

The Burden of Food Allergy

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According to many studies, food allergies are on the rise.

There is nothing greater than the bond between a mother and her child. Food, the basic building block of life, is supposed to be nurturing and yet it can cause a deadly reaction. This dissonance causes stress and anxiety for families of kids with allergies.

Mothers are primarily involved in their child's health care (fathers usually defer to mothers to manage their child's allergies and know the medical history).

Quotes from parents:

"Food allergy takes everything frightening about being a parent and magnifies them a million times"

"I live in fear each day. A constant fear that my daughter will lose her life to allergies. The fear consumes me and sometimes it is unbearable"

Versus the statements from other parents:

"I think it's important that we remember that these are children who have food allergies rather than let food allergies define our children"

"It's important to remember your whole child not just their allergies. I try to be as careful as I can and then enjoy my child and let the rest go"

Allergies are an *invisible, chronic disease* (the child is well until they are not). What can make them unwell is the basic sustenance of life. Some families are controlled by their child's allergies while others seem to take it in stride.

Definitions:

Not all adverse reactions to food are a true allergy. Allergists often spend much of their time convincing families that their child does NOT have an allergy (i.e. a rash when their child eats ranch dressing does not mean the child has an allergy).

An adverse reaction to a food= a clinically abnormal response to ingestion of a food or food component. This could be a food allergy or could be a food intolerance.

Food intolerance=an abnormal physiological response to ingested food or food component. It is not proven to be immunological (i.e. idiosyncratic (MSG, Sulphites), pharmacologic (caffeine), metabolic (lactose intolerance), toxic (pesticides, shellfish poisoning).

Food Allergy (FA)=immunologic reactions (usually IgE mediated), ingestion or skin contact/inhalations of food or food additive. Unrelated to any physiologic effect of food. May include other immunologic reactions to food (i.e. Celiac disease).

Anaphylaxis=serious allergic reaction that is rapid in onset and may cause death.

Anaphylaxis likely present if there is an acute onset of illness with involvement of skin/mucosa PLUS one of the following:

respiratory compromise, reduced blood pressure, end organ dysfunction OR a significant drop in blood pressure after exposure to known allergen for that person.

It is rare for an allergic reaction to lead to death but every parent worries about this outcome.

Incidence:

8% of children less than 3 years had an adverse reaction to at least one food.

Food allergies affect 4-6% of children and 1-2% of adults.

Peanut allergies affect 1.3% of school aged children

There has been an increase in hospital admissions for systemic allergic disorders (British National Hospital Statistics 1990-1 to 2000-1)

There has also been an increase in prescriptions for Epipens. Peanut allergies still account for most hospital admissions. Allergies to food, bees/wasps and medications are the most common.

Studies:

Psychological Burden of Peanut Allergy (Primeau et al, 2000) looked at the psychological burden of peanut allergy. They compared the disruption in activities of daily living between kids with a peanut allergy versus kids with rheumatological disease and the disruptions were higher for kids living with the peanut allergy.

Food Allergy and Quality of Life-Parental Burden Questionnaire (Cohen et al, 2004) illustrates that parental burden is high. Areas of affect include family/ social activities, school, increased time for meal prep, health concerns, emotional issues. The more numbers of allergens (over 2), the more the quality of life is affected.

Burden of Food Allergies (Gillespie et al, 2007): questionnaires of mothers of children with food allergies (6-12 years old) show that living with the risk of food allergies affects families differently. Some families incorporated the risk while others saw massive implications in their lifestyle. Living with fear: risk to life, fears surrounding diagnosis, fears for the child's present and future safety and fears about how their children will adapt as they go out into the world on their own.

Food Allergy Quality of Life Parental Burden Questionnaire (Springston et al, 2010)

Study of more than 1100 caregivers showed that the impacts varied widely. The exception was that everyone in the study indicated were troubled by the social implications stemming from their child's allergies. Interestingly, there is a correlation showing that the more educated the parent is about allergies, the lower they score on their quality of life reports. Other factors that contribute to lower quality of life include, ER visit in the last year for an allergic reaction, multiple food allergies, and allergies to specific foods such as milk and egg (since those allergens are in so many different foods= increased stress).

Why do food allergies cause lowered quality of life? Factors that contribute to this decreased quality of life include fear, constant vigilance, worries about cross contamination, worries about exposure at school and child care settings.

Children's Health Questionnaire (Sicherer et al, 2001) comparing food allergic children to the general population. Rates of general health, parental emotion, family activities all ranked lower EXCEPT for family cohesiveness. Interestingly, family cohesiveness is higher in families who have a child with allergies. This is likely because families members have to work together to keep the child with allergies safe.

Peanut Allergies versus Diabetes (Avery et al, 2003) compared families with a child with a peanut allergy versus a child with diabetes and impacts on fear. The families of the peanut allergic kids showed increase in fear of mistakenly eating peanuts (versus concerns about hypoglycaemia), increased fear in eating out and increased fear about diet and health impacts.

Peanut Allergy and the Family (King et al, 2009) looked at mothers versus fathers and psychological quality of life indicators. Mothers had worse quality of life than fathers (increased scores for anxiety and stress). Children with peanut allergy (versus non allergic sibling) had poorer quality of life, physical health, school and general quality of life ratings.

Mental Health and Quality of Life Concerns in Food Allergy (Ravid et al, 2012) There was a lower quality of life, increased anxiety and increased psychological stress in families with child with food allergy.

Food Allergies and Activities of Daily Living (ADL's) (Bollinger et al, 2006) Food allergies increased time spent doing meal prep and planning, social activities were more complicated, increased stress, affected school attendance and caused some families to elect to home school their children for fear of a reaction at school.

Impacts on Activities (Cummins et al, 2010) Parents may avoid activities outside the home for fear of reactions or may prevent children from attending parties and school trips. Parents may have difficulty separating from their child and may be overprotective. Children may have anxiety about holidays, attending parties, using public transit, eating out and shopping.

Food Hypersensitivity Family Impact (FLIP) Questionnaire (Mikkelsen et al, 2013) 94 families with food allergy versus no food allergies completed the questionnaire. Families with food allergies had increased stress in their daily life and had increased nutritional concerns.

Bullying and Allergies

Bullying is something that physicians have not been asking their patients about and this needs to change.

Shemesh et al (2013) interviewed 200 kids at a food allergy clinic and found that 29% of kids reported being bullied (although not all allergy related). Of those kids, 31% reported being bullied because of their food allergy. Of these kids, 24% of the parents knew about the bullying—half of the parents did not know. Once the parent knew and intervened on behalf of their child, the child's quality of life scores improved, while the parent's quality of life scores decreased.

The bullying behaviours reported included: teasing about the allergy, waving food in front of the child, child being forced to touch the food, food being thrown at the child, damaged belongings.

60% of food allergy bullying had occurred at school. Schools and teachers need to be made aware of these statistics.

Parent's Experiences:

Parents of kids with food allergies report stress, fear, increased feelings of responsibility, impact on all activities of daily living, increased time with shopping, cooking, educating others and worries about their child not being included because of their allergies. This can lead to overprotection and separation anxiety.

Strategies to Reduce the Impact of Anxiety, Stress and Fear:

Food challenges and Increased Quality of Life (Knibb et al, 2011):

Mothers report very high anxiety on the day of the food allergy challenge but 3-6 months later, quality of life for the mother and the child has improved and anxiety has lessened. Interestingly, these findings were independent of the outcome of the challenge (pass or fail).

Severe and Fatal Food Reactions(UK) (Macdougall et al, 2002)

Risk of severe reaction is .19 per 100,000 per year.

.002 per 100,000 are near death reactions.

.008 per 100,000 reactions are fatal.

Incidence of Fatal Food Anaphylaxis in People with a Food Allergy (Unasunter et al, 2013)

Risk of fatal anaphylaxis is 1.8 per one million people. By comparison, death by accident or murder (in the US) is 1 in 10,000. Death from anaphylaxis is just slightly higher than the risk of death by lightning. Compared to other activities that we do everyday, the risk is low.

Strategies to Decrease Anxiety and Fear (Ravid et al, 2012):

Physicians need to routinely evaluate event related anxiety by asking the parent and the child with the allergy how they are coping.

Validated food allergy specific assessment of quality of life are available and should be used by physicians. This can identify families struggling with anxiety and help them find ways to deal with it.

Physicians should impart knowledge about the illness in a supportive and reassuring way by trying to put things in perspective for the families and showing them that successful management of a food allergy is possible. Under most circumstances, a food allergy should not lead to significant disability.

Physicians should inquire about food allergy bullying at routine visits and advocate for a food allergic child's specific needs at school.

Food challenges may increase overall quality of life as it confirms the persistence or tolerance of a specific

food, demonstrates to the parent the successful management of allergic reactions should it occur in the challenge and reaffirms the extent of avoidance that is needed to protect the patient. Physicians should also consider referral to mental health providers should excessive distress and anxiety be present in the child or parent.