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Organizing allergy and being a ‘good’ parent: parents’ narratives about their children’s emerging problems

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ABSTRACT The article focuses on the early and problem-solving phases of the child’s illness trajectory and on how child allergies are constructed and organized by the parents in a moral everyday context. The parents’ narratives were reconstructed as narratives, describing the pathways parents take before they decide to seek professional medical aid as well as showing how they construct themselves as responsible parents. Before consulting health professionals the parents have often tried a range of different ways to define, control and manage their children’s various problems. Allergy problems were interpreted and responded to differently, depending on the way they emerged in everyday life. Acute reactions quickly led to an illness definition and a diagnosis. Gradual and diffuse problems were not so easily defined. They were at first interpreted and responded to as normal infant problems, but, through the parents’ readiness and various situational and temporal clues, they were organized as symptoms of illness. Parents seek medical aid when their own strategies fail or do not fully work, but their decisions are also formed within a pre-problem context of their moral accountability as parents.

KEYWORDS *allergy; emerging problems; identity; illness behaviour; parenthood*

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Introduction

In the everyday context, illnesses often appear as minor functional changes in the body, as pain or as sudden bodily reactions or dysfunctions. For the person suffering from these problems, it is often not evident what is happening to him or her. Frequently the person tries to adapt to the bodily

changes or the pain by trying to frame these as something that is going to go away. Certain remedies like painkillers and sleep are used and evaluated (Alonzo, 1984). It is likely that professional help is sought when the bodily problems do not stop or even become worse, in spite of the remedies tried (Emerson and Messinger, 1977).

This means that in an everyday context, the first part of the natural history of an illness consists at least partly of a social problem-solving process. There is a 'before' in any illness, when symptoms and problems are still being negotiated, grappled with or investigated, and have not yet been fully recognized, labelled or diagnosed as a particular illness. However, there is no distinct pre-period of illness and there are no clear-cut contours between the different 'phases' of asymptomatic, symptomatic and illness. In fact, most individuals have at least some bodily discomfort or symptoms despite being presumably 'healthy' (Zola, 1973).

Allergy, and especially food-related allergy, is an important problem when children are affected as parents generally do not know from the beginning whether their child has an allergy or not or how serious it might be. Some children develop severe and complex allergies with a risk of an anaphylactic reaction that can be life-threatening, while other children may simply have to change their eating habits in order to function normally. Food-related problems are also known to 'mimic' other illnesses, and the manifestation of symptoms can be very imprecise and non-characteristic, ranging from sleeping problems, vomiting, diarrhoea, general discomfort, to dry and red skin, rashes and crying. In addition, laboratory tests successfully used with pollen/pet allergies and other airborne allergens are not sufficient in diagnosing food-related problems (Sicherer et al., 2001).

Consequently, both health professionals and parents can have a hard time recognizing and managing the illness. For parents this means that they have to be able to recognize and differentiate symptoms that potentially indicate the presence of allergy not only from other 'benign' everyday problems, but also from symptoms of other kinds of illnesses.

In infants, bodily changes, symptoms and signs are part of the very nature of being a child and thus of caring for a child. Nonetheless, parents somehow discriminate bodily symptoms from behavioural changes in the child when deciding upon when the symptom is to be viewed as 'problematic' (potentially ill) and thus worthy of medical attention. Research dealing with how individuals recognize symptoms and falling ill (Radley, 1994) has mainly focused on the individual's own bodily experiences and less on how parents recognize and understand the 'falling ill' in terms of their children.

The aim of this article is to focus on the social problem-solving processes that parents engage in when trying to understand their children's symptoms and problems. The problem-solving process includes the parents, their actions (or non-actions), their perception and their interpretation of their child's behaviour and symptoms. This means that finding out what problems afflict your child also puts your identity and value as parent at risk.

Being a good parent implies being a parent that responds quickly, adequately and in a responsible manner to your child's problems. Thus investigating the problem-solving process also means focusing on the parents' ways of accounting for their own actions and their parenthood.

One way to understand this social problem-solving process and the parents accounting for their parenthood is to analyse the parents' narratives about how they recognize, interpret and respond to their children's bodily problems. Collecting and analysing narratives about the pathway from detection of symptoms to medical help is a way to understand both how parents construct and organize their understanding of their children's allergy in a way that prompts them to seek professional, medical aid, and how they construct themselves as responsible parents.

A social approach to allergy

So far research on allergic conditions has mainly been based on a biomedical perspective, and has as such explored the immunology of the allergic conditions or other mechanisms behind reactions (Middleton, 1998; Sampson, 1999). However, there is a body of research that has investigated how allergic conditions affect different psychological and health-related variables in patients with allergic conditions. Some of these are descriptions of problems of caring for a child with an atopic condition (Arvola et al., 2000), coping strategies for children with food allergy and their families (Munoz-Furlong, 2003), quality of life in children with food allergy (Sicherer et al., 2001) and asthma (Reichenberg, 2001), and the role of psychosocial factors in the development of allergy (Gustafsson et al., 2002). These studies were all guided by practical medical and health service concerns, and allergy was studied and comprehended as a solely medical, individual or psychological problem.

There are a few examples of studies on the actual experiences (Zernike et al., 1997; Hansson-Scherman et al., 2002) or lay perceptions of allergy (Olin Lauritzen, 2003). Such studies have mainly been concerned with childhood asthma (Adams et al., 1997; Prout et al., 1999; Williams, 2000; Gabe et al., 2002), even though many children (and adults) suffer from multiple allergic conditions. It is known that adverse reactions to food are one of the most common offending environmental substances that individuals report getting symptoms and reactions from, but studies focusing on food intolerance are missing. Certain studies concerning the experience of asthma and allergy have moreover been guided by improving clinical practice (Zernike et al., 1997; Østergaard, 1998; Rydström et al., 1999; Englund et al., 2001).

Studying parents' narratives of children's allergic conditions, Olin Lauritzen (2003) deals with the lay perception of children's illness and focuses on how parents understand the causes, prognosis and chronic character of the illness. Her study shows that parents refer to a shared

knowledge about causes of allergic conditions such as lifestyle, physical environment and genetic causes, which is then re-appropriated and intertwined with the parents' own experiences. Child allergy is furthermore constructed as a family condition where parents link the explanations of allergic conditions to their own identities as allergic and non-allergic and to their family illness history. The meaning of allergy is thus constructed in the everyday context, but parents reflect upon and make use of expert and public discourses in this process (Olin Lauritzen, 2003). Olin Lauritzen's study points towards a localization of the parents' experiences in a social and cultural context.

However, neither Olin Lauritzen's study nor other studies on allergy (see Prout et al., 1999; Gabe et al., 2002) pay attention to how the parents and individuals make use of different cultural resources and medical discourses in the early process of discovering allergy and how definitions of different allergy symptoms are contextually embedded, that is, the social problem-solving process.

None of these researchers has shown in what way the parents' identities as parents are involved in the process of understanding and helping their ailing children. Of special importance is the fact that having a child that shows signs that may be interpreted as problematic or even as signs of a disease potentially puts the parental identity at risk. Failing to note or observe an important sign, or misinterpreting it, may portray the parents as less competent parents; or even worse, as bad or neglectful parents.

This means that in accounting for the discovery and coping with problems and symptoms in their children, parents also have to engage in impression management (Goffman, 1967), in the sense that they have to present, defend and sustain their parental roles, being 'good parents'.

The study

A recurrent problem for several studies about asthma and allergy experiences is that individuals have been recruited through and by the health care system (Bury, 1997; Zernike et al., 1997; Östergaard, 1998; Rydström et al., 1999; Englund et al., 2001; Gabe et al., 2002; Hansson-Scherman et al., 2002). These studies mainly include experiences of individuals with an already diagnosed asthma or allergy, notwithstanding that several illnesses, including allergy, are not defined and managed primarily within the health care services. Samples based solely on patient populations will limit the understanding and discriminate among valuable insights of the illness experience of allergic conditions (for a more thorough discussion of this issue see Conrad, 1987).

This article is based on a non-clinical population of Swedish schoolchildren with parent-identified food allergy. The population is, however, institutionally processed and produced. Today, many schoolchildren in Sweden have different exclusion diets at school, as they for health or

religious/ideological reasons need to avoid certain foods at school meals. The participants in the present study were selected from a previous study of 230 schoolchildren, aged six to 18 years, who had exclusion diets in school because of reported adverse reactions to food (Gunnarsson et al., 2005). The children's parents ($N = 215$) were interviewed over the telephone using a study-specific structured interview schedule with questions about health care contacts, diagnosis, food-related symptoms and other allergies.

For the present study 18 mothers and one father were interviewed, in most cases twice. They were selected on the basis of the information they previously had given about their children's illness and medical history. The inclusion was based upon a variation strategy and was taken to reflect the diversity of family heredity, children's symptoms/allergies and doctors' diagnoses in the whole population of children with exclusion diets. In this way it would be possible to understand the disparities that have emerged among the families in adapting to different conditions and to identify common patterns that cut across family cases.

Seven of the 19 interviewed parents had allergies themselves (five mothers and two fathers). Among the families without parental history of allergies, four families had relatives who suffered from asthma or allergy, for example, a child's grandparent.

We included parents whose children suffered from a variety of different food-related symptoms and other allergy problems, for example regarding how problems physically manifested themselves, such as eczema, gastrointestinal problems and airway problems. Sixteen children had asthma, 14 children suffered from eczema (knowingly related or unknowingly related to food intake) and 14 suffered from pollen or pet allergy. Eleven children had all of these problems: asthma, food intolerance and eczema or pollen/pet allergen. Five children suffered 'only' from food-related problems.

It was not always easy for parents to say whether or not the children had been diagnosed by a doctor as being food allergic or food hypersensitive. Not all parents were certain the doctor really had given a diagnosis of food allergy (or asthma), although all parents defined their children as either being sensitive or having allergy themselves and all children except one had visited a health professional for these problems at least one time in their lives. According to parent-structured statements in the telephone interviews (Gunnarsson et al., 2005), 21 of the 26 children were doctor-diagnosed as food intolerant, most children ($n = 23$) were also diagnosed with other allergies, and only three children, including two siblings, had not been diagnosed with any allergy.

Informed consent to contact the parents had been given by the parents in the first study. We sent a letter explaining the purpose of this study and then called and asked the parent who answered the telephone call if he/she wanted to participate. It was more likely for the mothers to say yes; in fact when fathers answered the telephone and were asked to participate, they often directed the inquiry to the mothers with statements like 'She knows

more about this – you can talk to her.’ We think this reflects the way family life is organized in Sweden, with mothers generally taking more responsibility in the management of children’s illnesses. The single father who participated also identified himself strongly as the parent managing his child’s health problem (the father was remarried and the child was mostly living with him).

There were five families that had more than one child with allergy, and two of these were not part of the first study population, in one case because the child did not have an exclusion diet at school and the other because she had finished school (23 years of age). The children’s (and one adult) ages ranged from seven to 23 at the time when the interviews were carried out. The first initial problems emerged at the approximate age of newborn up to seven years (mean 1.2 years) of age (only one seven-year-old).

The interviews

The interviews were conducted in the participants’ homes or their workplaces. Questions were open-ended and narrative-oriented, which meant that the parents were encouraged to talk about their experiences in ways that would elicit ‘free-flowing’ talk and stories. One single open question was put at the beginning of the interviews: ‘Could you tell me how you discovered that your child was allergic?’ Most parents responded to that question by telling a story that included how, when and where the problems started, what happened, different people that were present or became involved, what the parents did, what happened when they sought professional medical aid, what health professionals said or did and conclusions and evaluations of the events and actions narrated.

The stories were different in structure but had more or less all of these features in them. The first question opened up for the parents to start their story differently. One mother began her story during pregnancy, others began by telling about the symptoms and yet others began with a specific ‘discovery event’, which could be very vividly remembered and dramatic. In the case of more than one child with allergy, the parents would often speak more about the child (children) that seemed to have the most demanding problems. However, the interviewer (NG) tried as much as possible to follow up on all those children in the family that the parent talked about as having allergy, but without forcing the interviewee’s narration. The stories unfolded sometimes around just one of the children with allergy.

All interviews were tape-recorded and thereafter transcribed verbatim, resulting in a transcription including both words and other language features such as cries, laughter, sighs and pauses. The specific words used, how the speech is structured and why words are used in a particular way are important tools for understanding experiences and who people are (Riessman, 1993). In this study these have been used as a way of extending and strengthening the analysis.

The analytical questions were based closely on the data and represent the focal points in the aim of this study. They concerned the parents' recognitions and interpretations of their children's allergies, how the emerging problems were conveyed, the understanding and explanations of bodily problems that the parents explicitly or implicitly accounted for in the text, what remedies were sought and dismissed and what made them eventually understand the everyday problems in terms of illness (allergy) and thus worthy of medical attention. In the analysis, different important episodes were then identified and arranged in chronological order that represented when they occurred in 'real time', making up a storyline or trajectory of the process of the parents' construction, organization and understanding of their children's allergy.

The initial interview question used the word 'allergy', which most probably made the parents focus on their children's allergy as a specific problematic area rather than general health problems. The ensuing narratives were told from the viewpoint of the parents' present understanding, which would have an impact on their reconstructions of the past. The aim was to describe the way parents themselves, through their narratives, created meaning in past events and actions – how they in retrospect 'talked about' and remembered these events.

To the parents the process of trying to understand their children's problems was a process that unfolded over time. All the interview narratives consisted of two main temporal phases: (1) the pre-problem phase, consisting of an awareness of an allergy that sometimes led to preventative actions; and (2) the emergence of the child's bodily problems in the everyday situation.

(1) Pre-problems: allergy awareness and preventive actions

The concept of becoming or being intolerant of certain elements in the environment was reported to be present in most parents' lives before the onset of their children's problems. One mother with allergy said: 'I can't say that I am surprised that one of my children got it.' To the parents the emergence of the children's bodily problems was often preceded by a readiness both in thoughts and actions regarding risky environments and risky living commonly associated specifically with allergy. This readiness was sometimes preceded or further endorsed by the parents' own illness history. It was primarily mothers with allergies of their own that told mostly about preventive actions, or when other children in the family had allergies.

Parents talked about how they had tried to prevent ill health or allergy in their children in two particular ways. Some parents constructed the preventive actions as part of their awareness of allergy and ideas of what can cause allergy, or a general awareness that the environment and the parents' own actions could result in illness. Several parents mentioned prolonged breastfeeding as a way of preventing allergy or the avoidance of certain allergy-associated foods. Preventive food avoidance was often accounted

for by mentioning the food restrictions that the mother herself had due to her own allergy. For instance, one mother stated: 'he is never allowed to try certain things because I am totally convinced from my own allergy that he cannot tolerate them'. For this mother some foods were conceptualized as a potential threat to her child's health.

The other preventive modes mentioned by the parents were not directly related to allergy but were instead linked to what could be called 'ecological' lifestyle and thinking. These included actions directed at strengthening the children's immune system with garlic or other natural substances and vitamins. These actions were put forward as a way to strengthen the child's body (and mind) so that the child in the future could more easily tolerate the environment she or he might be exposed to.

Talks about preventive actions were most evident in the case of different foods, most likely because foods can be more easily avoided, although there were also elements in the accounts of parents like not buying a dog because the child had dry skin since birth. The idea of preventative actions became more pronounced in those cases when the families had an older child with allergy and tried to avoid allergies for the next child. For these parents, prevention meant being aware that the child they were about to bring into the world could develop allergies just like other members of the family. The inheritance of allergy as a medically defined risk factor is a concept that is known to be present in the parents' accounts of their children's allergies (Olin Lauritzen, 2003). The interviewed parents, however, not only talked about risk factors like allergy inheritance, but they also talked about how they actively attempted to take preventive measures.

In one interview, a mother who herself had asthma and allergy since childhood gave a vivid description of her 'worries' that her son would develop the same problems. She had previously stated that she breastfed her son for one year in order to prevent this from happening. Her report that this was 'recommended back then' also positioned her actions in the medical discourse at that time.

Example 1

I: You said that you breastfed for a long time, eh, eh ... have, what was your reason for doing that?

IP: Well, it was because it was recommended back then just to avoid allergies (...) the possibility that they could escape them because we just then when (her son) came (people) were really very worried about this, that he might have the same problems that I have. And I saw the hospital stays and the worry of what might happen and I don't know anyone directly, but I've heard about friends of friends who've, like I said, had asthma attacks and died and ... and I have one friend who has two little boys that eh

she has to have those adrenalin syringes
since it can happen very fast so that everything
I wanted was just negative then
I thought, was really scared
And I was going to, he looked so (...)
I mean everything seemed so good
and still I'm so glad it's so little.

In the mother's evaluation of her preventive action, the idea of her own allergy as a risk factor is evident. She also gives examples of other people she knows or has heard of with really severe asthma and uses these 'stories' as confirmation and justification of her own story and preventative actions. She evaluates her own fears with a distanced voice and narration (as though she feels she is exaggerating) perhaps because this was many years ago. However, in the last sentence, when she returns her story to the present, and says 'and still I'm so glad it's so little', the reality of those fears seems to prevail.

She also seems to claim implicitly in her story that the past preventive strategy of breastfeeding has been effective, and that is why her son's problems are 'so little', and thereby also position herself as 'a good mother' (Harré and Davies, 1990) who has tried to protect her child from illness. When she evaluates her actions, it appears she deems that they have been successful in at least not making her son's allergy any worse than it is, like in those horror stories she talks about. Later on in the interview, she also refers to herself as being 'her own doctor', and by doing that she identifies herself as more than just a competent mother, but rather as someone with extensive knowledge about allergy, similar to that of doctors' expertise.

The past breastfeeding and other past and current preventive actions are made meaningful to this mother and the listener through the way she tells about and interconnects these actions in a broader allergy story put together from her own history, peer tales and knowledge about allergy. This story is of an uncertain and potentially fatal illness, in which she sees herself as the one who is responsible for past and future happenings.

When the mother talks about making her son avoid certain foods, although she has never actually seen him ill, she does this because she truly believes that these food allergies will develop in the future. Her only hope seems to be able to defer them for a while: 'They might perhaps come earlier and perhaps will come quicker if he is allowed to try them; this is probably how I think.'

The pre-problem phase shows how parents organized their child's allergy, as something that preceded both the birth of the child and the emergence of bodily symptoms. Parents were aware of, ready for and sometimes even expected an illness like allergy to emerge, and some parents actively tried to counteract this. As parents, especially mothers feel responsible for their children's health (Cunningham-Burley, 1990; Olin Lauritzen, 1997), emphasizing preventative actions made before the child has fallen ill is also a way

to justify the moral correctness of their actions. Voysey (1975) and James (1983) found moral justifications to be a salient feature of parents' accounts when speaking about the action taken in response to the behaviours of their ill and disabled children.

(2) Emerging problems

In the next phase of the narratives, the children's problems are presented as emerging in an everyday context. Parents construct this process in two different ways – in an acute and direct way and in a more gradual and drawn-out way.

To the parents the bodily signs of acute problems were more evident and were quickly responded to in terms of allergy and of 'seeking medical aid' – progressively leading to a medical treatment and an often immediate and confirmed allergy diagnosis (like a positive test result pointing to a specific offending allergen). For the parents the problem-organizing pathway was fairly straightforward.

The gradual problems had a different and more open pathway. It was possible to outline four main interpretative and responsive strategies of the emergence of these bodily signs: (a) at first bodily signs were considered and managed as 'normal' infant (child) problems; (b) eventually these signs became recognized as symptoms of illness (allergy, other illnesses), whereby some parents turned to the child health care centre for advice; (c) other parents tried different self-diagnosing and self-treatment strategies; and (d) when these failed (or were only partly successful) and/or a new situation arose, these parents also turned to the child health care centre or sought other medical aid.

It was evident when the parents sought medical help that the diagnosis of gradual problems was neither immediate nor always confirmed as allergy in the same sense as was the case with the acute reactions. Test results, as in biological markers (IgE antibodies), were not found in all these cases, and the association with a specific offending allergen or cause could not always be made either by the doctor or the parent. Consequently, there remained at least some diagnostic uncertainty even after a diagnosis had been made.

Acute reactions

In their interview narratives, emergence of certain types of bodily problems is presented by the parents as being forced on them in a very direct and sometimes extreme and traumatic way. This was often the case with suddenly discovered but temporary reactions, distinguished by lower airway responses such as breathing difficulties or anaphylactic shocks. Parents often connected these acute reactions with the intake of certain types of foods. When the child gasped for air, reacted with a swollen face or in any other way reacted directly after eating some foods, parents often said that they

knew right away that something was wrong. As a consequence, their interpretations of these reactions in terms of allergy were quick, due to their very nature and the direct link that often could be made to what had caused the reaction.

In Example 2, a father tells the story of one summer day when he, his four-year-old son and the boy's grandparents were out sailing. The boy experienced difficulty breathing and turned 'red in the face' after eating 'one or two' peanut snacks. The father in the example underlines the knowledge about what had caused his son's reaction by emphasizing the fact that his son had never before eaten nuts or peanuts.

Example 2

IP: Eh, it was he must've been about four years old
we were out sailing with my parents and a couple of his friends
and he had brought along a bag of peanut snacks that I (laugh) had given him
that he then ate some with a good appetite
he had never eaten either nuts or peanuts before that
because he didn't like them, he didn't like snacks even when he was little
And so he ate I don't know if he ate one or two
And got breathing difficulties he got red in the face
And went to his grandmother and said – my throat itches and it was very painful
But, as luck would have it, my father is allergic to horses and dogs
he developed that when he got older
and so he had, his allergy medicine, and it was Tavegyl.
So he got a quarter of a tablet from my mother then, his grandmother, so to speak and
I guess it took a, a while, but it got better, so to speak with that
and then he didn't get any more (laugh)
Then, we went and had him tested,
and he turned out to be allergic to peanuts and to soybeans
and then to timothy grass and a lot of other stuff.

The story about the acute reaction was told in a straight, progressive way without any signs of discontinuities or disruptions, something that was otherwise characteristic of the parents' narratives. It is linearly and chronologically organized and is built up around four events: (1) the son eats a peanut snack; (2) he has an adverse reaction; (3) medicine is given; and (4) the family goes to the primary health care centre to have him tested and he is diagnosed with allergy.

All parents telling about an acute problem also tell about seeking and receiving medical aid that resulted in a specific allergy diagnosis confirmed by a medical test. That a diagnosis was specific meant that parents were told exactly what kind of allergen substances the child was allergic to and the remedies were then directed at, if possible, removing or avoiding them.

The straightforwardness of the acute respiratory allergies is very similar to what Calnan (1983) has described in people's decisions about seeking medical help for minor cuts (open lacerations or penetration wounds).

Calnan (1983) found that in terms of minor cuts the identification that something was wrong, the assessment of significance of the cut and the decision to act (seek medical help) was direct and brief. The similarities of such different types of symptoms as acute allergy problems and minor cuts gives some indication that there are general elements and phases in the help-seeking decisions that are unrelated to symptoms or conditions, but rather relate to how symptoms emerge and the salience of these symptoms. Symptoms appearing quickly and intensively are possibly more difficult to ignore or normalize.

Gradual problems: from normal to problematic

In the narratives of other parents the emergence of the child's problems was more gradual and lasting. These stories included problems related to the stomach as for instance diarrhoea, constipation, stomach-ache and vomiting, but also eczema and cold-like symptoms like a runny nose/eyes and cough, subsequently related to asthma. In the interview narratives, these problems were presented as emerging gradually and were at first not always directly associated with 'something being wrong'. Instead they were often at first thought of as 'normal problems' of having and caring for small children. Allergy-associated conditions like eczema could also at first be comprehended by the parents as 'pretty normal'. These are all examples of normalization strategies, commonly used in the everyday organization of troubles (Radley, 1994).

Parents' talk about how their observations of children's cold-like, skin- and stomach-related problems changed over time as they become more and more aware that the children had problems that could not be considered 'normal'. This awareness altered the parents' perceptions of their children's bodies. In retrospect this moment often was identified as a turning point, creating a before and an after in the parents' stories. This shift in the parents' 'awareness' of the child's body and problems apparently opened up the possibility of new interpretations and new actions, including looking for causes and seeking professional help.

This shift in awareness can be illustrated by an interview with a mother whose daughter fell ill with cold-like symptoms when she was about six months old and the parents at first believed that it was 'just a cold' (Example 3).

Example 3

I: Tell about, was she, in what way was she sick when you discovered it?

IP: She was so terribly runny-nosed

eh like her nose ran all the time and she was kind of well, if you think of a real cold

(a real one) sort of, and coughing a lot and so that

because in the beginning I thought of course that she just had a cold

but since it never went away, it just continued

then we realized that there was something wrong here
and my first reaction, since we had cats
then it was like OK, now I'm sure
she's allergic to cats
that's how it was.

The turning point in the second paragraph marks the parents' retrospective shift in their understanding of their daughter's problems: 'Then we realized that there was something wrong here.' To the mother this shift follows a first definition of the problem, which at that time no longer was thought of as a 'mere cold'. A cold is something that is considered a 'normal problem', as part of having children at any age, but the daughter's cold-like symptoms did not fit the usual temporality of a common cold. Hence, it was the duration of cold-like symptoms that became the clue for a potential illness. Furthermore, their cats were a situational clue that the problems were related to allergy. Sensitivities to furry animals like cats and dogs were readily identified as a cause of children's problems.

The mother in the example above removed the cats right after she recognized the connection between the cats and her daughter's problems. She states that she did so 'before the doctor said so', thus also claiming her competence and the correctness of doing so. This first remedy however partly fails, which we can tell from the continuing narrative of the mother (Example 4). She goes on to tell about how she came to recognize that her daughter was also having problems from different foods, such as tomatoes and apples.

Example 4

I don't think that I had considered before what the problem really was
until this connection with the cats
made me investigate things in another way,
her nose started to run and I took away the cats
and everything just continued the same.
I have been so darned objective and tried to find out what was wrong,
you could say (laugh), but
then I have also found certain things
so, it was in that connection,
at the same time that I got more vigilant.

When the problem continued even after the cats were taken away, this made her actively start to 'find out what was wrong' and become 'more vigilant' of her daughter's bodily signs and changes. In this mother's case it is difficult to discern a special time in the narrative when she decides to seek professional medical aid, although it seems that an illness 'investigation' was actively initiated by the mother at the child health care centre, because of the girl's prolonged cold-like symptoms.

It was common that parents in their interviews referred to an increased 'awareness' in terms of stating that they 'had to' become like 'detectives' to

discern what the causes of the children's problems were. It was more than merely 'awareness' in that sense. Once the children's problems had been interpreted as abnormal, what was salient in the parents' stories was their problem readiness. Being detectives meant for the parents being able to help their children through finding out what was wrong. Not knowing what was causing the children's problems was frustrating. 'Not knowing' may also be thought of as threats to their identities as good mothers.

Thus the different paraphrases of 'doing everything they could or should' that several parents used in their narratives entails moral statements that in some cases clearly followed on from the encounter with medical professionals and the non-legitimization of the children's initial symptoms. For example, before the story in Example 5 the mother says, 'his stomach was very upset, and of course, one is not stupid but in fact quite knowledgeable, he had colic, but we fought on, did everything we should.' Later on (Example 5) she also tells about how the doctor did not 'quite believe her'. Her talk about her knowledge and competence also points out that she was right in her suspicions and that she, despite what the doctor 'believed', had actually done the right thing for her son (who later on was diagnosed as allergic to milk protein and soy). The moral justification of action this mother made in relation to her child was recurrent in the gradual onset stories in this article, especially in the cases where parents had to struggle, not only to define the child's problems and the situation, but also to receive a diagnosis. Voysey (1975) also found that it was particularly in situations where the parents' competence was being questioned, that they needed to present an orderly definition of the child's condition, and hence to show their good work as parents.

Parents mention different situational clues as a way of recognizing allergy-related problems and defining the situation. One mother noticed that her son was getting symptoms in the spring every year, and this became the clue that something was wrong. Another example is the mother spoken about earlier who understood that the bottle-feeding of her son was connected to his vomiting symptoms; at first she attempted self-management by removing the bottle and replacing it with solid food. When this fails and the child continues vomiting, she 'comments on it to the doctor'.

Example 5

The symptoms were very severe stomach pains.
sleeplessness.
but those are things that babies (chuckle) can have
it doesn't have to be allergy
But when we fed him with the bottle
he threw it all up again
it just gushed, he vomited heavily
then we understood
I: What did you do then?

IP: I commented on it to the doctor but he didn't quite believe me
because his weight didn't drop
and I mean that during this time he had started to eat ordinary food
we understood that the bottle wasn't good
so clearly we went over more and more to porridge and other things
but he kept on vomiting.

Again we can see how the mother presents the different responses as following the other. The child's different problems are at first interpreted as normal infant problems (as colic – and he received special medicine for that). When he starts vomiting heavily the parents then understand that something is 'wrong' (the bottle-feeding being the clue). Because of this, a first remedy is tried (eating solid food). When this strategy fails, the mother 'comments upon' this to the doctor. Note the use of the word comment in the mother's story. By using this phrase we are being told that she already has regular contact with a doctor (at the child health care centre) – which is the typical case in Sweden (see Sundelin, 2000). Parents in Sweden do not always need *actively* to seek medical aid, especially for diffuse and minor symptoms when their children are small, as they can ask the doctor or other health professionals about health issues at the child's regular check-up.

Maintaining parental identity

The parents' stories signify not only how they organize their understanding of their children's allergies before seeking medical aid, but also how they represent themselves in their present situation in relation to the interviewer, and perhaps even more important, in relation to medical professionals (who are often imaginary listeners to their stories). Especially mothers observe their young children closely to discern what is normal or not in their children's behaviour (Cunningham-Burley, 1990; Olin Lauritzen, 1997), and worrying that something could be wrong is a 'running theme' in mothers' accounts during pregnancy and birth according to Olin Lauritzen (1997).

Parents organize their children's problems retrospectively as being possible to influence with their readiness and different strategies. Having control means for many parents in this study being able to help their children (to relieve their 'suffering'), and at the same time presenting and maintaining oneself as a good, morally responsible, parent. For instance, food avoidance is a way for parents to try to control the child's well-being and health in terms of preventing illness, as well as a means of defining the situation and interpreting symptoms.

As has been brought out in this study and several other studies about the accountability parents have for their children (Voysey, 1975; James, 1993), the pathway to the doctor for parents is different from that of which Zola (1973) speaks. Although it is true that parents seek medical aid when they no longer can live with the situation, (or rather when their strategies do not fully work), parents' decisions are also formed within the pre-problem

context of their moral accountability and the continuous construction of a moral parental identity.

The social problem-solving process presented in this article is a culturally defined way of understanding and organizing child illness that may be more or less non-illness specific. However, it might be argued that there is a greater moral responsibility to do the 'right' thing in suspected allergy and food allergy, than is the case for parents dealing with other types of chronic illnesses, as the social and physical environment and lifestyle choices are particularly manifest in medical theory and clinical practices of allergy (Platts-Mills et al., 2005) and in lay concepts (Olin Lauritzen, 2003). When parents acknowledge that they might be in a position to help their children by removing, for example, certain food items from the child's diet, the moral pressure to know what to do and how to respond 'correctly' may become even greater. The paradox for parents in discovering and defining child allergy is that the actual suspected social and environmental causes of children's problems (food, objects and situations) also can help the parents to organize and define their children's problems and the situation. Situational clues are thus used, changed and elaborated on by the parents – leading to a definition of the situation and to a decision to seek professional help. For parents trying to work out what is wrong with their children such situations and places that may carry meanings associated with danger and risk for children with asthma and allergy (Rudestam et al., 2004) can also carry meanings of remedy and resolution.

A further conclusion from our study is that parents do not consult health professionals as blank pages. Parents scrutinize the children's problems carefully before seeking medical aid, and seek professional help with the 'social baggage' of an already constructed and organized illness. Consequently, the recognition of how parents make sense of bodily signs and symptoms in their everyday life will have implications for the medical practice and especially for the encounter between parents and health care professionals. Parents will most likely weigh the definitions, information and remedies given by health care professionals against their real-life experiences and organized illness, testing medical explanations and either accepting or rejecting them. This will have consequences for how parents understand, listen to and relate to medical advice and recommendations and for 'compliance' with medical treatments.

Listening to parents' individual stories and seriously focusing on their way of organizing and reorganizing child allergy in moral terms thus becomes an important clinical tool for doctors and other health professionals (see Clark and Mishler, 1992; Kleinman, 2006). If they can successfully relate the parents' own knowledge to their clinical work it may significantly affect satisfaction with care and compliance. Gradual awareness of allergy is also linked to an uncertain diagnosis, and paying more attention to the consequences of the onset of these particular symptoms may create a better

basis for negotiations between parents and health professionals in how to define and treat these particular symptoms (Conrad, 1985).

References

- Adams, S., Pill, R. and Jones, A. (1997). Mediation, chronic illness and identity: The perspective of people with asthma. *Social Science & Medicine*, 45(2), 189–201.
- Alonzo, A.A. (1984). An illness behaviour paradigm: A conceptual exploration of a situational-adaptation perspective. *Social Science & Medicine*, 19(5), 499–510.
- Arvola, T., Tahvanainen, A. and Isolauri, E. (2000). Concerns and expectations of parents with atopic infants. *Pediatric Allergy and Immunology*, 11(3), 183–8.
- Bury, M. (1997). *Health and illness in a changing society*. London: Routledge.
- Calnan, M. (1983). Managing 'minor' disorders: Pathways to a hospital accident and emergency department. *Sociology of Health and Illness*, 5(2), 149–69.
- Clark, J.A. and Mishler, E.G. (1992). Attending patients' stories: Reframing the clinical task. *Sociology of Health and Illness*, 14(3), 344–71.
- Conrad, P. (1985). The meaning of medications: Another look at compliance. *Social Science and Medicine*, 20(1), 29–37.
- Conrad, P. (1987). The experience of illness: Recent and new directions. *Research in the Sociology of Health Care*, 6, 1–31.
- Cunningham-Burley, S. (1990). Mothers' beliefs about and perceptions of their children's illnesses. In S. Cunningham-Burley and N. McKeganey (Eds.), *Readings in medical sociology*, pp. 85–109. London: Tavistock/Routledge.
- Emerson, R.M. and Messinger, S. (1977). The micro-politics of trouble. *Social Problems*, 25(2), 121–34.
- Englund, A.D., Rydström, I. and Norberg, A. (2001). Being the parent of a child with asthma. *Pediatric Nursing*, 27(4), 365–73.
- Gabe, J., Bury, M. and Ramsay, R. (2002). Living with asthma: The experience of young people at home and at school. *Social Science & Medicine*, 55(9), 1619–33.
- Goffman, E. (1967). *Interaction ritual: Essays on face-to-face behaviour*. New York: Doubleday.
- Gunnarsson, N., Marklund, B., Ahlstedt, S., Borell, L. and Nordström, G. (2005). Allergy-like conditions and health-care contacts among children with exclusion diets at school. *Scandinavian Journal of Caring Sciences*, 19(1), 46–52.
- Gustafsson, P., Kjellman, M. and Björkstén, B. (2002). Family interaction and a supportive social network as salutogenic factors in childhood atopic illness. *Pediatric Allergy and Immunology*, 13(1), 51–7.
- Hansson-Scherman, M., Dahlgren, L.O. and Löwhagen, O. (2002). Refusing to be ill: A longitudinal study of patients' experiences of asthma/allergy. *Disability and Rehabilitation*, 24(6), 297–307.
- Harré, R. and Davies, B. (1990). Positioning: The social construction of selves. *Journal for the Theory of Social Behaviour*, 20, 43–63.
- James, A. (1993). *Childhood identities: Self and social relationships in the experience of the child*. Edinburgh: Edinburgh University Press.
- Kleinman, A. (2006). *What really matters: Living a moral life amidst uncertainty and danger*. Oxford: Oxford University Press.
- Middleton, E., Ed. (1998). *Allergy: Principles & practice*. St Louis, MO: Mosby.
- Munoz-Furlong, A. (2003). Daily coping strategies for patients and their families. *Pediatrics*, 111(6), 1654–61.

- Olin Lauritzen, S. (1997). Notions of child health: Mothers' accounts of health in their young babies. *Sociology of Health and Illness*, 19(4), 436–56.
- Olin Lauritzen, S. (2003). Lay voices on allergic conditions in children: Parents' narratives and the negotiation of a diagnosis. *Social Science & Medicine*, 58(7), 1299–1308.
- Östergaard, M. (1998). Childhood asthma: Parents' perspective – a qualitative study. *Family Practice*, 15(2), 153–7.
- Platts-Mills, T.A.E., Erwin, E., Heymann, P. and Woodfolk, J. (2005). Is the hygiene hypothesis still a viable explanation for the increased prevalence of asthma? *Allergy*, 60(suppl. 79), 25–31.
- Prout, A., Hayes, L. and Gelder, L. (1999). Medicines and the maintenance of ordinariness in the household management of childhood asthma. *Sociology of Health & Illness*, 21(2), 137–62.
- Radley, A. (1994). *Making sense of illness: The social psychology of health and disease*. London: SAGE.
- Reichenberg, K. (2001). *Children with asthma and their families: Coping, adjustment and quality of life*. Göteborg: Nordic School of Public Health.
- Riessman, C.K. (1993). *Narrative analysis*. Los Angeles, CA: SAGE.
- Rudestam, K., Brown, P., Zarcadoolas, C. and Mansell, C. (2004). Children's asthma experiences and the importance of place. *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 8(4), 423–44.
- Rydström, I., Englund, A.D. and Sandman, P. (1999). Being a child with asthma. *Pediatric Nursing*, 25(6), 589–95.
- Sampson, H. (1999). Food allergy. Part 1: Immunopathogenesis and clinical disorders. *Journal of Allergy and Clinical Immunology*, 103(5, part 1), 717–28.
- Sicherer, S., Noone, S. and Munoz-Furlong, A. (2001). The impact of childhood food allergy on quality of life. *Annals of Allergy Asthma & Immunology*, 87, 461–4.
- Sundelin, C. (2000). The importance of the child health services to the health of children. *Acta Paediatrica: An International Journal of Paediatrics*, 89(Suppl. 434), 1–80.
- Voysey, M. (1975). *A constant burden: The constitution of family life*. London: Routledge & Kegan Paul.
- Williams, C. (2000). Alert assistance in managing chronic illness: The case of mothers and teenage sons. *Sociology of Health & Illness*, 22(2), 254–72.
- Zernike, W., Corish, T. and Henderson, S. (1997). An exploratory study from the patient's perspective living with allergies. *Journal of Clinical Nursing*, 6(5), 371–7.
- Zola, I.K. (1973). Pathways to the doctor – from person to patient. *Social Science & Medicine*, 7(9), 677–89.

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