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# Discovery and management of child allergy from the parent perspective

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## ABSTRACT

The overall objective of this thesis is to extend the knowledge and deepen the understanding of care-givers management of child allergy, especially of suspected food allergy. This is done by describing and exploring how parents with children who have exclusion diets at school discover and responds to their children's allergy-related problems.

The first study focuses on the whole group of children (n 230) with special diets at school from the viewpoint of parents' knowledge and management of the children's problems. It addresses questions regarding (1) whether or not the children have had contact with health care, (2) whether or not they were diagnosed with food allergy, (3) to what extent they had other allergies, (4) what characterized their food-related symptoms, (5) if these symptoms were consistent with the clinical experience of food allergy (6) and any differences in parents' reports of the extent of children's food-related problems in regard to whether they had sought health care or not. The results showed that the majority of parents had consulted doctors for their children's problems, and most children had been diagnosed by a doctor. Most children also had other allergies or asthma in addition to their food-related problems. The children's food-related problems were consistent with the clinical experience of food allergy. Parents who had sought medical aid for their children's problems described more extensive and potentially life-threatening (e.g. anaphylactic) symptoms than did the parents who had not sought professional help. Overall, the characteristics of children's symptoms were similar in both groups and were considerable enough to explain why they avoided certain foods and had exclusion diets at school.

The second study addresses the question of how parents discovered developing bodily symptoms when the children were young, how they interpreted and responded to the problems before they decided to seek professional medical help and how they came to the decision to seek help. Nineteen parents were interviewed about the problem-solving process consisting of two temporal phases: (1) the pre-problem phase, or the period before the child's problems had emerged, (2) and the emerging phase where bodily problems were discovered and managed differently depending on the emerging nature of the problem that were either (2.a) acute (airway problems) or (2.b) more gradually appearing (stomach problems and eczema) in the families' everyday lives. To understand and manage the time period before the child was born, before he/she had developed any symptoms and the phase when the symptoms emerged, parents used different self-diagnostic techniques and methods. They experimented with different temporal and situational clues that eventually led them to explain their children's symptoms as indicating

something wrong, and not as normal children's problems, as they had first thought. Only when parents could not fully explain the child's symptoms or make the problems disappear or improve, did they often seek medical advice or care at the child health care centre.

The wide-ranging knowledge and experience parents have of their children's allergies are a result of their active strategies and by reinforcing themselves as active and in control they also demonstrated their moral responsibility as parents. The fact that the child's whole lifetime and different temporal contexts are used by the parents in their decisions about seeking professional help, eating habits and exclusion diet at school is an important factor that has to be considered in clinical practice. Health care professionals have to listen to what parents have done before seeking medical help, who they are and how they want to be seen by others because this would improve the communication between parents and health professionals as well as the parents' satisfaction with health care.

Key Words: allergy, exclusion diet, illness behaviour, help-seeking behaviour, care-givers strategies, narratives

## SAMMANFATTNING

Det övergripande syftet med denna avhandling är att öka kunskapen om och fördjupa förståelsen för föräldrars sätt att hantera barnallergi, speciellt misstänkt födoämnesallergi, genom att beskriva och utforska hur föräldrar med barn som har specialkost i skolan upptäcker och responderar på barnets allergirelaterade besvär.

Den första studien beskriver och analyserar hela gruppen barn med specialkost i skolan utifrån föräldrars kunskaper om och hanterande av barnets besvär, och besvarar frågor om (1) barnen haft kontakt med sjukvård, (2) om de blivit diagnostiserade, (3) i vilken uträkning de hade andra allergier, (4) hur deras födoämnesproblem såg ut och (5) om symptomen var konsistenta med klinisk erfarenhet, (6) samt om det var någon skillnad på föräldrarnas beskrivningar av barnens problem om de sökt vård eller inte. Resultaten visade att majoriteten av föräldrarna hade sökt vård någon gång för barnets besvär, flertalet barn var diagnostiserade av en läkare och att de flesta hade andra allergier eller astma förutom sina födoämnesproblem. Deras födoämnesproblem överrenstämde med den kliniska erfarenhet som idag finns om födoämnesöverkänslighet. Föräldrar som uppsökt vård för barnens besvär beskrev mer omfattande och potentiellt livshotande ( ex. anafylaxi ) problem än de föräldrar som inte hade sökt vård. Utöver detta var barnens problem likartade och barnens sammantagna och omfattande problem gör det möjligt att förklara varför de undviker viss föda och därmed har specialkost i skolan.

Den andra studien besvarar frågan hur föräldrar upptäckte framträdande kroppsliga symptom hos barnet när det var litet, och hur de tolkade och hanterade problemen innan de sökte professionell hjälp, och vad som gjorde att de sökte hjälp. Nitton föräldrar intervjuades om denna problemlösarprocess bestående av två temporala faser, (1) perioden innan barnets problem hade framträtt, (2) samt själva framträdande fasen där problemen upptäcktes och hanterades olika beroende på om problemen uppträdde (2. a) akut (luftvägsbesvär) eller hade en mer (2.b) gradvist (magproblem och eksem) framträdande roll i familjen vardag. Föräldrarna använde olika självdiagnostiserande tekniker och metoder både innan och efter barnet var fött och hade utvecklat besvär och för att kunna förstå de framträdande allergiska besvären. De experimenterade med temporala och kontextuella ledtrådar som så småningom ledde till att föräldrarna kunde förklara symtomen annat än som ”normala” småbarnsproblem som de först trodde de var. Först när föräldrarnas egna metoder inte kunde förklara barnets problem fullt ut

eller få barnet problem att försvinna eller bli bättre, sökte de oftast professionell medicinsk upplysning eller vård på barnvårdscentralen (BVC).

Den omfattande kunskap och erfarenhet som föräldrarna har om sina barns allergiska besvär är ett resultat av deras aktiva strategier. Föräldrarna påvisar också sitt moraliska ansvar som föräldrar genom att presentera sig själva som aktiva föräldrar som har kontroll över situationen. Att barnets hela levnadsförlopp och olika temporala ledtrådar används av föräldrarna i deras beslut om att söka professionell hjälp, matvanor och special mat i skolan är faktorer som är viktiga att ta hänsyn till i den kliniska praktiken. Sjukvårds personal behöver lyssna till vad det är föräldrarna har gjort innan de söker vård, vilka de är och hur de vill bli uppfattade av andra, eftersom detta skulle kunna förbättra kommunikationen mellan föräldrar och sjukvårdspersonal och föräldrarnas tillfredsställelse med vården.

Nyckelord: allergi, special mat, sjukdomsbeteende, hjälp-sökarbeteende, föräldrastrategier, narrativ

## LIST OF PUBLICATIONS

This licentiate thesis is based on the following publications, which are referred to in the text with their Roman numerals.

- I. **Gunnarsson, N.\***, Marklund, B.\*, Ahlstedt, S., Borell, L.& Nordström, G. (2005). Allergy-like conditions and health-care contacts among children with exclusion diets at school. *Scandinavian Journal of Caring Science*, 19, 1-7.
- II. **Gunnarsson, N.** & Hydén, L-C. Organizing allergy: Parents' narratives about their children's emerging problems. Submitted.

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## INTRODUCTION

This licentiate thesis intends to contribute to knowledge that can be used in clinical practice, by deepening the understanding about the strategies parents use to discover and manage their children's allergies. It also aspires to contribute to the social science research of care-givers illness and help-seeking behaviour in terms of allergy. How care-givers such as parents manage their suspicions about children's allergies and what they do in terms of management and seeking professional help have not been well described and explored earlier, especially in relation to food-related symptoms and in decisions about eating habits and food exclusion at school. This thesis seeks to describe and explore these aspects through different methods, using both a telephone survey and retrospective narrative interviews.

Most children with allergies are diagnosed and treated within primary health care (Foucard, Hedlin & Kjellman, 1998). However, there are no diagnostic instruments for food-related allergies that can be used easily in primary health care practice to decide accurately whether a child has food allergies or not, or what foods cause the child's symptoms (Pascual, et.al., 2000). Symptoms of food allergy are often non-specific in young children, ranging from sleeping problems, vomiting and diarrhoea to general discomfort, dry and red skin, rashes and crying. This may create considerable trouble for parents who try to understand and respond to symptoms in their children which they suspect are related to food allergy. At the same time, going to see a doctor may not help, because clinical professionals cannot always give clear answers to parents about their children's conditions. As a consequence, parents may have difficulty knowing what to do to help their children. In addition to the difficulties of diagnosis, the knowledge of what causes allergic conditions is still limited (Illi, et.al., 2001), although great advances have been made in research, pointing to lifestyle factors such as diet and reduced physical exercise, as well as infections as possible explanations (Kjellman, 1998; Platts & Mills, 2005)

Many children suffer from different allergies and there is a great interest in allergy research from public arenas such as the media and patient associations. These distribute knowledge and opinions on allergy in society, through pictures and text on the Internet, allergy conferences and other forums. Because of the public interest in allergy lay people today have considerable information and awareness of allergy-related medical theories, medical concepts and research findings. Individuals and care-givers are known to merge their personal experiences of illness

with different medical explanations to explain and make sense of their own or others' illnesses (Bury, 1997; Olin Lauritzen, 2003; Roll Bennett, 2006).

Different theories about the increase and development of allergy that circulate in the media also contribute to the strong cultural connotation in society about the individuals' or care-givers responsibility for their own or others' health and illness. People's homes, ways of living and close surroundings are presented as dangerous; there may be risks of illness everywhere, in what people eat and what they do or don't do (Eriksson & Quarsell, 2000).

Considering this, and the fact that the knowledge about why people develop allergies is still limited, together with the lack of specific diagnostic instruments for certain types of allergies that can easily be used in clinical practice, it thus becomes both interesting and important to study how people manage their suspicions about allergy. It is especially important how parents deal with their suspicions about their children's problems, as allergies develop early in life. Parents, especially mothers, are known to observe closely their children's reactions and behaviours as part of their parenting (Cunningham-Burley, 1990).

Several questions can be formulated in regard to how parents manage suspicions about allergy in their children. One important question that will be addressed in the thesis is that of the processes through which parents discover symptoms when the child is young and how they interpret and respond to these symptoms before they seek professional help, contributing to a social scientific field also known as illness and help-seeking behaviour (Mechanic, 1962; Bury, 1997). How this early process is accounted for by care-givers and how parents in their narratives present the transition from normal to problematic allergy symptoms that are worthy of medical attention is not known.

Another significant question addressed is what decisions parents make about the child's eating habits and about food avoidance at school. There is no previous knowledge about *why* children have exclusion diets at school and to what extent this is due to parents suspecting allergy. These aspects are of importance because of the widespread suspicion among people today of a strong connection between the consumption of certain foods and allergy problems and the many school children that avoid certain foods without first seeing a doctor (Brugman, et.al., 1998). Hence topics worth studying are to describe the children's illness and medical histories, the characteristics and magnitude of these children's allergy problems, to what extent parents have

felt it necessary to seek professional medical aid for their food-related problems and if and how they have been diagnosed.

Finally, these questions have practical importance, especially in the clinical context. It is necessary for the patient to believe that the doctor or other health professionals pays attention to the patients' individual problems for him or her to go to see a doctor in the first place, and thereafter continue the contact with health care and perhaps follow treatment agreements. If the patient does not believe that he/she is being acknowledged or listened to, the doctor may have difficulties in attaining enough medical information to make a diagnosis and give effective treatment (Stewart & Sullivan, 1983, Mishler, 1984).

How parents think and act concerning their children's suspected allergies is significant knowledge for clinical practice as it can facilitate the meeting and communication between health professionals and parents.

## AIMS

The overall aim of the thesis is to extend the knowledge and deepen the understanding of caregivers management of child allergy, especially suspected food allergy, by describing and exploring how parents with children who have exclusion diets at school discover and respond to their children's allergy-related problems.

This was done by describing health care contacts and diagnostic testing among school children with exclusion diets and comparing the magnitudes of allergy-like conditions among those children who had vs. those who had not consulted health care professionals for their food-related problems (**Study I**), and by exploring parents' narratives about how they recognise, interpret and respond to their children's bodily problems (**Study II**). Collecting and analysing narratives about the pathway from detection of symptoms to medical help is a way to understand how parents construct and organize their understanding of their children's allergies in a way that prompts them to seek professional medical aid.

## **KNOWLEDGE AND RESEARCH ABOUT ALLERGY**

This chapter reviews aspects of the knowledge and research of allergy and asthma in two contexts, that of biomedicine and that of social science. The first part of the chapter presents medical definitions and knowledge about allergy with a particular focus on the clinical difficulties of symptoms, diagnosis and treatment of food allergies. The second part presents the social scientific knowledge of chronic illness and allergy, and introduces studies that focus on peoples' illnesses and help-seeking behaviour, parents' understanding and explanation of children's allergy, consequences of asthma and allergy and different adaptation strategies used by children, their parents and others, for example how people try to maintain a normal life despite their allergies.

### **Allergy in the context of biomedicine**

#### **The allergic (atopic) conditions**

Allergy is a common health problem among children, and in Sweden one in four children is reported to suffer or have suffered from an allergy (Wickman & Lilja, 2003). Allergy in children involves many different conditions, definitions and mechanisms. The medical definitions of allergy were originally developed from the patients' clinical symptoms, and have continually changed with increased knowledge (as reviewed by Hed, 1998). Children may today be hypersensitive to many different substances, but only the conditions that can be medically proven to include the immune system are defined as allergies (Johansson, et.al., 2001).

There are different types of immune responses and the most common and well defined is the IgE mediated antibody reaction involved in the atopic diseases of asthma, hay fever (rhinitis), eczema and food allergy (Ahlstedt & Murray, 2006). Atopy means the inherited tendency to form IgE antibodies after normal contact with common allergens. Once sensitized, any new exposure to the allergen may lead to the development of allergic symptoms. The IgE mediated reaction can be diagnosed with IgE antibody tests in blood and on the skin, together with a clinical examination([http://www.aaaai.org/media/resources/academy\\_statements/practice\\_papers/allergy\\_diagnosis.pdf](http://www.aaaai.org/media/resources/academy_statements/practice_papers/allergy_diagnosis.pdf)). The allergic conditions can involve different organ systems such as the skin, the upper and lower airways, and the gastrointestinal tract, and it is not uncommon that a child can have symptoms from two or more organ systems or suffer from more than one allergy (Sampson, 2004).

Different allergies may come and go in a child's life. The natural history of allergic conditions is not fully understood but the phrase "allergy march" was coined to describe the disease course of allergic conditions and how one allergic problem may follow another in the course of a child's life. The march may start in infancy with symptoms from the skin (eczema) and then with symptoms from the gastrointestinal tract often caused by food allergens (e.g. milk and eggs), and later on with symptoms from the respiratory tract in forms of wheezing, asthma and hay fever (Wahn, 2000; Illis, et. al., 2001).

### **The non-allergic conditions**

There are other clinical conditions without any known immunological mechanisms that are very similar to the allergic conditions. The knowledge of these non-allergic problems is generally scarce and only some of these problems are well understood, for example enzyme deficiency in lactose intolerance. Other non-allergic conditions are unspecific bronchial hyperreactivity and food intolerance. The distinctions between allergic and non-allergic conditions are difficult to make in clinical practice (Ahlstedt & Murray, 2006), although the allergic reaction frequently manifests itself early in life and is often more severe and persistent than the non-allergic reaction (Sampson, 1999). It is particularly difficult to differentiate symptoms from the gastrointestinal tract, which is the area that is most frequently affected in food allergy and food intolerance (Sampson, 1999).

### **Symptoms in food allergy and food intolerance**

To know if a child is hypersensitive to foods in any way is complicated. It may be difficult to link the suspected food to a manifestation of symptoms in the child, regardless of the underlying mechanism. Food hypersensitivity includes all abnormal reactions to foods, both immunological (food allergy) and non-immunological (food intolerance). Some children with allergies have negative test responses and some who do not suffer from allergy have positive results (Lilja, 1998). This is more evident in food-related problems than with other allergies (Sampson, 2004). Furthermore, delayed reactions are also known to occur several hours or days after ingesting the food.

Because of these difficulties the prevalence of clinically significant food allergy in children is not clear. Nevertheless, there is a significant gap between the self- or parent-reported food allergy



prevalence and the prevalence of verified food allergy (Sampson, 1999). In Sweden, 20% of schoolchildren and adolescents report adverse reactions to certain foods (Marklund, Nordström & Ahlstedt, 2005). Although the IgE mediated food allergy is more prevalent in young children and individuals with atopic diseases (Sampson, 1999) it has been estimated to be between 4-8% in children and younger individuals (Sampson, 1999; Sampson, 2004). However, this may be due to food hypersensitivity having other unknown immunological and non-immunological mechanisms that are not captured by means of current tests.

A child that suffers from food allergy can experience several different symptoms. These may include symptoms from the skin, atopic eczema and itching, hives (urticaria), eczema, symptoms from the respiratory tract and gastrointestinal tract such as angioedema, OAS (oral allergy syndrome which results in mouth itch, swollen lips, blisters and swollen throat) and nausea, vomiting, diarrhoea or constipation, stomach pains, failure to thrive, and symptoms from the airways like runny eyes and nose (rhinitis) and asthma (Sampson, 2004). A particularly acute and severe adverse reaction is anaphylaxis, which results in symptoms in all of the above areas, including blood circulation (Sicherer, 2002).

Food intolerance is most frequently seen in infancy and symptoms are mainly provoked by cow's milk or soy protein-based formulas. In older infants and children egg, wheat, rice, oat, peanut, other nuts, chicken, turkey and fish sensitivity cause similar symptoms (Sampson, 1999). Food reactions are also known to vary at different times and in the degree of severity. Sometimes a child may tolerate the offending food and sometimes he/she will not, or the child may experience a mild reaction at one time and a day or two later a more severe reaction will occur (Sampson, 2004; Dannaeus & Foucard, 1998).

Many children outgrow their food allergies. As many as 80% of children outgrow their sensitivity to milk within the first 3 - 5 years of life, and about 60% their sensitivities to egg, wheat and soy (Sicherer, 2002). The allergic conditions may change over a child's lifetime; different new allergies can develop and others may disappear. However, Sicherer (2002) states that it seems to be increasingly common that food allergy in children persists up to school age, which would make the need of exclusion diets at school increasingly more common, at least in contexts like the Swedish one where midday meals are served at school.

## **Diagnosis and treatment**

The best way to find out if a food item might be responsible for children's symptoms is to do provocation tests. This is done through triggering symptoms by supplying the allergen to the symptomatic organ. In food allergy diagnosis it is preferable to perform a double-blind, placebo-controlled oral food challenge (DBPCFC). This is considered to be the only gold standard method for diagnosing food-related problems (Bock, et. al., 1988).

The DBPCFC method has the advantage of being able to reproduce and validate the link between symptoms and the offending food both in non-IgE mediated food allergy and in food intolerance. Delayed reactions from foods can be missed with this method and false results are possible because of confounding factors such as infections and physical exercise. As with all provocations the method may also be potentially dangerous as well as extremely laborious and time-consuming. Its usefulness in health care practice is thus limited, and the method is mainly used in research (Bock, et.al., 1988; Zuberbier, et al., 2004).

Another common way to diagnose food-related problems is to eliminate the suspected food from a child's diet and watch what happens. Parents are often recommended by the doctor to try this at home. However, as food reactions are known to vary at different times and in the degree of severity, both elimination and provocation tests can be inconclusive and difficult for the doctor to evaluate (Lilja, 1998; Sicherer, 2002). This is why diagnosis of food allergy must always be made together with a thorough clinical history (Ortolani, et al., 1999).

There are still no pharmacological treatments for food-related problems, in contrast to asthma and hay fever, although promising combinations of immunotherapy and anti-IgE therapy has been tried (Sampson, 2004). Treatments are often limited to having parents try to exclude the offending food from the child's diet (Spergel & Pawlowski, 2002).

Hence, parents often have to both diagnose and manage their children's food problems by themselves and this may be a difficult task, especially when diagnosis of food allergy is unclear. Food avoidance is seldom easy, even in the case of a verified food allergy, and many parents do not know what the child may need to avoid or what may be unnecessary to do in terms of lifestyle changes.

## **Conclusion**

The fact that children's problems were defined and diagnosed as *allergy* by their parents or a doctor has been accepted for the purpose of this thesis, regardless of whether the diagnosis is correct or not. It is the parents' own perceptions and experiences of their children's problems that are in focus here, and both allergic and non-allergic problems affect children's and families' everyday lives in different ways. Additionally, because many food-related problems is difficult to verify, especially in primary health care practice where most suspected food problems are diagnosed and treated, health professionals, schools and families are left to deal with suspected food allergies in their own way.

Parents understand and explain their children's problems from a cultural and social context that is wider than just a medical one. Like many medical terminologies, that of allergy has expanded outside the domains of biomedicine, and is also used in daily language as a metaphor for things people may have strong feelings about, such as foods, mothers-in-law or politics. It is important to gain knowledge about the wider cultural and social meaning of allergy because it influences people's choices of lifestyle, eating habits, living accommodations and their patterns of consumption (Eriksson & Qvarsell, 2003).

## **Allergy in the context of social science**

Studies reviewed in this section come from the social scientific tradition focusing on illness and health, and the relatively few studies that have explored parents' and children's experiences and notions of asthma and allergy. The biomedical perspective of allergy provides important knowledge about potential causes, mechanisms, diagnosis and treatments of the allergic and non-allergic conditions. But it does not tell much about how individuals and care-givers discover, interpret and respond to bodily changes and symptoms, how parents understand and explain the allergic conditions, what consequences allergy has on children's and their families' lives and how they adapt to and cope with these in their everyday lives. Chronic illnesses and illness experiences are complex and are known to be affected by psychological, social and cultural factors (Bury, 1997).

To gain more in-depth knowledge about the social perspective of allergy other methodologies must be used, for example interviews with people whose lives and situations we would like to explore.

### **Illness and help-seeking behaviour**

The “discovery” of bodily signs and symptoms does not automatically compel people to seek medical aid. Most people initially try to manage their emerging symptoms by themselves and it is only when these various home remedies fail that they go to see a doctor (Emerson & Messinger, 1977; Bury, 1997)

How people recognise and respond to symptoms and how they come to use health care services in this process is research most often studied by social scientists (Mechanic, 1968; Freidson, 1970; Zola, 1973; Stewart & Sullivan, 1982; Calnan, 1983; Young, 2004). Among the first researchers to acknowledge and shape this research was Mechanic (1968) using the concept of *illness behaviour* to describe the process of how people and those close to them perceive, evaluate and especially act upon symptoms in different ways. From this and other early studies many others have followed on the subject of help-seeking and illness behaviour. However, certain research in illness behaviour has tried to find psychological, socioeconomic, cultural and other factors that can explain why and how people seek medical care (Radley, 1994; Bury, 1997; Young, 2004). But finding factors that account for help-seeking behaviour in populations generally fails to take into consideration the social process people go through when recognising symptoms, falling ill and deciding what to do.

Several studies have shown that people’s illness and help-seeking behaviour involves a series of pathways or decisions from the initial symptom recognition to illness responses and treatment. It is in relation to particular family, work and other aspects of a person’s social life that the decision about who is sick is determined (Stewart & Sullivan, 1982; Calnan, 1983; Cunningham-Burley & Irvine, 1987; Richt, 1993; Young, 2004; Uehara, 2001; Morgan et al., 2004). It is known that people use their social networks, termed lay referral systems (Freidson, 1970), to find out the significance of their symptoms (Radley, 1994; Bury, 1997).

It is also known that many symptoms, both minor and more severe, are not taken to the doctor. Symptoms that people seek medical advice for are not always more severe than those that they do not seek help for (Mechanic, 1968; Zola, 1973; Emerson & Messinger, 1977; Radley, 1994;

Bury, 1997). In general it seems that people perceive themselves as sick and go to see a doctor when symptoms interfere with their lives and when the adjustments that the individual or the family have made to bodily signs and symptoms fails (Zola, 1973; Stewart & Sullivan, 1987; Radley, 1994).

Alonzo (1984) described how a situation or context in which the symptoms appear decides whether or not the individual can contain or manage the symptom without direct medical consultation. In some situations people presume that they will experience certain bodily discomfort and therefore do not comprehend the symptom as a sign of something wrong, while in other situations the same bodily signs and symptoms would be seen as deviant and a possible symptom of illness (Alonzo, 1984). The containment of symptoms is affected by a person's or/and other peoples' commitment to the situation.

If people are to be successful in enduring bodily discomforts and illness symptoms and can do so without seeking medical help, they need to have situational resources to manage their signs and symptoms. Resources include anything that the individual and others perceive as aiding them in their management of symptoms and their adaptation to the situation both in the present and in the long term. These resources can include factors like previous medical advice, home remedies, prescribed medications and sleep/rest (Emerson & Messinger, 1977; Alonzo, 1984).

There are numerous studies on the illness and help-seeking behaviour of general symptoms and about the general decision-making processes (Emerson & Messinger, 1977; Alonzo, 1984; Young, 2004; Ogden, 2007) and on different illnesses such as MS and diabetes (Stewart & Sullivan, 1987; Richt, 1993) and recently, for example, in terms of cultural pathways in psychiatric illnesses (Uehara, 2001; Morgan et al., 2004). Although allergy is one of the most common chronic illnesses among children in the modern world, there are no studies that have focused on the discovery process of allergy, in terms of food-related problems and exclusion diets, and the help-seeking behaviour of care-givers who suspect allergies in their children.

### **Parents' understanding and explanation of children's allergy**

In understanding and explaining health and illness in various ways people use complex systems of values, ideas and practices, known as *social representations* (Herlich, 1973; Bury, 1997). These lend order to people's material and social worlds, and make communication possible between people so that each person can name his/her own personal world and the world they share with others. For instance, it is well known that physicians' and patients' illness representations differ a great deal (Kleinman, 1988; Platt & Keating, 2007).

In terms of child allergy, parents' explanations reveal a complex pattern that intertwines medical explanations and the parents' own experiences of allergic conditions (Olin Lauritzen, 2003; Roll Bennet, 2006). For instance, parents reflected on different causes of their children's allergies that they referred to as "shared or generally known" (Olin Lauritzen, 2003; Roll Bennet, 2006). In these they included aspects of the physical environments such as bad or polluted air, chemicals and housing, elements of the families' lifestyle such as having pets at home, smoking and different types of foods that should be avoided (Olin Lauritzen, 2003; Roll Bennet, 2006). Many parents also believed that allergy was caused by a combination of different causes and that these were individual (Olin Lauritzen, 2003). Parents' understanding was often connected to what they believed they could do in order to influence the children's problems (Roll Bennet, 2006).

Olin Lauritzen (2003) found three different explanation narratives that were used by the parents to understand children's allergy. Some parents talked about their children's allergies as something temporary, saying that the child had been ill but was now healthy again, and these parents normally did not view their children as allergic. The most common explanation found among parents was that the child was generally perceived as healthy but had episodes of illness. These parents said they "did not know" if the child had allergy. Other parents were convinced that their child suffered from an allergic condition. These were the parents that had either accepted a previous allergy diagnosis or parents with non-diagnosed children that had been convinced from the beginning that the child was going to be allergic (Olin Lauritzen, 2003).

### **Children's experiences of the consequences of asthma and allergy**

Allergy is known to have significant impact on health-related quality of life in children and their parents (Meltzer, 2001; Sicherer, Noone & Munoz-Furlong, 2001; Marklund, Ahlstedt & Nordström, 2004, 2005). Studies show a reduced health-related quality of life among children with food allergies, according to both the parent's and children's own statements (Sicherer,

2001; Marklund, Ahlstedt & Nordström 2004), and in populations of both medically verified allergy (Sicherer, 2001) and self-reported allergy (Marklund, Ahlstedt & Nordström 2004, 2005). In a study by Nocon & Booth (1991) a positive correlation was found between the severity of asthma symptoms and the social impact of the illness in adults and small children. It has also been shown that breathing problems, such as wheezing and asthma when the child is young provoke anxiety in the parents that may lead to problematic family interactions (Gustafsson, Björkstén & Kjellman, 1994).

Such studies are important, as they show that allergy has both social and psychological impact on families and on children's lives, regardless of whether children had correctly diagnosed allergies or not. But these studies do not tell much about how individuals experience their illness and how they manage the affect it has on in their everyday lives. Interview studies on different illness experiences, including allergy and asthma, show that the different explanations and strategies that individuals or parents favour are not related to the severity of individuals' or children's problems (Schneider & Conrad, 1981; Radley 1994; Bury, 1997; Prout, Hayes, & Gelder, 1999; Olin Lauritzen, 2003).

By focusing on people's interview accounts and how children and care-givers experience the *consequences of illness* in their everyday situation, aspects that emerge are connected to the meaning of illness and how the onset and persistence of symptoms may disrupt the flow of normal everyday living and create a growing uncertainty in individuals' and families' lives (Charmaz, 1993; Bury, 1997). Chronic illnesses may in different ways be potentially disabling, and self-care activities and different daily routines at home, at work and in school may become problematic (Bury 1991, 1997; Gabe, Bury & Ramsay, 2000).

In terms of the consequences of allergy some authors have interviewed children about their experiences of asthma, and these studies show that the children were often unable to participate in physical and social activities at school (Prout, Hayes, & Gelder, 1999; Gabe, Bury & Ramsay 2000; Rudestam et al., 2004).

Children's experiences of asthma also shaped the children's experiences of place (Rudestam, Brown et al., 2004). Their asthma affected the time they spent outside, being active and meeting friends. In comparison with their non-asthmatic peers the children with asthma were more sensitive to "dirty" places or places that were connected with asthma triggers. They were less

likely to visit new places or sparsely populated areas. Instead they preferred places that offered safety and family support. These children described asthma as something existing outside of themselves, over which they had no control.

Although asthma is described by the children and parents as having a negative impact on their everyday lives, the children also describe themselves as active in regard to their illness (Prout, Hayes & Gelder, 1999; Gabe, Bury & Ramsay, 2000). The children talked about how they had found ways to manage their problems that could help them to feel less disadvantaged; these included mobilizing social resources such as peers and teachers at school (Gabe, Bury & Ramsay, 2000).

### **Adaptation strategies – maintaining a normal life**

To limit the practical and social consequences of chronic illness, individuals and their families become preoccupied with managing symptoms, and both short- and long-term management strategies may be used (Radley, 1994; Bury, 1997). The different *adaptations* that people make in response to illnesses are a way for the ill to bridge self, identity and social action (Bury, 1982; Charmaz, 1993). Children with asthma and allergy, like other chronically ill individuals and their care-givers, have been found to minimize the affect the illness has on their lives by trying to reconstruct a normal life, a process known as a *normalisation* (James, 1993; Adams, Pill et al., 1997; Bury, 1997; Prout, Hayes & Gelder, 1999; Hansson-Scherman, Dahlgren & Löwhagen, 2002; Roll Bennett, 2006).

Prout (1999) and co-worker found that children with asthma did not present their illnesses as being very problematic, despite the inability they experienced in joining in physical and social activities. It was considered “normal” occurrences for them to sneeze and cough, and the children still thought of themselves as well (Prout, Hayes & Gelder, 1999). Symptoms like wheezing and coughing were also experienced as quite normal occurrences by the parents and the symptoms were not directly associated with asthma, although all children had received an asthma diagnosis (Prout, Hayes, & Gelder 1999).

According to Prout (1999) and co-workers children and their parents were primarily concerned with maintaining and producing a sense of *ordinariness* in their everyday lives. Strategies like removal or avoidance that included getting rid of furred animals or changing carpets were not used much. Both the children and the parents were more prone to use asthma medication in



managing asthma problems. The authors argue that asthma medications were more useful in keeping up the ordinariness of the families' everyday lives because taking medication did not affect the families' lives as much as lifestyle changes did. However, parents of children with eczema and allergy did discuss removal strategies and how they had tried to avoid different foods (Roll Bennet, 2006).

Another aspect of maintaining a normal life is that parents often relate and compare their children's illness symptoms to those of other individuals who have much worse problems (James, 1993; Prout, Hayes, & Gelder, 1999; Roll Bennet, 2006). Some parents said that their children with eczema were accustomed to their problems, and unaffected by their allergies (Roll Bennett, 2006).

To maintain a normal or ordinary life is also closely connected to people's identities (Radley, 1994). Adults with asthma rejected and distanced themselves from asthma, or redefined their social identity of asthma, especially when their perception of being asthmatic yielded a strong negative and stigmatising mark (Adams, Pill & Jones, 1997). In particular they denied or distanced themselves from the asthmatic identity when and if it was perceived as being a threat to their self-images (Adams, Pill & Jones, 1997; Hansson-Scherman, Dahlgren & Löwhagen, 2002).

A common picture in these studies is that children with allergies, their care-givers and other people try to maintain a normal life through different normalisation strategies, aimed at either rejecting a diagnosis or illness identity, concealing the illness identity or by accepting and using medication in order to maintain a sense of "ordinariness" in their lives.

### **Knowledge gaps in the social course of allergy**

In regard to the above studies there are still some gaps in the understanding and knowledge about the social aspects and social course of allergy. An improved knowledge of these aspects could complement the vast biomedical field and growing understanding of allergy in terms of causes and biological mechanisms. Specifically there is a lack of knowledge about how care-givers such as parents interpret and respond to different allergy-related symptoms before they decide to seek professional medical help and before the children are diagnosed with allergy. In general, allergy has been a neglected research area for social scientists interested in illness behaviour, although allergy has been the most rapidly increasing condition, affecting four times as many children today as it did four decades ago. Few studies have explored care-givers illness behaviour

and how they understand and act when family members fall ill. Most research on illness behaviour has focused on individuals own “falling ill” process (Radley, 1994; Bury, 1997). Another aspect not well understood is how time and morality influence the illness behaviour of care-givers. Finally, knowledge about how parents manage suspected food allergy at school and in terms of food avoidance is lacking.

This thesis is an attempt to show how, for example, foods, time and situations are evaluated and used by the parents in the process of discovering and managing allergy problems in their children and in their decisions about exclusion diets and professional help-seeking.

## METHOD AND DATA

In this thesis two methods were used to describe and explore the ways parents manage their suspicions of children's allergy (see Table 1; page 21). In the first study a quantitative survey approach with structured telephone interviews was used to describe parents' reports of the magnitude of different allergies, symptoms, diagnosis and health care contacts among children with exclusion diets. In the second study narrative interviews were carried out to explore how parents construct and present the process through which they "discover" their children's allergies.

### Study population

#### Children with food certificates for exclusion diets

The schools in Sweden serve a warm mid-day meal for the children, and children who suffer from food allergy may need different exclusion diets or special meals. Beside food allergy, other reasons why children avoid foods in school include religion, ideology and illnesses such as diabetes.

In Tyresö, a municipality south of Stockholm the exclusion diets were organised by means of specific food certificates. Tyresö municipality was chosen as the site of the study for two reasons. First, there was already a research contact between the Karolinska Institute and the municipality, and secondly there was already an interest in the municipality about how well the food certificates fulfilled their purpose. This made it possible to collect and systematize the information needed to describe and explore the problem of suspected food allergy.

Eight percent of the children in the Tyresö public schools had exclusion diets at school. However, according to school nurses and kitchen staff many of these special meals were not eaten and the benefit of these special meals seemed not to be fully utilized by the children. The reasons behind the diets and how many children had exclusion diets because of suspected food allergy were not clear. There was no previous knowledge about this group of children with suspected food allergy in terms of their problems and their contact with health care despite the fact that they were served these special meals at school.

The food certificates included information about the different reasons for exclusion diets and what foods that the children should avoid. Different food items such as known allergens, for example egg, milk, and soy, and fish and pork in terms of religion were specified in the certificates. A medical statement was not required to obtain exclusion meals. The school nurses wrote and administrated the certificates based on parents' or the older children's information. The certificates were then forwarded by the nurses to the school kitchen where all meals were prepared.

## **Sampling procedure and study participants**

### **Study I**

Consent to collect the food certificates were obtained from the municipality and an ethical committee at Karolinska Institute. All food certificates that school children had in the last quarter-year of 2001 were coded by the diet consultant and then collected by the two authors (NG & MB). In all, 7216 schoolchildren were registered at 17 public schools in the municipality and 8% (n 602) of them had a record of certificates for exclusion diets. Approximately half of the food certificates (n 272) had been issued for reasons related to religion or ideology e.g. vegetarianism, or for diseases such as diabetes, celiac disease and ulcerative colitis or mere dislike for certain food.

As the purpose of the thesis was to extend the knowledge of parents' perspective of their children's allergy-related problems, we only included those children whose parents suspected food allergy. After eliminating the 272 children with other reasons for food exclusion, including the six children who clearly just disliked certain food, 291 children remained. These food certificates indicated food avoidance because of some kind of adverse reaction.

The food certificates could change considerably for each school term, and it was found that the schools had difficulties keeping them accurate and up to date. From the 291 food certificates, information about 17 children's home addresses or phone numbers was missing and thus 274 children's parents could be contacted. The parents initially received a letter with information about the study and were informed that they were going to be called by telephone within two weeks. They were encouraged to phone or return an attached note if they did not want to be contacted. In all, 13 parents declined participation. Another 31 children were excluded as their parents said that their children did not have any food restrictions at school anymore. The schools had simply failed to remove these certificates for the coming school term. Thus, the final sample

of children who had exclusion diets at school in November 2001 because of suspected food allergy comprised 230 children. As some of the 230 children were siblings, 215 parents were selected to participate in the first study. Only one parent in each family was asked.

The majority of the participants were mothers (80%). Several of the fathers said that it was the mothers who had the most knowledge about the children's problems, so what the fathers often did was to hand the telephone over to the mothers. All parents understood and spoke Swedish. The majority of parents had either a university degree (39%) or had attended secondary school (50%), and this was representative of the municipality as a whole.

## **Study II**

In Study II a smaller and more specific sample (Patton, 1990) was selected from the whole group of parents of children with exclusion diets for suspected food allergy and nineteen parents participated. According to Kvale (1997) 10 to 15 respondents are customary in "normal" qualitative interview studies. Nineteen parents were considered to be quite sufficient for the purpose of this study, as narrative interviews are often extensive and lengthy.

The selection of parents was made from the information parents gave about their children's problems in Study I. The inclusions were made from a "maximum variation" strategy (Patton, 1990, Conrad, 1990). A wide range of variation was chosen on dimensions related to the children's medical and illness histories. These reflected the diversity of the dimensions in the whole population of children with exclusion diets. A variation sample makes it possible to both understand the disparities that emerge among the families in adapting to different conditions and to identify the common patterns that cut across parent cases (Patton, 1990).

Sample judgments in terms of diversity were made regarding children's age, age of onset of symptoms, type and severity of different food-related symptoms, diagnosis and diagnostic results, as well as the presence of other allergic conditions, such as asthma, eczema and hay fever. The children's problems had to be perceived to be significant by the parents. Thus, a parent who stated that the child only had reacted once to a food item, such as strawberries, was not included.

Three parents were selected particularly because they had reported in previous telephone interviews that they had not consulted health professionals for their children's allergy-related problems. However, it was clarified by the parents in the interviews that all children expect for

one had visited health care at least once. Five families had more than one child with allergy, but not all siblings had a food certificate at school. Two of these children were not part of the food certificate study population, in one case because the child did not have an exclusion diet at school and in the other because she had finished school (23 years of age). For the parents with more than one allergic child they mainly focused on the child that seemed to have the most demanding problems. However, follow-up questions were sometimes directed also at the other children's problems.

According to the statements made by the children's parents' in the telephone interviews 21 of 26 children were doctor-diagnosed, and 15 had tested positive with some kind of allergy at least once in their lives. In addition, many children had other allergies besides their food-related problems. Sixteen children had asthma, fourteen children suffered from eczema and fourteen from hay fever (pet/pollen). Eleven children had all of these problems – asthma, food allergy and eczema or hay fever. The children's ages were between 7 and 23 at the time when the interviews were carried out and the mean age of when the first initial problems emerged was 1.2 years, with an age range of newborn up to 7 years (only one child at 7 years).

There were also mainly mothers participating in the study; there were 18 mothers and one father. The reason that only one father participated was the same as in Study I. Six of the mothers were single parents and two were of non-Swedish background (from England and Chile). A letter was sent out to the selected families to inform them about the project, stating that they were going to receive a telephone call where they would be asked to participate. The parent that was first spoken to over the telephone was the parent that was asked to participate.

**Table 1** Number of subjects, data collection and data analysis in the two studies

	<b>Study I</b>	<b>Study II</b>
<b>Number of Subjects</b>	215 parents (230 children)	19 parents (26 children)
<b>Data Collection</b>	Structured telephone interviews Postal questionnaire	Narrative Interviews (Mishler, 1986)
<b>Data Analysis</b>	Descriptive statistics Fischer exact test Mann-Whitney U test	Narrative analysis (Mishler, 1995, 1999)

## Data Collection

### Study I

The data collection was made initially through telephone interviews with all parents of the whole population of children with exclusion diets. Later on, the interviews were also complemented with a postal questionnaire. The postal questionnaire (with questions similar to those of ISAAC, Asher & Weiland, 1998) asked questions about the allergic diseases, hay fever, asthma and eczema, and different food items that were missed in the telephone interviews and that were important to know about for a fuller picture of the children's allergy history and food-related problems. In the cases of siblings with food certificates the parents were asked in the telephone interviews to respond separately for each child, and a postal questionnaire was sent for each child. The interviews were carried out by both authors (NG) and (BM), equally and randomly. A structured interview schedule was used that included 21 different questions. The answers were recorded during the interviews in different response categories corresponding to those in the ISAAC studies (Asher & Weiland, 1998). Before doing the interviews NG and BM agreed on how to ask the questions and on other aspects that were important in order to keep the interviews as similar as possible (Rosengren & Arvidson, 1992). For instance, there was an agreement that the response alternatives should be specified to the parents only if they did not know what to respond.

The study started out as a descriptive survey. The decision to use telephone interviews instead of doing the entire data gathering through postal questionnaires was made because there are methodological problems of how to formulate written questions so that respondents understand them as intended (Rosengren & Arvidson, 1992). With telephone interviews questions could be clarified during the interviews. Another reason for doing telephone interviews was related to the poor response rate that can often be the result of doing just postal enquiries. It was regarded as more likely that individuals would participate if they were contacted in person. In our case the response rate was 94% for the interviews. Eighty per cent of the parents returned the postal questionnaire whereas the other parents were contacted and asked questions over the phone.

## **Study II**

Data was collected (NG) through narrative interviews (Mishler, 1986) that were carried out in the participants' homes or workplaces. In these interviews the purpose was to obtain stories from the parents about how they came to understand and interpret the children's symptoms and behaviours as something medically wrong. The decision to use a narrative approach was made because it has advantages over other qualitative approaches in exploring a process, such as recognising and responding to illness symptoms that include different time episodes, social contexts, events and decisions. It is known that people tell stories when they have something important to say, and when they need others to understand their experiences (Polkinghorne, 1988). Illness narratives may help individuals and families to create coherence and make sense of their everyday lives and the disruption of life that often accompanies illnesses (Hydén, 1997).

One single open question was put at the beginning of the narrative interviews: "could you tell me how you discovered that your child was hypersensitive?" Most parents responded to that question by telling a story that included: (1) how, when and where the problems started, (2) and what happened, (3) mentioning different people that were present and what they did/said, (4) what the parents themselves did and how they felt/thought and (5) their conclusions and evaluation of the events and actions included in the story. The stories were different in structure but had more or less all of the above features in them.

The initial question kick-started the parents into telling their stories in different and personal ways (Mishler, 1999). For example, one mother began her story at pregnancy; others began by telling in detail about the children's symptoms and yet others with a specific "discovery event",



which could be very vividly remembered and dramatic. Follow-up questions and the second interview guide was made in connection with this first narrated story. Sometimes these first stories were extensive, sometimes short, and the subsequent dialogue concentrated on these first told events and actions. Most parents were interviewed on two occasions, but four parents were interviewed just once. Three of them were chosen to complement the first selected parents. In the first study these parents had given the information that they had not had any contact with the traditional healthcare system, although they had experience from alternative medical care. As they were the last interviews and what they told had many similarities with the other parents' stories, it was decided that it would be enough to interview them only once in order to catch the core variations of their stories (Mishler, 1986). With the fourth parent several attempts were made to schedule a second interview. However meetings were re-scheduled and missed, so in the end there was a short second interview made over the phone, just trying to fill in gaps in the first interview. The first interviews lasted between 45 min. and 1 ½ hours. The second interviews were often shorter, between 30 min and 1 hour.

The interviews were recorded and transcribed verbatim by NG. Certain interview passages were later corrected and transcribed in more detail with pauses, speech overlap and so on. The ambition of the narrative analysis was also to capture the forms and structures of the parents' experiences and why they chose to tell about their experiences in a certain way (Gee, 1986; Riessman, 1993). Some information was written down by hand, for example when the parent told about things after the tape recorder had been turned off.

## **Data analysis**

### **Study I**

The analysis of the data was made by descriptive statistics and cross-tabulation for comparisons between groups. To investigate if there were any differences in proportions between the groups of children who had consulted healthcare and those who had not in terms of the extent of their food-related problems and other allergies, the Fishers exact test (two-sided) was used. The Fishers exact test gives more accurate figures when one or both groups are small. The Mann-Whitney U test was used to determine differences regarding age of onset of food-related problems between the same groups. A statistically significant difference was considered to be at <0.05 p- value.

## Study II

The narrative analysis employed here was inspired by Mishler's studies (1995, 1999). In a first step the interviews were analysed by reconstructing the parents' stories and their accounts into a "real-time" chronological order. A storyline was constructed by retracing past events and actions talked about by the parents and placing them in a sequential order. Each event or action was viewed as "dependent" upon the other; one event led to certain actions and these actions in turn led to certain outcomes and so forth (Mishler, 1995, 1999). In a second step the individual parents' storylines were compared to each other, to find variations and similarities between them. In a third step a common pathway was found and conceptualised, as a problem-solving process that included two distinct temporal phases.

Specifically three things were traced in the first analytic step. These were: (1) any actual events that were documented without any reference to what the parents thought about them, (2) parents' actions, what they said they did in response to these events, and (3) the evaluations and interpretations that were made by the parents around these events and actions in order to make sense of them.

The specific events and actions (1 and 2) that each parent talked about were visually organised by hand in a timeline on a sheet of paper, and showed the chronological order of events in parents' stories, what action parents took in response and so on. For example, one timeline started when the child started behaving differently or showed visible symptoms at about 1 year of age, and ended with the diagnosis of milk protein allergy at 13 years of age. In between these times several events and actions had taken place. Parents emphasized some actions and events more than others and in this way they indicated what they considered to be important. The storyline could cover several years or only a few years, all depending on how quickly a satisfying problem "resolution" was made and how long it took for the parents to know what was happening with the child or to have their children's problems diagnosed. The findings in this study end at the time when parents decide to seek medical aid, although the storylines of parents and their children's lives with allergy goes beyond this time.

In the second step the individual parents' storylines were compared with each other and in the third step a common process was found in the data. The problem-solving phases were "time nodes" in each parent's storyline and were the same for all parents. Finally, the parents' unique

and individual speech flow was also part of the analysis and the interview examples show how they organised events and actions in series of different units like stanzas (Gee, 1986).

As it was not possible to follow the parents over time when the emergence of children's problems took place, the study relies on retrospective data. The problem with retrospection is that the parents may have difficulty remembering what happened and what their responses were at the time of the actual events (Patton, 1990). One way of possibly reducing some of the memory deficiency is to do more than one interview with each respondent (Kvale, 1997). This was also done in the study. The common actions parents told about in their narratives also validated each individual finding. When the similarities in actions and explanations kept turning up in each interview, independent of individual differences, this was taken as validation of the analysis and the storyline that was created in and between parent cases (Mishler, 1999).

The reconstructed narratives are not to be viewed as a correct historical reconstruction of what "actually happened" (Mishler, 1999). There is no way of truly capturing this, as it is usually not possible to follow people over any longer period of time, and all experiences and remembrances of the past that people tell about are inevitably made from a present time and understanding (Riessman, 1993). The problem-solving processes created in this study illuminate the parents' personal ways of defining and responding to their children's symptoms, and they also shed light on the shared cultural ways of illness and help-seeking behaviour of carers (Mishler, 1986, 1999).

## SUMMARY OF FINDINGS

### Study I

Nearly all parents (93%) had consulted health professionals for their children's allergy problems in general and a few percent less (85%) for specifically food-related symptoms. Sixty-eight percent of the children had been doctor-diagnosed with food allergy, most with a positive allergy test. The majority of the children were reported by their parents to have several allergy-like problems and symptoms from many different offending foods and other substances. The parents reported that 82% of the children had the allergic diseases of asthma, eczema or hay fever, and 53% had reacted to other types of allergenic substances, such as furred animals, pollen and mites.

The children who had seen a doctor regarding their food-related problems had more complex and medically severe allergies than the other children. It was only in this group that the children with breathing difficulties and anaphylaxis were found, indicating more acute and life-threatening symptoms. The parents also reported significantly more offending food items per child than in the other children and more frequently asthma, eczema and pet allergy, and an earlier onset of children's food-related problems. However, the characteristics of food-related symptoms and the reported food items in the two groups were similar.

The results showed that the children had food-related problems that were consistent with the clinical knowledge of food hypersensitivity, and that they had such food-related problems and allergy-like conditions that may well explain their food avoidance and why they needed exclusion diets at school.

### Study II

The discovery of child allergy was described by the parents as a social problem-solving process. Two main temporal phases made up this process and these were termed *the pre-problem phase* and *emerging problems*.

*The pre-problem phase* took place before the child was born, during pregnancy or before any bodily signs and symptoms had emerged. During this phase parents were concerned about the risk of illness and ill health and some parents told about preventative strategies like eating foods that could be health protective or avoiding certain foods and situations that were known to be

allergenic. The actions taken in this phase were made to prevent either illness in general, allergy in particular, or to reinforce overall good health.

*The emerging problem* phase, which is emphasized in the study, began when the parents “discovered” behavioural and bodily changes and symptoms and began to view and respond to them as symptoms of illness and ended with seeking medical aid. Parents told about the discovery process in two different ways – in an acute and direct way and in a more gradual and drawn-out way and these were connected to type of symptom and how the symptom emerged in the families’ everyday lives.

*Acute problems*, like lower respiratory reactions (breathing difficulties or anaphylactic shocks) were immediately defined as something wrong and were also responded to quickly as a problem in need of medical attention (and diagnosed as allergy). Parents could often connect the symptoms to something the child had eaten. The problem-solving process was brief and straightforward and was told in a linear way by the parents.

*Gradual emerging problems* (especially stomach problems and eczema, but also some cold-like symptoms) were defined more gradually and were more tentatively responded to (and diagnosed). (1) At first these symptoms were interpreted and responded to as normal everyday children’s problems and not as signs of illness. (2) Over time parents’ views changed, often as a result of symptom duration, children’s ages or the parents’ actions, and an often prolonged period of trying to find out what was wrong began for these parents. Parents had at least two strategies they used in this process – self-diagnosing techniques in form of temporal and *situational clues*. The phrase *situational clues* meant that they either (a) carefully observed any naturally occurring situations when the children was eating something to discover symptoms, or (b) experimented with different situations and interactions to try to establish causal links between objects, substances, places and children’s symptoms.

Parents often sought medical help after their own methods and strategies had either failed or only partly or temporarily succeeded to fully explain or make the child’s symptoms disappear or improve. Parents’ stories also held moral accounts about how particularly the mothers positioned themselves “good mothers” who had tried and were continuously trying everything they could to help their children.

## DISCUSSION AND IMPLICATIONS

The decisions that parents make concerning their children's health and eating habits, as well as those concerning seeking professional help, are based on the knowledge and experience the parents have attained of their children's problems through extensive experimenting and exploration of what is normal and not normal behaviour and symptoms in their child. What the parents do to understand their small children's emerging problems influence how and when they seek professional help and the decisions they make about what the child should eat at home and most likely also at day care as well as later on at school. This indicates that parents will continue to be active and to experiment with different clues and situations as their children's illnesses progress in different ways.

It will be argued here that parents' behaviour before seeking help, especially for problems such as eczema, stomach problems and some flu-like symptoms, will affect not only how and when parents seek medical help but also, in different ways, their meeting with health care and health professionals. One problem that practising doctors and other health professionals might have is that they are not aware of the parents' own experiences and knowledge and their way of managing and treating the child's problems. The intention here is to discuss what it is parents do and try at home and how they reason in the process, and to relate this to what implications it might have for clinical practice and the communication between health professionals and parents.

### **Situational clues and markers for discovering allergy**

Parents involved in this thesis both examined different situations to know what was wrong with their children, as has been described before by Alonzo (1984) and others, and closely observed children's behaviour and bodies as part of their parenting (Cunningham-Burley, 1990; Lauritzen, 1997). However, parents are not just passive interpreters or observers of the situation and of their children's bodily changes and behaviours. Compared to many of the previous studies on illness behaviour, parents in this study also created situations and situational clues from which their understanding and their responses emanated.

Parents of children with suspected allergies show themselves to be much more proactive than shown in much previous studies on illness behaviour (Emerson & Messinger, 1977; Stewart & Sullivan, 1982; Calnan, 1983; Alonzo, 1984; Bury, 1997; Morgan, et. al., 2004). They actively used

their environments, situations and the different clues that they controlled and created to find out if their suspicions about allergy might be correct. Different foods and duration of symptoms were used and controlled by the parents, for example by first removing a pet cat from the house or food from the child's diet, then observing and evaluating their actions. Paradoxically, the actual suspected causes of children's problems (food, objects and situations) are thus used, changed and elaborated on by the parents and acknowledged to also have the potential to help them to resolve their children's symptoms. This may be in contrast with situations in other chronic illnesses like Multiple Sclerosis, and this kind of controlling and manipulation of different situational markers<sup>1</sup> by the parents in their discovery of allergy is perhaps not applicable to other chronic illnesses.

Care-givers have another outlook on family members' problems than the affected person him/herself has. For example, the fact that the parent has the possibility to observe the child's body and behaviour from the "outside" might make it easier for care-givers to scrutinize and control different situations and clues in the process of falling ill. Care-givers do not have access to what their affected family member feels, and the particular proactive and attentive controlling of parents' actions and the surrounding situations might be something that is particular to both care-givers illness behaviour and the allergic conditions.

In this study parents' activities seem to strengthen their case and work as their resources. Alternatively, it may be interpreted as their strategies working against them. For example, many parents seemed almost compelled and obligated to be experimental and extra vigilant with regard to their children's health and their bodily symptoms. These mothers said that they "had to be like detectives" to be able to help their children. When parents acknowledged that they might be in a position to help their children only by removing, for example, certain food items from the child's diet, this kind of accountability also put a great deal of moral pressure on them to know what to do and how to respond correctly. Knowing how to respond culturally "correctly" is linked to being responsible parents and is something that all parents have in common when caring for children and in managing different illnesses and disabilities in their children. However, with suspected allergy for which the social and physical environment and lifestyle choices are so

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<sup>1</sup> Situational markers can be juxtaposed with the biological markers that doctors use in their diagnoses. In the social course of allergy it is situations, objects, food, and time that are controlled and manipulated by the parents to define and understand children's problems, as compared to IgE antibodies and other biological and clinical markers used in clinical practice to explain and diagnose allergy.

manifest in medical theory (Platt-Mills, 2005; Bråbäck, 1995) and among people (Olin Lauritzen, 2003) it might be argued that there is an even greater moral responsibility to do the “right” thing in suspected allergy and food allergy, than is the case for parents dealing with other chronic illnesses and disabilities.

Parents in this thesis displayed through their actions and the words they used to describe their awareness that the choices and decisions they make in their everyday life may be grounds for sickness in their children, or grounds for making the child well. This discussion is more applicable to the allergy problems that have a drawn-out and gradually appearing trajectory, at least in the emerging problem phase. With the acute respiratory reactions the parents’ illness- and help-seeking decisions are much more clear and direct.

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. This was contrary to peoples reactions to minor illnesses (e.g. headaches, pains in stomach and chest, swollen and infected areas, problems with ears, eyes and nose) where the decision-making process was more elaborate and tentative (Calnan, 1983). 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 not condition-specific.

It also again indicates that it is not the severity of symptoms that influences the help-seeking behaviour but rather the way symptoms emerge and whether people can make sense of them. This is why, despite the fact that minor symptoms like some food problems may be less medically severe, it is still important for health professionals to pay special attention to these problems.



## Parents' decisions about eating habits and exclusion diets

Other aspects of parents' decision-making are the temporal clues that parents use to understand and manage the emergence of children's symptoms, which also give important knowledge about how parents decide about eating habits and exclusion diets at school. Parents participating in this thesis take into consideration the child's whole lifetime in the decisions they make about what children can eat and what they should avoid, at home and in school. The parents' decision-making process connects the past, the present and the future, and parents constantly evaluate and reevaluate their actions from these different temporal contexts.

Many allergy symptoms were reported by the parents in the initial discovery phase to be unpredictable; problems could come and go at different times, and new problems could arise. These are also known to be characteristics of the illness course of chronic conditions (Stewart & Sullivan, 1982; Bury, 1997; Roll Bennet, 2006). The fact that allergy problems change over time and are very unpredictable makes children's problems difficult to control for the parents as children grow older and start day care and school. Some parents mentioned that the children's symptoms became worse after starting school. Exclusion diets at school might be a safety net that parents use when they are unsure of how the child will react to food at school and when they no longer can observe and control their children's illnesses, a process that is central to parents' management strategies.

This means that although it is known clinically that allergy problems come and go (Wahn, 2000; Illis et al., 2001), and most children do get better and can tolerate more foods as they grow older, it does not necessarily mean that the individual child is considered to be completely allergy-free by the parents or that the families' eating habits automatically change. When the doctor makes a diagnosis and treatment suggestions from current allergy tests and the child's clinical symptoms and hopefully also carries out a careful clinic history, (Ortolani, Bruijnzeel-Koomen et al, 1999), parents' decisions are based on a variety of lifetime and social contexts. These contexts may include different ages of the child, prior symptoms, the parents' own past illness experiences, other people's "horror stories" that linger in their memories, their own tried and failed strategies, and concerns about future worsening of symptoms or the development of new allergies.

## **Being a “good mother”**

The actions taken in regard to children’s illness reflect a mode of action parents take to make sense of what is happening to the child, but also to deal with the responsibilities of parenthood and the specific accountability they are faced with concerning suspected allergy, as discussed earlier. The proactive strategies parents use might be interpreted as a way for them to attain moral recognition from others.

As most parents in this thesis are mothers the concept of good mothers is used to argue the moral claims that parents make. The mothers talked about themselves as active, responsible, competent and rational mothers who were in control of the situation, despite the difficulties that they may have faced in understanding their children’s problems and what to do about them. They reflected about what they did and evaluated the consequences of their actions, and what they perhaps could have done differently, and thereby positioning themselves as “good mothers” that had tried and were still trying “everything possible” to understand and manage their children’s symptoms.

To position oneself as a good mother means in this context that the mothers sought to present themselves as the kind of mothers they wanted to be seen as, by themselves and others (Harré & Davies, 1990; Riessman, 1993). Studies have shown that parents and other people tell “moral tales” that portray them as righteous and responsible when faced with different situations like divorce (McCarthy, Edwards & Gillies, 2000), making sense of a diagnosis of dyslexia (Zetterqvist Nelson, 2000), explaining allergy (James, 1993; Roll, Bennet 2006), in interview situations (Riessman, 2001) and in parents’ meetings with health care (Baruch, 1981).

One way of exemplifying how the mothers in this thesis positioned themselves as good mothers is through those mothers who had tried to protect their children from illness and allergy. Some mothers had taken several preventative actions before and after the child had been born and although their children did develop allergies, they still talked about their strategies as being effective. For example, one mother said that the child had such “little problems”, implying that her strategies of prolonged breastfeeding had proven to be successful and that she thus had done what she acknowledged in retrospect to be the responsible and correct thing, according to what was known and advised about how to prevent allergy at that time.

As it is known that mothers closely identify with being the parent who cares for the child and who knows what is best for him/her (Cunningham-Burley, 1990; Olin Lauritzen, 1997; Roll, Bennet, 2006; Cunningham-Burley, Beckett-Milburn & Kemmer, 2006) this is probably why the struggle with the specific responsibilities that are connected with parenthood are so salient in these mothers' stories.

## **Implications for clinical practice**

Most parents in this thesis had sought health care help for their children's allergy-related problems at least once in their children's lives, and in most cases during the initial problem-solving process. Among the four parents in the second study who had experience of complementary and alternative medicine none of them had used this kind of help before first seeking help at child health care<sup>2</sup>. Complementary and alternative medicine was used by these parents only after their own strategies and the child health care had failed to find out what was wrong with their children. This is important, because if parents experience that they receive help from the child health care in this early discovery process they might not perceive it as necessary to seek professional help elsewhere.

In order for the parents to feel that they receive help from child health care and other health care agents, the findings from this thesis suggest a few things that health professionals need to recognise. For example, when parents consult a health care professional the experiences and knowledge that they have gained through their own experimentation will influence the way they understand, listen to and relate to medical advice and recommendations. This is why it becomes important for doctors and other health professionals to know what it is parents have done before seeking health care help, so that they can relate to this in their clinical work.

One possible way for doctors and other health professionals to do this is by linking their clinical findings and treatment suggestions to the different remedies and strategies the parents have already used (or are using). This is important, as several studies have shown that doctors and patients seldom agree on what is important to do with the illness in terms of management and treatment (Daltroy, 1993; Gillissen, 2004). It has also repeatedly been found in studies that the doctors' way of communicating with patients and how information is given significantly affects

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<sup>2</sup> These findings are not shown in any of the papers.

patients' satisfaction with care, patients' health and functioning and compliance (see, for example, review studies by Daltroy, 1993; Gillissen, 2004).

Considering the findings in this thesis and previous studies on illness behaviour and patient-doctor communication, it is suggested that health professionals can achieve more efficiency in their work to help children and their parents when they enter into a dialogue with the parents and acknowledge the parents as equal experts on the children's problems. This also means that health professionals have to respect the parents as active agents who make their own choices about how to deal with their children's problems, and that care-givers and patients still may choose not to follow doctors' advice. It has been frequently shown in the sociological literature on patient-doctor encounters that patients often negotiate or bargain with their doctors about what to do with their problems, and it is argued that absolute agreement between doctors and patient is not an efficient or even desirable treatment goal in chronic illnesses (Conrad, 1985; Stewart & Sullivan, 1987).

For health professionals to meet parents as equal experts and respect their choices and decisions it is important for them to know first that parents' decisions about treatment regimes and food restrictions are made from different temporal and social contexts, and second that seeking professional medical help is, especially for the mothers, not merely about receiving a diagnosis and effective treatment or about receiving advice for children's problems. It is also about their identities and moral character as individuals and as parents. The fact that mothers experience that they are being recognized as competent and responsible parents by health professionals is likely to shape the doctor-parent meeting in a positive and mutual direction that will take into consideration both the doctors' medical expertise and the particular expertise of the mothers (Conrad, 1985). This means that doctors and other health professionals can support and guide the parents' own expertise and help and encourage them in what they are already trying to do for their children.

## **Methodological considerations**

This thesis does not claim to fully capture the complexity of how parents discover, understand and manage allergy, and especially not how they use such complex matters as time, morality and identity in the process. However, it does produce some particular knowledge about the different

strategies that the parents use to understand and manage their children's emerging problem and suspected allergy.

## **Study I**

### **The possibility of generalisation**

Study I was aimed primarily at delineating the suspected food allergy situation among schoolchildren with exclusion diets and at attaining more knowledge about the illness and medical characteristics of this population. As this study is limited to one municipality and to a particular population, there are two questions about the possibility of generalising these findings that can be asked. Can this study be generalised to all children and their parents in Sweden who have exclusion diets at school? Can it be generalised to all children with suspected food allergies, even to those children who do not have exclusion diets?

Because this population has not been studied before, and there is no other data with which to compare our findings and as only one municipality was included, it is not possible to make any predictive generalising statements about the children with exclusion diets in Sweden. The knowledge collected about this group is still valuable as it gives important indications of parents' management of the suspected food allergy in their children and on what illness grounds decisions on food avoidance are made. The findings that most children with exclusion diets had sought health care, been diagnosed, had positive allergy tests and so many had been treated at a specialist clinic, indicates for instance that these children overall have a clinically defined illness. In this respect there is no reason why the schools in this municipality should be very different from other schools in Stockholm and all over Sweden. All schools have some way of organising exclusion diets and special meals, although not necessarily with food certificates. How schools organise their special diets has to be considered. One important factor is whether or not other schools in Sweden demand a medical certificate for issuing exclusion meals. Although there is no available information on this, it is nevertheless likely that it is on the parents' initiatives that different food diets are issued in most schools in Sweden, and the findings from this study may be applicable to other schools where this is the case.

The finding that schoolchildren who avoid food at school have defined illnesses is contrary to the situation in the open population of schoolchildren with suspected food allergy in countries such as Netherlands and England. Those studies report between 40 and 48% of non-medical contacts

among schoolchildren who avoid food at school and another 21% that had not been diagnosed. Perhaps the exclusion diet group is more “allergic” than an open population of suspected food allergy. Then again, these differences are probably due to the selected population, as exclusion diets at school after all are institutionally processed and controlled. The differences can also depend upon differences in the health care system in Sweden compared to those in other countries in Europe, with regard to the fact that all children in Sweden attend a special child health care program (Sundelin, 2000) and parents can easily utilize primary care regularly and without any cost.

In conclusion, as there are no available figures of suspected food allergy among an open population of schoolchildren, made in a Swedish context (such figures may appear in the ongoing EUROPREVAL study, with funding from the European Union), any generalised predication of those children with suspected food allergy without exclusion diets at school is difficult to make from this study. As the non-health care group was much smaller than the health care group, it is possible that the differences between the groups might be understated in a larger sample. The differences between these groups in an open population, also including those children with suspected food allergy but without exclusion diets at school, would perhaps be greater.

Still, regardless of the study limitations, valuable knowledge about children with exclusion diets has emerged in this study and also of a non-clinical group of schoolchildren with suspected food allergy.

## **Study II**

### **Credibility and transferability**

In the narrative analysis the parents’ different storylines were constructed to show the strategies parents used in their understanding and management of their children’s problems. The aim was to match the parents’ understanding (their stories and accounts) with the understanding that was created by the researcher (the pathways and interpretations) in order to establish some kind of *credibility* that may be attributed to various respondents’ experiences (Guba & Lincoln, 1998).

An attempt was made to stay close to the parents’ own wordings and narration in the narrative analysis and in the emergence of the discovery process of allergy. Still, the chronological order created as part of the analysis was not the way that all parents favoured for organizing time in

their own stories. This might be considered to be a limitation. A conscious decision was made to analyse the stories in this way, because the chronological storyline is an analytically workable way to capture the retroactive processes of illness and help-seeking behaviour (Mishler, 1995).

The interpretations of parents' narratives are made in the specific context of a particular research situation. The active and somehow rational problem-solving process that emerged and was created through the narrative analysis chosen is more complex than it might seem, when considering different possibilities of the research situation. For example, are the findings a result that mainly emanated from this particular research situation and how the parents wanted to portray themselves in this setting, with this particular listener (Riessman, 1993)? Is the accountability parents express through their use of words and way of telling their stories more a response to the interview questions and how they were put, rather than something they experienced? It has been pointed out that researchers might have moral undertones (although they are not aware of it) in their questions that interviewees pick up on and respond to (Riessman, 1993).

The position taken on these questions is that any illness behaviour involves a narrative performance that reconstructs time, identity and morality in certain ways. People do not tell about past happenings without interconnecting time and trying to show who they are or how they would like to be represented by others (Riessman, 1993). The subject positioning as good mothers and as active and rational persons is therefore understood in this thesis as part of the social course of allergy.

The findings in Study II are not to be expected to be generalised in the sense of having a predictive value in different settings and over time. What is to be considered is instead whether the findings might be *transferable*, meaning that others who wish to apply the study and its results to their own situations can do so (Guba & Lincoln, 1998). This kind of naturalistic or pragmatic generalisation is made when researchers, clinical practitioners and others draw their own generalizing conclusions from the study (Kvale, 1997). However, the condition of a transferable study is not based on the reader having to agree with the results, but rather on the reader understanding and judging the interpretations made from the study.

To ensure that researchers, clinical practitioners and other readers can judge the credibility and draw their own implications and conclusions from the study findings, lengthy interview citations were used and extensive and detailed accounts of method of analysis were given.



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