wait, I might just as well;....exactly something like a rash or like"

**Family 021a:** "I can't remember for how long time he had it (Fever/Pneumonia), but you see, I kind of caught up with it so the Penicillin could quickly make the fever fall "

**Family 122b:** "you desperately try to find some kind of treatment, so you can go back to work; there are so many things, it is not only the sick child;.... also, the physician could just try to do something, but you might as well ride out the storm"

**Family 087:** "penicillin... well, it does have an effect and makes you feel much better in a day or two when you start taking penicillin, and of course that's pretty cool in some way that they are

getting so much better, but I don't like it, there is something unnatural about it "

**Family 021b:** "I sort of share with them what is wrong...no reason to call the doctor if it is only high fever...when I call I have already made up my mind that they need either a Panodil or something else"

**Family109:** "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"

**Family 045b:** "there must be a reason why they get it all the time; in example X it was something with her ears and in example Y it was something with her tonsils"

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

**Family 134:** "Virus – then you have inconvenienced them again (physician didn't approve the signs"

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

**Family 034:** "before I start giving Panodil, it might be better, especially because the pain is sometimes eased; then it is kind of difficult, .. so it is difficult to call on your doctor and say (If signs disappearing).. it might be better that; it wasn't the professional attitude, I might have been told to wait until next day and contact my own doctor"

**Family 154a:** "it beats me that, as parents, 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" (disagreement about the seriousness of the signs)

**Family 154b:** "Virus, it is a phrase used incessantly by physicians; it can't be right that everything can be a virus... a sore throat, it is just a virus. It is such a nice explanation. You don't have to study for so many years to become a physician, you may just as well swab yourself with those colours aren't we"

**Family 122c:** "if the physician takes the time to listen, then you may accept the answer that nothing can be done, and they will get through it "

## **Discussion**

The study showed that parental conceptions of sickness and health are situated, socially constructed concerns that form explanatory models to which parents resort to explain their child's illness and that such models shape illness definitions and influence the doctor-parent communication

The study design allowed parents with varied experiences to be singled out for interview <sup>12</sup>. Both parents participated in 50% of the interviews, which may indicate that they found the study to be important. The interviewer was a general practitioner, which may have made parents feel at ease and confident, but it could also have caused them to focus too much on the medical aspect. Only 50% of the invited cohort participated; maybe because of the name of the study "Parents' to small children with recurrence illness". Some of the participating parents' explained that they did not see their child as particularly ill.

### *Lay people's illness definitions*

This study shows that the parents are very sensitive to changes in the child's normal behaviour during daily activities and play. Their sensitivity is probably fundamentally human, connected to staying healthy and being able to care for the helpless child. Staying healthy as a central life event is cited as: "Lay people's view of health integrated healthiness as something to strive for. Health might be considered achieving harmony and equilibrium in daily life; and healthiness provides the freedom to live life to its fullest" <sup>13</sup>. The parents perceived health and possible illness as a continuous process, just a part of normal life, which they acted on. Helmann supported this, stating that the parents have to react when signs manifest themselves, because their illness definition is rooted in a social context, e.g. how the child was sleeping, and in a bio-medical context, e.g. occurrence of fever or nasal secretion <sup>3</sup>.

Parents and physicians were basically facing the same problem of how to ascribe meaning to signs heralding minor and serious illness that are minimal or non-existing. Parents felt that they had to react and that the physician failed to acknowledge the purpose of the consultation unless the child was really ill, even if they could not possibly know whether the disease would develop into serious illness.

This study showed that a particular situation arose when parents were dealing with a child who was more often or more severely ill than "a normal child". In this situation the communication took a turn if parents felt that the physician did not understand them. The parents then intensified their search for an explanation, asking numerous questions in an attempt to make the illness episode connect with their lives <sup>14</sup>.

### *Reactions to the signs*

The parents' early reaction to small signs seemed useful in many ways. They sought first to determine the nature of the illness and then to start treatment to re-establish normality in their daily lives. The parents' ambition to have the child's health restored as quickly as possible can be interpreted as an expression of the priorities of modern working life: parents' lives are rooted in working communities where responsibility and job performance enjoy high priority <sup>15</sup>.

If the signs continued, they started fearing something was wrong with the child's immune system and that it would affect the child's development and future health. This kind of concern has also been described in other studies <sup>16</sup>. A recent study supported these worries, because it showed that recurrent infections seemed to continue up into the school years <sup>17</sup>, which may have an adverse effect on old age mortality <sup>18</sup>. It may therefore be hypothesized that the health care system is not good enough at handling children with recurrent infections

### *Lay people's misunderstandings about how physicians works*

The emotional response of the parents contrasted with the rational response of the physician who acknowledges the purpose of letting the signs become manifest or disappear as a result of the body's defence. We found that the parents' disrespectfulness towards the physician was rooted in misunderstandings about how the physician handled the parents' illness story. However, investigations show that the physician uses cues from the child's parents in his decision-making about acutely and severely ill children <sup>19</sup>.

Particularly vexing to the parents were situations where they failed to make sense of the physician's vocabulary and explanations, e.g. if the physician ascribed the illness to 'a virus' or said that 'it is nothing' <sup>20-22</sup>. This would, for example, be the case when the



parents knew that the child was ill and felt that they might as well have stayed at home because they felt that it did not help to consult the physician. A single positive dimension of the 'virus explanation' was that the parents could avoid the use of antibiotic. Parents surprisingly did not think of virus infection as something dangerous, even if the media have reported several examples of aggressive viral disease like HIV, Ebola virus and avian influenza.

### *The medical task*

The physician enjoys a unique position as a healthcare provider, but some parents voiced concern because they felt that they could not draw on this resource in an atmosphere where they felt that they were not welcome. Experienced parents valued the knowledge they obtain from the visits to physicians. They obtained knowledge that could be used later for managing the care for their ill children without physician attendance, as also reported by others<sup>23</sup>. Acceptance of the parental contribution could be a precondition for improving parental knowledge of illness in children and help them improve their coping strategies and practices<sup>24</sup>. It would also seem to be a precondition for successful verbal interaction where the physician and the parents establish a common ground. As a means of establishing such common ground, the physician should explain which signs were used for assessing the illness, how signs were interpreted, the intervention threshold and how the anamnesis and the result of the examination of the child were interpreted<sup>25</sup>. Furthermore, the physician should explain the meaning of the word 'virus', e.g. "One of the common micro organisms that small children have to deal with in order to stimulate their immune system".

Table 1. Interview guide

|   |
|---|
| Tell me about a time when your child was ill, for example the last time?    |
| Do you do anything specific to make him/her feel better when (s) he is ill? |
| What worries you most, when (s) he is ill?                                  |
| When do you consult the physician with your ill child?                      |
| Do you have positive or negative experiences with the physician?            |

What are your thoughts and experiences when giving your child medication?  
 Do you have any ideas why your child becomes ill?  
 What do you think makes your child well again?  
 What about the other children and your relationship with your spouse?  
 How do you manage caring and your everyday activities when your child is ill?  
 Do you have any experience with alternative and complementary medicine?  
 Looking back, is there anything you would wish were different?  
 Anything else you want to tell?  
 What did you think of the interview?

Table 2. Children’s Signs of Illness

Downhill - feel something is wrong - a bit weak - to be unwell - did not breast-feed so much - she is sensible of - to be rotten - attack - dead-beat - did not eat so much - can’t get them to take liquid - wouldn’t walk or crawl - apathetic - remain passive - don’t put on weight - not to be oneself - feel a change - just wants to slouch - muddle-headed - difficult breathing - a lot of rattle in the chest - one can hear when it is there - shortness of breath - breath frequency raised - coughing- rattle in the throat - sounds as a sea lion - sounds as a pair of bellows - he choked on it - could hardly eat - big tonsils - two white sponges - not eaten - swollen glands - throwing up - explosive vomiting - obstipation - acid pooh - wound behind - bad stomach - diarrhoea - fever - high fever - piping hot fever - fever cramp - burning hot - couldn’t hear - no proper language - no language progress - puts hands to his ears - choke - snotty, first white then green - constantly running nose - very apathetic - can’t make contact - limp - distant - absent - losing contact - roll his eyes - just looking into the air - blood running - flow from the ear - pour out with infection - curl up the legs - a violent fit of weeping - awful pain - crying - tore his gum - prolonged fits of crying - violent crying - can’t find peace - signal when you touch her - wouldn’t lie on his back - wouldn’t stretch his legs - has a rash

Table 3. Cause

A lot of new experience (new day-care) - Stress - New impressions - General influence - Draught from windows - Ear pressure from flying - Catch a cold - Too much clothes - Damp house - Something grows in the damp - Poor indoor climate - Wall-to-wall carpet - Small rooms (more dust) - Just something - Bombing with dust and scales from a cat - Wood burning stove - Old house with cold floors - Moist neighbourhood with marshes - Air-condition - Concrete houses - Infection spread by other children - Institutions - Infection spread by siblings - Smoking - Parents infected at work - A lot of contact to other people - Pollution of the streets ----

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