

EXPERIENCES OF PARENTS OF PRE-K TO GRADE FOUR CHILDREN WITH FOOD ALLERGIES

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The purpose of this study was to investigate the experiences of parents of pre-K to grade four children who had food allergies. Also examined were the management strategies put in place by the participants to assist the children deal with their unique situations. An in-depth interview was conducted with ten parents whose children had food allergies. Results of the interview indicate that the children's allergies were identified between ages six months and two years. Most of the parents reported that their children were aware of their problem(s). The most challenging issues for the parents were getting the specific food allergies diagnosed by professionals and staying alert all the time. Parents indicated that they were confident about their children's safety and well-being in school that had adopted a no-peanut policy.

Introduction

Scholarship on the prevalence of childhood allergies attest to the fact that allergies in children are on the increase and that allergies are the leading cause of hospital emergency department visits for *anaphylaxis* — extreme allergies to various substances — (Sampson, 1999; Ross, Ferguson, Street, Klontz, Schroeder, & Stefano, 2008). Parents and health professionals also confirm that childhood allergies pose a lot of problems to parents and that families with children with allergies are highly stressed and live in fear and anxiety (Couzin, 2007) about their children's health situation. Nowak-Wegrzyn (2003), in her work on approaches to food allergies, confirmed that food allergies is the only disorder with no specific therapy; a situation which potentially poses a lot of problems for parents when severe reactions to food allergies occur.

With respect to specific allergies, despite the fact that cow milk contains good nutritional value for children and can help with children's development, Foucard (1985) discovered that cow milk also contains such allergens as β -lactoglobulin and A-lactalbumin and caseins that can cause severe allergic reactions in children. It is important to note that allergic reaction to cow milk may affect such organs as the skin and the gastrointestinal track (Bahna, 1980). Also, allergic reactions from cow milk could be felt within few minutes or several days (Foucard, 1985).

Concerning nuts, especially peanuts, the literature indicates that its allergic prevalence among children has increased within the last decade (Sicherer & Sampson, 2007). Also, scholarship on peanut-related allergies indicates further that the cooking method used contributes to differences in allergen reaction and that roasted peanut has the potency of allergens than boiled or fried peanuts (Pomés, Butts, & Chapman, 2006). Couzin (2007) also attested to the fact that children with peanut allergies have lower quality of life than even those with diabetes because they cannot go out to many places or attend some festivities like cruising in the supermarket, birthday parties, camps, and others.

Nowak-Wegrzyn's (2003) work on food allergies showed that the diagnoses of multiple food allergies may limit or subject children to unbalanced nutrition diet and this may consequently create health and hardship to the child in particular and his/her family in general. The above-mentioned fact is bolstered by McCubbin (1993) and Hovey (2005) who showed that the diagnosis of illness disrupts order in families.

A systematic attention to the above literature and others examined for this study, show that very little has been done on the actual experiences of mothers whose children have such allergies. This study, therefore, first and foremost investigates the experiences of parents of pre-K to Grade four children who have food allergies. Also examined are the management strategies that help the parents to deal with their unique situations in and out of the school environment.

Method

A qualitative technique, *narrative inquiry* (Connelly & Clandinin, 1990), was used in gathering information from the research participants. Using participants' narratives enabled us to examine their exact words and subsequently enabled us to understand their shared experiences (Morrison-Beedy, Cote-Arsenault, & Feinstein, 2001), their unique experiences, the real meaning behind their narratives, and their beliefs about their children's conditions (Lee, 1997).

Participants Selection

Ten parents from Indiana were recruited upon approval from an institutional review board, the Indiana University Human Subjects Committee. The parents were recruited through *purposeful sampling* (Patton, 1990). Participation was restricted to parents with children in school in order to find out their unique experiences in and out of the home. The parents were contacted through e-mail and phone calls. Participants were recruited from a 50-mile radius from Indianapolis, the capital of Indiana.

Instrument

The instrument used was pilot tested for six months before being used in this study. Twenty-five participants were involved in the pilot study. The pilot instrument consisted of a thirty-item questionnaire that asked about parents' experiences with their school aged children who had various developmental deviations. Eighteen of the pilot study questionnaire addressed food allergies in pre-K to grade 4 children and those were used in this study. The instrument consisted of a set of closed-ended and open-ended questions. The first part consisted of questions that dealt with participant demographics.

The questionnaires were administered on ten parents with children with various food allergies who were in pre-K to grade 4. These parents did not take part in the pilot study. Besides completing the questionnaire, the parents were also interviewed. The interview questions included various probes and stimuli and these provided the research participants with an opportunity to narrate their personal experiences. It also afforded them the chance to ask pertinent questions in the course of the interview.

Procedure

The interviews were done between January and March, 2008. Both face-to-face and telephone interviews were conducted for about an hour each in order to get in-depth answers needed for this qualitative study. Participation was voluntary.

Coding

The content of the data that was generated was closely examined by the authors. Each author coded the data separately. After examining the individual codes, the authors came up with four broad common themes based on parents' narratives, namely: (a) Time and events surrounding the identification of the food allergy; (b) Symptoms of Allergies (c) Challenges and management strategies employed by parents; and (d) Policy that has worked for them.

The analysis done was based on participants' utterances.

Results

Of the ten parents interviewed, eight identified themselves as white, and two identified themselves as non-white. The two who identified themselves as non-white were foreigners who recently immigrated to the United States. The majority of parents (8) who were interviewed were female and they were all married.

Participants reported that they had an average of two children with an average age of 6.36 years. From data gathered, it was discovered that majority of the parents had an average of one child who had food allergies (see Table 1 on next page).

Table 1
Food Allergy Details for Study Families

Families	Number of Children	Age of Children with Allergies	Kind of Food Allergies
Family # 1	2	4	fish
Family # 2	1	3	cow milk
Family # 3	1	4	wheat and Soy
Family # 4	1	7	nuts
Family # 5	4	7 & 3	cow milk
Family # 6	2	7	nuts
Family # 7	2	6	eggs & nuts
Family # 8	3	10	egg-yolk, nuts, casein, cheese, milk,
Family # 9	2	12	gluten and casein
Family # 10	2	7	nuts
Total 10	20	-	-

Time and events surrounding the identification of the food allergy

From parents' narratives, all the children's food allergies were diagnosed between ages six months and five years (see parents' narratives below about when their child was diagnosed with food allergies).

Time Allergy Was Diagnosed

- Parent 1: *When he was 2 years old after a meal of fish.*
- Parent 2: *At 10 months old when I stopped nursing and formula didn't agree with her*
- Parent 3: *By the time she was about 2 her eczema had become really bad. Her skin was always dry, causing her to want to scratch, especially in the winter months when the air in the home is much drier. We tried using a humidifier and several types of moisturizers but nothing seemed to work.*
- Parent 4: *Facial rash after coming in contact with peanut butter we found out around 22 month*
- Parent 5: *Around 15 months old he started cow milk for first time and that is when his allergies started*
- Parent 6: *When I stopped breastfeeding at 8 months old*
- Parent 7: *He was 9 months old, I had no idea that the symptoms my son exhibited were in any way related to food allergies.*
- Parent 8: *At 6 months old, we supplemented breast milk with formula, and every time he was given formula he would cry and cry and cry.*
- Parent 9: *When she was 3 years old*
- Parent 10: *Almost 5 years when we discovered that he has allergies*

Symptoms of Allergies

With regards to the first symptoms of their children's allergies and how such allergies were detected participants reported observing such symptoms as severe dry skin, eczema, skin rashes, vomiting and choking, constipation, diarrhea, excessive mushy bowel movements, fever, red eyes, and difficulty breathing, in their children.

- Parent 1: *On the way home from the restaurant he threw up 3 times in 5 minutes. He became very tired and lethargic and he spiked a high fever, we took him to the emergency room and by then he had hives all over and in his ears. The doctors thought he had a severe ear infection and sent us home with antibiotics.*

- Parent 2: *She got excessive diarrhea after taking milk so we saw the pediatrician and they switched her to soy milk*
- Parent 3: *She had severe dry skin and eczema. We first took her to our family doctor who referred us to an allergist. The allergist conducted the scratch test on her back. It was very painful and traumatizing to her. He concluded that she had an allergy to soy. Which we came to find out is used as filler in almost all processed foods.*
- Parent 4: *Facial rash our pediatrician discovered this after several months*
- Parent 5: *He had eczema on the face and upper arms. He also had constipation. Our pediatrician and Family doctors all gave him fiber stuff for constipation and steroid cream for the eczema. None suggested stopping the milk! Although she continued to have the eczema on his face*
- Parent 6: *Rash and excessive mushy bowel movement for some time*
- Parent 7: *He had one bout of severe vomiting and choking and had to be rushed to the ER. After that he constantly had a fever between 101 and 104 with a slight rash/eczema for almost a month. Blood in urine and stool test didn't give any answer and I was going from one pediatrician to another until he was diagnosed with eggs and nuts allergies.*
- Parent 8: *You could see a change in his eyes after having formula, he would cry and cry and cry. He also had difficulty breathing*
- Parent 9: *Poor sleeping habits, hyperactivity, stomach pain, and behavior problems*
- Parent 10: *Vomiting, lethargy, throat pain, and stomach pain*

A majority of the parents reported that their children were aware of their problem(s) and that whenever they went to restaurants they inquired about foods that they might be allergic to.

Parents' Challenges

A majority of the parents reported that the most challenging problem for them was getting the specific food allergies diagnosed by professionals. The following excerpts show challenges parents encountered before their children were diagnosed with food allergies.

A parent noted:

Just getting her diagnosed was the most challenging part so far.

Another parent noted:

It was very difficult with the egg allergy to get it diagnosed. A lot of foods contain eggs, so there were a lot of things he couldn't eat and was tempted to try.

Yet another parent reported:

We did everything humanly possible for our son to have a nice sleep but each time that he fell asleep he woke up after each hour crying. We explored all possible causes of his sleepless nights and few minutes of naps to no avail. After struggling with what was the main cause of his sleepless nights and crying, we found out that he had multiple food allergies when we took him to an allergy doctor. Although our family doctor and the allergy doctor all gave us valuable information to help our son we were still living in fear that our son might touch something which could trigger his allergies.

Challenges faced by the Families in and out of Home

Parents reported that they were unable to eat their own favorite food due to their children's allergies. Furthermore, they reported that they spent many hours in checking food labels to ensure the safety of their children. Other participants noted that they were unable to eat with their families in restaurants due to the children's allergies whereas some complained about their children's inability to eat food served by the school system. The following explain some of the challenges faced by participants.

A parent remarked:

Dealing with foods that have fish parts in them, you would be surprised how many foods use

fish parts as fillers, yogurt, gummy bears, tons of things you would never think of. We also have to watch how things are cooked, like in restaurants, if they use the same grill for fish as they do for chicken then he cannot get chicken.

Another parent said:

Me, wanting to eat peanuts! Especially peanut butter cups!

A mother wrote:

Our family rarely was able to attend family gatherings or visit restaurants because of the lack of gluten/casein free foods and the possible risk of cross contamination. Eating gluten/casein would cause symptoms to reoccur and last several days.

Two parents whose children had peanut allergies wrote:

First

He used to come home with his eyes almost red. Now that he attends a school in which peanut is not served in the school he comes home looking healthy and we always don't have to think about him during lunch time.

Another parent wrote:

Back to school issues – he attended Kindergarten in TN. The school system there had already adopted a no peanut policy in their kitchen. School lunches would not contain any peanut or nut products. Children could bring their own peanut butter sandwich or crackers to school in their lunch box. As it is here at BCSC, I pack a lunch for him every day because they provide peanut butter and jelly sandwiches daily. Then, they couldn't guarantee me that the tables would be cleaned in between lunch periods – thus the potential for peanut butter smudge on the tables. So, they did make one table in the cafeteria peanut free – no one can sit there with peanut butter or peanuts of any kind. This helps but when they take lunches on field trips or have short days the menu usually is peanut butter sandwiches. This is when they are either eating in the classroom or on a bus. His teacher tries very hard to avoid this and always informs me when he will be in a situation like that so we can try to figure something else out for him. I used to feel really bad about not wanting others to be deprived of their peanut butter (which I too love) but one day I was listening to talk radio show Dr. Laura Schlessinger. She was talking with a mom whose child was in class with a child allergic to peanuts. She was complaining about not being allowed to send in peanut butter crackers as a snack for her child. Dr. Laura immediately responded asking her did she hear what she was saying. That her child would not starve by not eating peanut butter crackers but this other child could DIE. She recommended having a spoonful of peanut butter at the door waiting for her child when she got home if it was such an issue. Wow – that was just what I needed to hear. I tend to be a people pleaser and don't want to upset others but sometimes (as in this case) you do whatever you have to, to keep your child safe.

Summary and Recommendations

From the data, several interesting findings transpired from parents' narratives which warrant mention. First, although some of the parents were somehow at peace to know the specific cause of their child's problem when their child was diagnosed with a specific allergy. However, they were surprised about the number of foods that contained the things that their children were allergic to and the limited options the children had in eating at school.

Although participants attested to the fact that the information they received from their allergy doctors and their primary care physicians was helpful to them, some participants still described their situation as living in *fear*. The research participants' description of their situation as living in fear is also articulated in the work of (Couzin, 2007). The above description stemmed from the fact that parents were not sure when their children's health would be in a danger in case the child got in contact with things they were allergic to at school.

Furthermore, the parents talked about the sacrifices that they had to make in order to prevent their children from getting in touch with things that could trigger their allergies. Participants' narratives attested to the fact that some attended field trips and other school events with their child to ensure the safety of the children.

An observation of the parents' narratives also points to the fact that half of the children had nuts allergies. It was therefore not surprising that some parents were happy with schools where peanut in particular and nuts in general were not served at the schools' premises. Such parents advocated for

schools to take peanut off from their menu since its presence on the menu constituted a death trap for children with peanut allergies. Some participants suggested that school systems that had adopted the *no-peanut policy* (with respect to meals served in the schools) helped their children to stay healthy in the school environment. They concluded that if all school districts would adopt a *no-peanut* or *no nut products policy*, this would ease their anxieties during school hours.

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