CHILDHOOD FOOD ALLERGIES: Psychosocial Impact of Anaphylaxis

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Letting Go
Management – Vigilance & Preparedness

Food avoidance across multiple environments

Reaction preparation

- symptom recognition and assessment
- availability of appropriate medications
- ability and confidence to administer auto-injector if needed.
Childhood Food Allergies

Quality of Life (QoL) is THE Measure of Disease Burden

Emotional impact and management demands are constant:
- Disruptions in daily activities (meal preparation, social events, eating out, play dates, sports, other caregivers)
- Elevated anxiety and depression among caregivers.
- Lower overall QoL
- Even when compared to other chronic childhood illness groups (Type I diabetes, rheumatologic disease) families living with food allergies report lower QoL.

Avery, King, Knight, & Hourihane, (2003). Pediatric Allergy Immunology, 14, 378-382
Anxiety – Key Predictive Factor for Reduced QoL

Anxiety about anaphylaxis is very common

Over 50% of children/teens report feeling frightened about a reaction/eating the wrong thing.

Anxiety typically decreases as routines are established

But, anxiety may increase with:

- New incidents of accidental exposure, reactions
- Transitions (school entry, middle school, camp, etc.)

Potential for death

Mandell et al., 2002; Rouf et al., 2012; Klinnert & Robinson, 2008; Flokstra de Blok et al., 2008; Flodstra de Block et al., 2009

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School/Anxiety and QoL

Parents worry because they are not present at school and therefore cannot prevent exposure and treat reactions.

One third of families in a US survey reported significant impact on their child’s school attendance and 10% reported home-schooling because of food allergies. (Bollinger, et al., 2006)

Self-reported food-induced anaphylactic reactions in the UK, nearly 20% were at school. (Ugaz, et al., 2005)

Greater than 30% of parents of children with food allergies reported more than one visit a month to school to discuss child’s food allergy.

Parents also report heightened frustrations caused by hostility from others, particularly from school personnel and extended family members.
Anxiety and Uncertainty

Possibility of accidental ingestion even when allergy management strategies are in place and followed.

Unpredictability around severity of symptoms following exposure to a food.

Ambiguity regarding the level of risk posed by certain situations and foods.

Lack of awareness on the part of others.

Dunn Galvin & Hourihane, 2009; Gillespie et al., 2007

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Family Adaptation: Response to Anxiety

Taking preventative measures in response to anxiety = protective stance.

Excessive measures can limit appropriate developmental and social activities.
Integrated **Balance**

Effective Food Allergy Management/Developmental Role and Activities.

Too much vigilance induces fear/anxiety in the child which impacts sense of trust in the environment, adults, self.

Too little vigilance can result in accidental exposure, trauma and/or increased medical intervention.
Separation

Many parents find it difficult to separate from their food allergic child.

Many parents with food allergic children accompany them in social situations beyond the age at which non-allergic children are accompanied. (Mandel, et al., 2005)

Food allergic young adults (18-22) who had experienced anaphylaxis rated their parents as more overprotective than did food allergic young adults who had never experienced anaphylaxis (Herbert, et al., 2008)
Preschool and Early School Years
Developmental Aspects

Young children are impulsive = greater risk.

Rely heavily on adults to keep them safe.

Actively exploring environment (cross-contact issues)

Begin to verbalize food allergies.
Magical Thinking

Egocentric = the world revolves around me.
How Anaphylaxis is Portrayed in Movies
Young Children
Food Avoidance at School

Strategies –

- child eats only food from home
- allergy/peanut-free table
- no sharing of food
- parent/teacher are responsible for food avoidance
- medical alert bracelet
- child is encouraged to advocate in developmentally appropriate manner
Birthday Parties – Social Outings

Birthday celebrations

Invitation to friend’s home.
Opportunity to Demonstrate Positive and Flexible Problem Solving

Use these social interactions to provide scaffolding and problem solving for your child.

It is a great time to practice coping skills prior to emerging into adolescents when children are less likely to listen.

Model reading labels, communicating with adults, finding the positive aspects of food allergies.
Young Children and Reaction Preparation

Symptom Recognition = Adult & Child

Availability of Appropriate Medications = Adult

Ability and Confidence to Administer Auto Injector if Needed = Adult

Food Allergy Action Plan = Adult
Young Children and Bullying

What is bullying?
Obvious teasing, threats or aggression.
Sarcastic remarks.
Social isolation.

In young children the fear of the unknown can increase bullying.

Why can’t Jane sit next to me during lunch?
Why won’t Johnny eat my birthday cupcake?
What is that mystery snack box all about?

Less bullying behavior among very young children due to their ego centric sense of self.
Vignette: Anaphylaxis in 7 Year Old

- 7 y.o. female with peanut and tree nut allergies.

- Christmas 2013 – grandfather’s colleague made a “special” plate of allergy-free cookies.

- Took a bite of cookie – tasted funny – throat began to itch.

- Went to the ED – had epi at home but didn’t think they should give it.

- Observed her for several hours – going to send home and she had bi-phasic reaction (10-20%).

- Hives, respiratory distress, change in blood pressure.

- Gave epi, observed for 4 hours and sent home.
Vignette: Anaphylaxis in 7 Year Old

Met with her 6 months after the event. Having stomach aches and mother is getting her from school several times a week.
Refuses to eat any type of cookie except Oreos.
No longer trusts adults, especially grandfather!
Fearful of eating at school – often does not eat her lunch.
Hyper vigilant.
Sleep disturbance – wanting to sleep with parents.

Fear of death!
The Tween Years: Ages 9-12

Solidifying friendships – larger social circle.
Greater independence
More group activities – sports, church, scouts, dance
Greater time away from parents.
Increased Anxiety

Most anxiety is observed between 6 and 11 years of age.

Children are capable of comprehending their food allergy, but their level of ability to self-protect against exposure remains inadequate.
Food Avoidance Across Multiple Environments

School
Sports Activities
Sleep overs
Camp
Social Events
With greater independence comes GREATER:

- Stress
- Coping Skills!
- Anxiety
- Confidence

Problem solving
Tween Years and Middle Childhood

**Increased anxiety and uncertainty**

Greater cognitive understanding of risk. It’s not black and white (can follow the rules and still have a reaction, parents can’t guarantee safety)

More responsibility for allergy management.

Less “structured” environment.

Trust issues (variability in other’s awareness of allergies)

Klinnert & Robinson, 2008

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Conner is an 11 y.o. male with peanut, tree nut, and sesame seed allergies.

His friends are trying out for a soccer team and ask him to join. He makes the team.

Conner’s parents cannot be at the practices and will miss some of the matches.
Vignette – Letting Go

Conner will be confronted with:

- Snacks after practice.
- Several team meals at local restaurants.
- Swim party and dinner at coaches home.
- Concession stand food at tournaments.
How to Cope?

1) Conner’s parents feel the risk is too great – they tell him he can play soccer with his friends at school. He declines the offer to play on the team.

2) His parents allow him to only participate in the events they can attend for fear he will have an accidental exposure.

Avoidant coping strategy = missed opportunities to model positive coping.
How to Cope?

**Positive Problem Solving – Flexible Approach**

**Snack** – Conner’s mother volunteers to provide the snacks and other team members pay a set fee to cover the cost.

Conner brings a “safe” snack from home.

**Team meal at restaurant** – Connor and his parents call the restaurant and ask about peanut/nut-free options. They look at the menu on line and choose what Conner could order. They role play to practice how he will manage the restaurant.

Connor attends but eats prior to going and orders a drink.

Connor’s parents go with and sit away from the team but are there to support Connor should a food allergy issue arise.
How to Cope?

Swim party & dinner at coaches home = Conner’s parent(s) have Connor talk to the coach and ask about the menu. The coach will provide burgers and hot dogs, side dishes are pot luck. The buns will not contain sesame seeds. Conner brings a “safe” dish and chooses to eat a burger with no bun.

His parents discuss the “risk” associated with pot luck and ask Conner how he will manage his food choices. Opportunity for cross contamination – what to do?

Concession stand food = Conner’s parents are not comfortable having him purchase food (cross contamination, many nut products, Conner is not good about reading labels) as they will not be at the tournament. He takes his own snacks.
Be Prepared
Reaction Preparation

Symptom Recognition = Child & Adult

Availability of Appropriate Medications = Adult & Child

Ability and Confidence to Administer Auto Injector if Needed = Adult
Tween Years and Bullying

Recent study in Pediatrics (Shemesh et al., 2013) assessed prevalence of bullying among food allergic children (n=251).

32% of children reported having been bullied, at least once, due to food allergy.

They were followed for a year with 50% return rate of questionnaires. (Annunziato, et al., 2014)

What predicted resolution of the bullying were

1) younger age
2) parents were aware and “did something about it.”
Bullying and Teasing

Additional studies: 30-35% of those 5 and over had experienced food allergy-related bullying/teasing

86% multiple incidents
82% occurred at school
65% reported verbal teasing
57% physical events
58% of parents reported knowing about the bullying
*Parent intervention was associated with remission.

Lieberman et al., 2010, Shemesh et al., 2012; Amnuziato et al., 2014

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Bullying

Clinical Examples

Threats, “I am going to smear this peanut butter on you.”

Child breathed heavily in the face of peanut allergic child and said, “I just ate peanuts – what are you going to do about it?”

A “friend” pretended to have an anaphylactic reaction. The allergic child believed it – became panicked and thought she was having a reaction too.

Food allergic child was not allowed to attend a meeting with his classmates because the teacher thought there might be peanut residue on the table.
Managing Bullying and Teasing

Ask children about bullying (towards them and others)

Communicate with school personnel as necessary

Tell an adult
   It is not tattling – being responsible for your health

Assertive, confident approach.

Spend time with supportive peers.

Teach peers about food allergies – when they understand they want to help.

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ADOLESCENT YEARS: Ages 13-18

Friends become increasingly important.
Separation and Individuation.
Establishment of self identity.
Brain Changes
Interest in the opposite sex.
Hormonal changes – including stress hormones.
Adolescents and Responsibility

Parents report anxiety related to handing over the responsibility to their child for their risk assessment, avoidance strategies, and management of their food allergy.

Parents worry they will also transfer their anxiety to their child.

Adolescents strive to normalize their experiences and tone down negative (attention to food allergy) experiences.

Can result in insecurity and frustration.
Issues for Adolescents

- How to carry/use the EpiPen
- How to talk to peers about allergies.
- How to initiate an emergency plan
- How to identify safe foods/eating out
- How to talk to romantic partners.
- Drugs and alcohol (impact on judgment, allergens)

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Risk-Taking in Adolescence

Internet-based study of 174 13-21 year-olds

54% admit to eating at least a tiny bit of food known to contain an allergen
61% always carry self-injectable epinephrine
58% avoid foods with “may contain” labeling.
39% report not all friends know about allergies.

Sampson et al., 2006

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Let It Go?

NO

NO

NO
The Teen Brain: Still Under Construction

Studies of brain scans from early childhood to age 20.

Late changes in the volume of gray matter – cortex of the brain.

High point = brain volume of gray matter occurs during early adolescents.

Different parts of the brain mature at different rates: basic functions mature first (e.g., control of movement, senses).

More “top-down” control such as impulses and planning are the last to mature.
Adolescent Brain Development

Frontal Lobe = CEO or executive of the brain.

It’s involved in planning, strategizing and organizing, initiating attention and stopping and starting and shifting attention.

Adolescents and adults engage different parts of the brain to different extents during tests requiring calculation and impulse control, or in reaction to emotional content.

It’s rather unfair to expect adolescents to have adult levels of organization skills or decision-making before their brain is finished being “built.”
Brain Development – Food Allergies?

Food Avoidance

School – Social Activities
- less adult supervision
- more opportunities to eat out with friends.
- greater social pressures – embarrassed to ask about ingredients.
- more likely to take risks

The CEO of the brain is out to lunch!
Adolescent Reaction Preparation

Symptom Recognition = Adolescent

Availability of Appropriate Medications = Adolescent and Adult

Ability and Confidence to Administer Auto Injector if Needed = Adolescent and Friend/Adult

The CEO of the brain is out to lunch!
Fatal and Near-Fatal Reactions

Report in 1992 looked at 14 cases: 6 children had died and 7 nearly died and required intubation. (Sampson, et al., 1992)

Three of the six children that died had been prescribed epinephrine but none had it available at the time of the reaction.

Four of the six children that died were adolescents (14, 14, 15, and 16 y.o.)

Five of the seven near-fatal children were adolescents.

2001 – similar report assessed 32 cases of fatality due to food allergy. 17 were adolescents and 5 were young adults (20-21 y.o.). (Bock, et al., 2001)

The majority did not have epinephrine available or it was given too late.
Availability of Appropriate Medications

Adolescents have to carry their auto injector!

Their friend(s) should know how to administer it.

If they do not carry the auto injector there should be consequences –
  take away privileges – phone, car, sports
Take Home Message

You can find the balance between keeping your child safe and allowing a developmentally appropriate life.

It is not always easy!

Never be afraid to ask for help.

Model positive behaviors for your child.

Let the responsibilities “go” a bit at a time.
Thank You!

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THANK YOU!