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Research Article

I Expect the Doctor to Listen– It Could be Something Uncommon- Parents' Recall of a Factual Worrying Infection Episode of their Preschool Child

Adriana Maria Ioan and Margareta Söderström

[1]*Department of Public Health, University of Copenhagen, Denmark*
[2]*Department of Respiratory Medicine and Allergology, Skåne University Hospital, Sweden*
[3]*Health Care Centre of Linero/Östra Torn in Lund and the Primary Health Care Region Skåne, Sweden*

***Corresponding author**

Adriana Maria Ioan, Department of Respiratory Medicine and Allergology, Skåne University Hospital, Inga Marie Nilssonsgata 46, plan 2, 21428 Malmö, Sweden; Tel: 4640336925; Email: AdrianaMaria.Ioan@skane.se

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Abstract

Objectives: To explore parents' dread related to their ill child and elucidate anxious parents' attitudes.

Methods: Qualitative study using answers in a questionnaire inquiring for parental memory recall of a worrying episode of infection of their preschool child.169 preschool children 3-5 years of age from nine preschools in Malmö, Sweden, participated in spring 2009.

Results: A total of 117/169 (69 %) shared their concerns. 20 % stated they had never experienced an infection episode that worried them. Remembered episodes occurred equally often when the child was newborn (0-3 months of age), >3-12 months and older (>1-5 years of age).Common symptoms created anxiety, such as fever, coughing and vomiting. Uncommon diseases, namely ileus, fever seizures, Henoch-Schönlein purpura, hip arthritis were also reported. The most anxious element was, not knowing what disease the child had. Parents wanted to see a doctor when the child was feverish and apathetic, but also simply just for being examined. They had to persuade medical staff, begging for investigations and pointing out that something was wrong with their child. Parents knew where to seek medical help, finding their way into the doctor, inspite of guarding nurses.

Conclusions: GPs ought to, besides updating their knowledge on common childhood diseases, learn more about the common of the uncommon diseases. Still, listen to the parents´ concern seems to be the wisest thing to do, capturing hints of a severe or an uncommon disease. As fever still remains the perpetuate reason to medical encounter, fever has to be demystified by health professionals.

INTRODUCTION

It can be difficult for parents' to know when a child of their own is so ill, that it needs medical help. Some children are often ill, while others seldom are. Parents thus have different experiences of their child being ill, and may have difficulties assessing the severity of the disease and consequently become concerned [1-3]. The most common childhood illnesses are still infectious diseases [4]. In the western world, today, most parents are well educated and medical advices are available through Internet [5-7].

In the Nordic countries, all children have access to a General Practitioner (GP). GPs in Sweden do not have a gate keeping function and parents can choose to see a paediatrician at the hospital as well for everyday illnesses. Even if parents carefully consider the decision to consult a physician [8], they often already have initiated a treatment of the ill child before they seek medical help [1,6,9]. Better understanding, by the health professionals, of parents' concerns may promote the communication with parents, making them feel satisfied and understood [2,4].

Parents' fears and anxiousness when their child was ill have been described in several studies some years ago [2,3]. One finding was that parents remembered for several years, those illness episodes of their child that really frightened them. Thus it could be fruitful to ask parents a decade later about the fearful illness episodes. The purpose of this study was to explore what symptoms that really worried parents and to elucidate parents' experiences with an ill child.

MATERIALS AND METHODS

The data collected was a part of a larger project concerning the health of 169 preschool children carried out at nine public preschools in Malmö, Sweden, in May 2009 [10,11].

In the study, the parents answered a questionnaire concerning their child's health. The following open-ended question was posed: "Tell me about a factual episode when your child had an infection that really worried you. What did you do to handle the situation?" Parents were encouraged to answer it as detailed as possible, and to write a short essay of a factual worrying infection episode the child had had. In this way we used the memory method, based on the German sociologist Frigga Haug's theory [12]. The written memories are used with the purpose to create distance and space for parental reflection, in order to explore and study parents' experiences and points of interests.

Analysis

The text was systematically analysed according to Giorgi's phenomenological method, modified by Malterud [13]:

1. All answers were assembled and read to get an overview;
2. "Meaning units" were identified and systematically coded into the categories: "Never experienced an episode + Time of the factual episode", "Management + Self medication", "Worrying symptoms" and "Worries, medical encounter, outcome".
3. The contents of each category were abstracted, decontextualised and condensated.
4. The contents were recontextualized and summarized.

RESULTS

52/169 (31%) provided no answer to the posed question, leaving 117 participants eligible for this analyze, which is a response rate of 69%. Equally response rates were found between parents of girls (70%) and of boys (69%). Parents provided long sentenced answers with detailed explanations, but also just brief words, very similar to a telegrammed text.

It emerged that the episode of illness engendering parental concerns, occurred at any time during the childhood so far, equally many among infants (zero - one year) as among children older than one year (Figure 1). The analysis of the text gave the following dimensions.

Perplexity of parents -"This has not happened yet"!

23/117 (20%) of the responding parents reported that they have never been distressed, since their child had not suffered from an infectious episode of illness or from other disease that had caused them great anxiety.

"*She has never been that ill. My child has never had any infections as far as I know and I cannot recall him being ill.*"

Recalled diagnoses and symptoms that worry parents

Parents mentioned specific medical diagnoses and symptoms, as well common as uncommon ones, the most common being otitis, colds, asthma, and vomiting diseases (Table 1). Symptoms that make parents anxious are first of all fever, coughing and breathing problems (Table 2).

When the parent is baffled: to initiate actions or let the illness run its natural course - that is the question

Parents are very distressed when their child is ill. While some parents try to stay calm, waiting for the symptoms to alleviate, apprehensive parents storm into the neighbour for help. Parents find shelters among family and friends and they get personal advice from friends who are doctors. The most alarming element

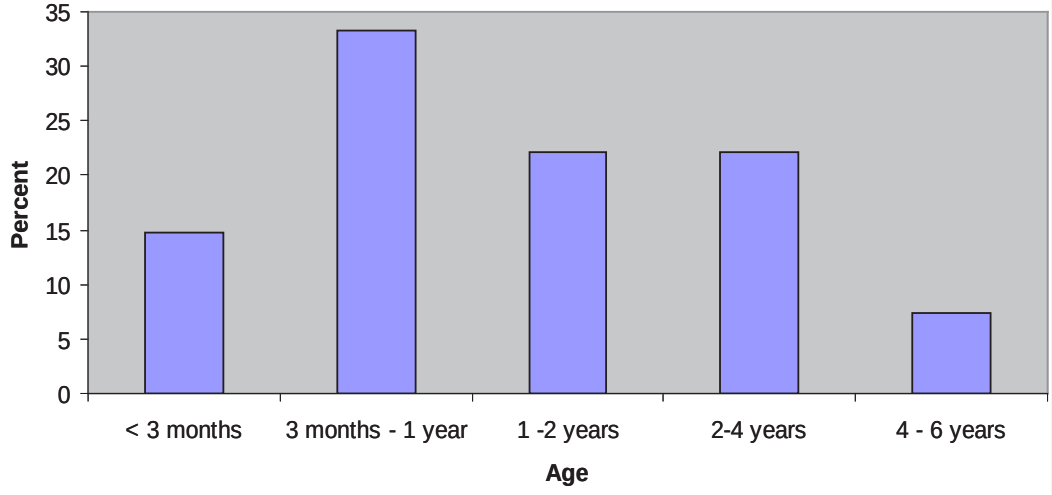

Figure 1 Proportion of children, subdivided in five age groups, where the parents reported a worrying episode of illness in their child.

Table 1: Diagnoses with belonging symptoms as remembered by parents describing a worried episode of their preschool child.

Diagnoses	Symptoms	Number of individuals
Otitis	*Eardrum perforation, pus running out, ear pain, crying*	16
Vomiting diseases and gastro-enteritis	*Vomiting, loose stools for long time, ate and drank very little and could hardly keep his food and liquids*	13
Cold	*Pus in the eyes, phlegm*	9
Pneumonia	*Fever*	6
Falsecroup	*Viral blisters in the throat, wheezing breathing, woke up in the night, coughing*	5
Respiratory syncytial virus infection	*Woke up in the night, wheezing breathing, difficult breathing, could not inhale air, pushy breathing very often, coughing*	4
Tonsillitis		3
Varicella		3
Bronchitis	*Coughing*	2
Cold asthma		2
Viral infectionNUD	*Sagging, exhausted, in a serious condition*	2
Aphtos stomatitis	*Pain in mouth, were feeling very bad*	1
Impetigo		1
Foot and mouthdisease		1
Salmonella		1
HenochSchönlein-purpura	*Red spots on the lower legs, awkward walking*	1
Parasite infection	*Worms infested in the thigh*	1
Asthma	*Coughing*	1
Ileus	*The child's life was in danger*	1
Lactoseintolerance		1
Hip-artritis	*Limping, pains*	1

Table 2: The occurrence of symptoms of preschool children that worries parents.

Symptoms	Number of individuals
Fever	17
Coughing	7
Fever convulsion	2
Wheezing, difficult breathing	2
Enlarged lymph-nodes on one side of the neck	1
Difficult to wake up	1
Sudden infection that made the child slack like a rag	1
Green coloured coryza	1
Difficult with the saturation	1
Snoring	1
Allergic reaction on penicillin	1
Food stuck in the throat	1

is lack of knowledge and doubtfulness, not knowing what kind of disease the child is having.

"After persuading the nurse, we could come into the doctor. Terrible, we did not know what it was; we thought she was going to die. We rushed into the neighbours' flat (nurse). Myself, I work within the medical service so I am probably not that easy stressed out."

Parents look after their beloved ill child in the same way they would be taken care of if they were ill themselves. Some stay at home with the ill child, not letting it attend day care until it is in good health again. The child is supervised all the time and parents make sure the child is resting and eats well. Parents consider that the child has to get essential and suitable food down, in order to recover. Parents sit up late in the evening and watch over the child, sleep with it and they take turns to watch it. Parents pay careful attention to their sick child and they stay near it, and assure themselves that it will be all right in time. They try to reduce the temperature by letting it sleep in a chilled environment and they also stay outdoors with it. Some parents keep a careful check on the hygiene and eventually take away the teat.

Some collect advice from friends and relatives and acquire information from Internet and from medical books. One parent mentions that his child needs few medications in order to get well again. Others administer antipyretics (paracetamol) to the ill child on a schedule basis. Some declare that they use their intuition and give the child pap or liquids with the spoon several times during an hour. Others relate that they wait for the episode to pass or take the situation with reason. Some are of the opinion that caring for an ill child is hard work and an economical burden.

Parents assess the child's regaining of health by taking notice of its wellbeing and state of happiness. Happiness is the first noticed positive sign. In parents' opinion this implies that the child is healthy.

Overt motives for a medical examination and the confusing encounter with health professionals

The child is seen by health professionals when it obviously is very ill, but also just for being examined. Parents get in touch with the medical service on the phone, enquiring information and help with the ill child, before they decide to see a physician at the health care centre or at the child emergency clinic at the hospital.

"They did not say, but we went to the child emergency clinic and there they said inflammation of the ear. Then I felt very unsecure and worried that the health care centre could do so wrong. It did not help, begged for tests and investigations. Got pneumonia, which was not diagnosed until after three visits at the doctor's. I was obstinate and had to stick to one's guns that something was wrong and that it was not just a usual cough. Trusted the medical service (at the paediatric emergency clinic), just a bell button press away. Was received with kindness at the emergency clinic. Calmed by the professional help".

Parents relate their disappointment with the ward when they experience the health care centre acting wrongly, although parents point out that something is wrong with their child. Parents consider the first encounter with health professionals

dissatisfactory, if they do not receive the expected help or they feel rejected. Other medical operators are then sought for, until parents are given an appropriate explanation or a specific diagnosis, in order to find out what disease their child is suffering from. In several instances, parents must be firm, insisting that their child is ill and assert that the child's symptoms must be taken into consideration. In such cases, the medical professional is encountered several times before the child is diagnosed.

Medical services are experienced as a great support and parents follow the given advice. They feel secure when they are favourably received and content when reliable professional medical staff ready to help surrounds them. Parents are less worried when their problems are smoothly solved.

DISCUSSION

The main findings of this analysis are that parents describe worries of children suffering common infectious diseases. A variety of rather uncommon diseases are also recalled. This forms the base for the first core concept, formulated as "*Knowing the common of the uncommon diseases".*

Parents describe many ways to access medical service. They seem to manage their sick child very carefully, according to the books and with intuition. Parents recall health professionals that do not listen to them, leaving the child undiagnosed with both common an uncommon disease. This forms the base for the second core concept, formulated as "*Listen to the parents - an old-fashioned rule in modern flashy medicine".*

Parents are still worried of fever, the most common symptom of infectious diseases as well as the reason to contact the health service, and they regard fever as a threat to children's wellbeing. This forms the base for the third core concept, formulated as "*Fever – to fear and to act Knowing the common of the uncommon diseases"*

Although 20% of the participating parents stated that their child never had been ill, in the remaining small group of 94 children, several uncommon diseases had occurred besides the many common infectious illnesses. This finding surprised us. In a welfare society with good preventive child health care and children coming from good socioeconomic conditions, severe diseases do occur less frequently than among socioeconomically burden children [14]. It could be reflected upon, if the many uncommon diseases are an effect of the increased occurrence of global travelling among children or a change in the immune competence due to better hygiene. Most GPs in the Nordic countries may serve a child population of the size that participated in this study and thus there is a great opportunity of seeing an ill child with an uncommon illness. But we do not see them anymore. May be, too many parents go past the GPs directly to other specialists when their child is sick, with both common and uncommon diseases. As a result, the GP looses skills in the encounter with children and thus in identifying the uncommon diseases. When parents omit GPs in favour of other specialists, too many children with uncomplicated diseases are gathered in the waiting rooms at the children's hospital emergency ward. We found that some parents could not at all recall a worrying episode of illness in their child, and that these parents were not aware that the child had had any infections at all. It could be reflected upon whether these parents' children had good health or if the children's illnesses were ignored. Other parents stated that their children had not had any infections yet – we ask if they somehow expect it to happen. Such parental beliefs and expectations are worth exploring in future studies. However, the proportions of children that never have been ill harmonize with the proportion found in Norway [15]. It could be of interest to study this healthy proportion of children, to find why they stay healthy during these years. Does it depend on an individual factor of the child, such as the immune system, or on a family factor that creates a healthy environment for the child?

Consistent with international findings children in our study were reported to have a similar constellation of symptoms and common childhood diseases. However, we found that among the common childhood illnesses, there prevailed other more uncommon diseases and symptoms [2,15-16]. In a list of the 200 most common paediatric problems encountered by paediatricians [16], we found some, but not all, of the uncommon diseases children in our study were reported to have had. In order to learn more about common childhood diseases, but also to keep updated on the uncommon, a medical doctor should look through such lists, especially nowadays, when Internet has become a central source of health information even for health professionals. New diseases are emerging as families of today are living globally. They travel around the world with their small children. Examples of such emerging diseases are infections with Cryptosporidium [17], multi-resistant bacteria or infection by the moose throat botfly Cephenemyia ulrichii larvae [18]. Continual medical education is the common way to update medical knowledge. Although children today seldom are severely ill, the GP should update his/her knowledge of the common of the uncommon childhood diseases in order to identify them and to find the proper level of care. Beyond that, the consultation process with the parents and the sick child is a very important arena for getting the idea of an uncommon disease, in order to catch the right diagnosis.

Listen to the parents. An old-fashioned rule in modern flashy medicine

It emerged from our study that parents demanded to be listened to, in order to receive a proper examination. Contrasting the findings of Voigt *et al*., [19], we found cases where parents had to put much effort to obtain a medical evaluation of their ill child. Parents in our study experienced the health care centre as a stronghold, because there, they had to insist on having their ill child examined – in the mean time, the emergency ward at the hospital was always open, thus, an alternative service to gain access to medical help. It may reflect the situation for parents in Sweden, where GPs do not function as gatekeeper to specialists. In Denmark, all inhabitants have been assigned a GP. But even so, the parents in Denmark are worrying and describe episodes with a non-listening doctor [7].

The well-educated parents in our study were skilled in recognizing changes in behaviour of their child. They seemed to be involved in the health decision and they strongly wanted to be active in treating the child. They knew where to seek information and where to turn when they needed help. Even so, it was troublesome for many of them to get what they wanted from the health care system and especially from the primary health care.

Parents can transmit their anxiety to their child. Allaying parental concerns, making them feel secure, helps reduce child's fear, thus creating a positive feedback loop [20]. But why do parents have to negotiate with health professionals to accomplish an examination for their child? Ignoring parents' statements and contributions to the anamnesis, enhances their discontentment and creates more fears. It makes it probably more difficult for the doctor to find the right diagnosis and to give the accurate treatment, which is detrimental for the ill child. Health professionals should welcome parents who fight for a diagnosis for their ill child. A parent child centred consultation style in the encounter may also reduce parents' fear of the child´s illness and lay the base for the doctor to find both uncommon diseases and severe infections.

Fever –to fear and to act

Even if the parents described how they looked after their ill child, the perpetuate threat eliciting great parental concern, was fever. The parents were from the middle class and they had professional duties that required them to enrol the child at preschools. They well knew of how to manage a childhood illness, due to better-acquired knowledge and contacts with the health services and they knew how to access medical help. They had different concerns and worries, than the disadvantaged parents described by Kai [2-3]. Parents in our study frequently administered antipyretics to the feverish child in order to combat the fever, while disadvantaged parents in Kai's study performed cooling procedures and were afraid of fever becoming a threat to the child. Meningitis never emerged as a threat to the parents in our study, while this was common among the mothers in Kai's article.

One may wonder why fever still is a problem for well-educated parents of ill children. Maybe medication of a feverish child alleys parents' anxiety and gives them a feeling of mastering the inconvenient situation of dealing with an ill child. Parents' fear of fever can also be reflected upon as a new challenging experience. They do not know how the new feverish episode will end. This reaction obviously encourages parents to pay close attention to their ill child and fight for a diagnosis when necessary. Informing parents about the essence of fever and fever reactions even today ought to be an important doctor's mission too as a trebled incidence of antipyretic overdosing has been reported over the last two decades [6].

CONCLUSION

When parents recall a worrying illness episode, the most common diseases (otitis, cold, gastroenteritis) are reflected upon. But still the experience of uncommon diseases was frequent in such a small group of healthy preschool children with good access to health care. Thus, general practitioners should still be updated on the common of the uncommon diseases. The study revealed that the well known and old advice "listen to the parents" still is an important mission in the medical encounter, in order to both get precision in the diagnose and in management of the illness episode. Even if fever is the infection symptom that worries parents most frequently, parents give proof of competent management of their sick child.

Strengths and limitations of this study

Even if we asked, for an infectious disease episode, parents reported from the most worrying episodes as well, many of who were not primarily of infectious origin.

The strength of our study is the increased internal validity through on-going analyse and discussion between the authors. The prevention not to confuse our presuppositions with knowledge obtained from the material and affirming our pre-study beliefs early at the beginning of the study is another potential of our project. Even though we studied a relatively small group, our work has been consistent in in-depth-analysing what it had to describe and tell about the specific matter in question. The participants in this study come from the same city, but from two different areas in the city, which gave a small variation in socioeconomic positions of the parents that are enriching the material. With a larger group of disadvantaged parents, the number of uncommon and severe diseases reported would have been even higher. However, even if the majority of the parents had university education, the habits to write an essay may be more difficult today, as most parents use computers that elucidate use of pencil and paper.

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