Psychosocial Well-Being: Living with Food Allergies

Learning Objectives:

- Describe the psychosocial dynamics of living with food allergies: challenges, emotions, and accomplishments
- Discuss approaches that build and enhance stability, security, and sensibility using challenging case scenarios
- Identify successful resources for assisting the food allergic patient and family

Disclosure

We have no potential conflicts to report regarding food allergies

2011 in U.S.: 5.9 million children under 18 reported Food Allergies

1997-2007: 18% increase in food allergies in children under 18

Building Stability, Security, & Sensibility

- Living With Food Allergies Feels Like You Are Navigating Through An Obstacle Course
  - Hurdles, Challenges, Surprises, & Uncertainties
- How Do You Promote Strength Vs. Fear?
  - Establishing an atmosphere of confidence & trust
  - Vigilance
- How Do You Tackle Uncertainty & Insecurity
Do You Know What Your Food Allergic Patient & Their Family Are Struggling with as They Live & Cope with Their Food Allergies?

FEELINGS
- Frustration
- Anger
- Sadness
- Fear
- Overwhelmed
- Worried
- Depression
- Shock
- Astonished
- Uncertainty
- Unhappy
- Denial
- Anxious
- Confused
- Stressed
- Guilt
- Powerlessness

Family Adaptation
- “It is imperative that health care professional not only understand the biomedical implications of the problem, but also the overall psychosocial impact that may be experienced after diagnosis.”

Parentsal Stress
- Excessive Demands
- Fear of Dying
- Financial Burden
- Uncertainty – Living in a state of sustained uncertainty
  - Ambiguity – confusion and disorganization within the family system
  - Marital Strain
- Interference with Routine
- Social & Emotional Isolation
- Navigating Schools, Travel, Eating Out
- “Living with Risk”
- “Living with Fear”

Life Threatening Food Allergies
- Promotes Anxiety & Fear
  - Not eating or missing special events
  - Management of the food allergy
- Depression
- Social Isolation
- Psychological Distress
  - Maladaptive coping responses that interfere with the psychological and social development and optimal functioning of family members
  - Impact on Relationships
Validated Instruments

- "The Food Allergy QoL Parental Burden questionnaire (FAO-L-PB) measures the parental burden associated with having a food allergic child."

- Validated instruments allowing parents to report on QoL in the child from the child’s perspective and for children and teenagers to report on their own QoL.

Food Allergy Quality of Life – Parental Burden Questionnaire (FAO-L-PB)

- 17 item instrument
- Focused on emotional responses
  - Sadness
  - Worry about future
  - Helplessness
  - General anxiety
- Family functioning impacted
  - Family/Social activities
  - School/camp
  - Meal preparation time
  - Health concerns
  - Emotional issues

Food Allergy Impact Scale

- Assess Impact of Food Allergy on Daily Activities
- 87 Families
  - 70% had significant impact - Aspects of daily life were affected & family meal preparation
  - 79% - Significant impact of going to restaurants
  - 10% - No engaging in activities with relatives
  - 11% - No play dates at friends’ houses
  - 10% - Missed birthday parties
  - 10% - Home schooled

Emotional Impact on Children with Food Allergies and Their Parents

- Many studies have shown that food allergies have a significant effect on the psychological well-being of children with food allergies and their families.
- Parents of a child with a food allergy may have constant fear about the possibility of a life-threatening reaction and stress from constant vigilance needed to prevent a reaction.
- They have to trust their child to the care of others, make sure their child is safe outside the home, and help their child have a normal sense of identity.

Emotional Impact on Children with Food Allergies and Their Parents

- Children with food allergies may also have constant fear and stress about the possibility of a life threatening reaction.
- The fear of ingesting a food allergen without knowing it can lead to coping strategies that limit social and other daily activities.
- Children can carry emotional burdens because they are not accepted by other people, they are socially isolated, or they believe they are a burden to others.

Time To Worry

- Age 7: Increased Anxiety = Cognitive ability to comprehend serious nature
- Adolescence
  - Most Common among teenagers and young adults
  - Risk taking, faulty perceptions of risk
  - Internet based Questionnaire 13-25 yr olds
  - 54% of 314 responses
  - Purposefully ate tiny amount of food containing allergen
  - Previous exposure without reaction
  - Judgment
  - Wanting to eat the food
  - Epi – carried epi (depending on situation varied)
Anxiety Among Parents of Children With Food Allergies

- Chronic illness is a risk factor for developing anxiety.
- Anxiety symptoms are prevalent in children with chronic illness.

Concurrent Disorders

- Concurrent disorders (medical and anxiety) seem to result in greater impairment than either an anxiety disorder or medical condition alone.

Burden of Responsibility

- The burden of responsibility that food allergy exerts upon individuals and their families can have a significant influence on QoL. Primeau et al. found that peanut allergy is a condition which forces parents to exert extreme dietary vigilance and face continuous uncertainty over the possibility of accidental exposures. Avoidance of food allergens requires constant vigilance and is complicated by the presence of irritants that is not always obvious. In a study of community allergic reactions to foods, 64% of participants were aware that they had a food allergy, yet over 50% were unaware that the food they were consuming contained the allergen. This reflects the difficulties associated with total allergen avoidance, and the burden taken on by those who see themselves as responsible for that avoidance.

Coping Patterns Effect Parental Response

- Study by Deena Mandell, et al 2002 discusses how families describe their adaptation to living with anaphylaxis in their child.
- Initial high anxiety proved motivating towards seeking education and resources.

Anxiety Among Parents of Children With Food Allergies

- Anxiety symptoms are prevalent in children with chronic illness.

Anxiety Patterns Among Parents of Children With Food Allergies

- Anxiety symptoms are prevalent in children with chronic illness.


Mary Klinnert PhD unpublished talk 2008
**Obstacles to Coping**

- Lack of public understanding/cooperation
- Inconsistent medical information
- Mislabeled and/or inconsistently labeled foods
- Multiple food allergies

Mandell, 2002

**Fear Factors**

- Anaphylaxis
- Death
- Restaurants
- Vacations
- Grocery Store
  - Food Labels
  - Holidays
  - Camp
  - Field Trips

**Expanded from The Kübler-Ross Grief Cycle**

- Shock
- Denial
- Anger
- Bargaining
- Depression
- Guilt
- Acceptance

**Coping**

<table>
<thead>
<tr>
<th>PROBLEM-FOCUSED STRATEGY</th>
<th>EMOTION-FOCUSED STRATEGY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Define problem</td>
<td>Distance themselves from stress by minimization</td>
</tr>
<tr>
<td>Seek potential solutions</td>
<td>Avoidance</td>
</tr>
<tr>
<td>Learn new skills to deal</td>
<td>Self-blame</td>
</tr>
<tr>
<td>New methods to manage</td>
<td>Punishment</td>
</tr>
</tbody>
</table>

Lazarus & Folkman, 1984

<table>
<thead>
<tr>
<th>FIREDR</th>
<th>BASKIN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support</td>
<td>Resilience</td>
</tr>
<tr>
<td>Hope</td>
<td>Action</td>
</tr>
</tbody>
</table>

**Strategies**

- Address fears
- Promote resilience
- Improve confidence
- Support
- Navy

Food Allergy Fun

Food Allergy side effects may include healthier eating habits, improved baking skills, and an increased number of meals together at the dinner table.

www.foodallergyfun.com  TGF 2012
### Educational Targets
**Food Allergy Management Strategies**
- Parents
- Grandparents
- Peers
- School
  - Child Care Providers
  - School Personnel
- Parties
- Sleepovers
- Holidays
- Restaurants
- Grocery Stores
- Camp
- Babysitters
- Celebrations
- Travel

### Dining Out
**RESTAURANTS**
- CALLING AHEAD
  - View ingredient list
  - Avoiding risky environments
    - Chinese restaurants if peanut allergy exists
- CROSS CONTAMINATION
- Preparing Food
  - Safe alternatives...
- EPI PEN
- Customized menu

**OTHER LOCATIONS**
- Speaks with Hostess
- Contributes items
- Have safe food
  - Alternatives... bring safe food with you
- Provide education
  - List of food allergies
  - Preparation
  - Cross Contamination

### School
- Food Allergy Action Plan
  - Picture
  - Epi Pen (2 dual boxes)
  - What
  - Where
  - When
  - Proper training annually
  - Meet with School Personnel and Team
    - Recognizing symptoms of allergic reaction and what to do
    - Letter to Families... communication with parents
  - Education/Awareness
    - Special Programming/Celebrations/Projects
  - Substitute Teachers / Aides
  - Not using food as incentive or reward
  - Lunch / Snacks – hand washing, not trading or sharing
  - Holiday Planning/Parties
  - Field Trips

### Noodles & Company

### Voluntary Guidelines for Managing Food Allergies in Schools and Early Care and Education Programs

### CDC’s National Guidelines for Managing Food Allergies in Schools
- On October 30, 2013, the Centers for Disease Control & Prevention (CDC) published “Voluntary Guidelines for Managing Food Allergies in Schools and Early Care and Education Programs” – the first national comprehensive guidelines for school food allergy management.
- This act is designed to improve food safety in the United States by shifting the focus from response to prevention.
Food allergies are a growing food safety & public health concern affecting an estimated 4%–6% of children in the U.S.

- Many schools and ECE programs have implemented some of the steps needed to manage food allergies effectively. Yet systematic planning for managing the risk of food allergies and responding to food allergy emergencies in schools and early care and education (ECE) programs remain incomplete and inconsistent.
- Studies show that 16%–18% of children with food allergies have had a reaction from accidentally eating food allergens while at school. In addition, 2% of the severe and potentially life-threatening reactions (anaphylaxis) reported at schools happened in children with no previous diagnosis of food allergy.

Recommendations in the following five priority areas

1. Ensure the daily management of food allergies in individual children.
2. Prepare for food allergy emergencies.
3. Provide professional development on food allergies for staff members.
4. Educate children and family members about food allergies.
5. Create and maintain a healthy and safe educational environment.

Obama Signs Bill to Increase EpiPen Availability in Schools

President Obama signs the School Access to Emergency Epinephrine Act in the Oval Office of the White House in Washington, D.C., on Nov. 13, 2013

Thirty states now have laws or guidelines in place allowing schools to stock undesignated epinephrine auto-injectors, but only four states (Maryland, Nebraska, Nevada, and Virginia) currently require it.
**Grocery Store**
- Reading Labels
  - Carefully and continually / ingredients change
  - Varying product size → different ingredients
  - Being smart when unsure
- Purchasing only with label
- FARE alerts
- Cosmetics, lotions, bath products

**Travel**
- List of food allergies in language of country
- Letter for flying with medication
- Notifying airline of food allergy prior and day of
- Travel with allergy-friendly food and medication with you

**Strengthening Coping Mechanisms**
- Building Skills
  - Having a food allergy management plan
  - Psychosocial parameters
  - Know emergency plan
  - Having and carrying at all times epinephrine
  - Having and knowing emergency numbers
  - Recognizing symptoms early & responding quickly
  - Communicating effectively
  - Not trading food
  - Learn how to read labels
  - Having a responsible adult in every environment
  - Maintain best achievable asthma control
  - VIGILANCE

**Case Vignettes**

**Resources**
- Newsletters
- Magazines
- Support Groups
- Internet
  - Blogs
  - Chats
  - Education
  - Forum
  - E-newsletters
- Counseling
- Education
- Psychoeducational (Kelmert M. & Robinson J.)
- Dietician

**Resources**
- FARE: Food Allergy Resource & Education (The Food Allergy and Anaphylaxis Network [FoodAllergy.org] and The Food Allergy Initiative (FAI) are dedicated to Food Allergy Research and Education with the mission of ensuring the safety and inclusion of individuals with food allergies while relentlessly seeking a cure. FARE combines FAI’s expertise as the most trusted source of information, programs and resources related to food allergies with FAI’s leadership as the world’s largest private source of funding for food allergy research.
- National Institute of Allergy and Infectious Diseases: Guidelines for the Diagnosis and Management of Food Allergy in the United States [http://www.niaid.nih.gov/health-topics/food-allergies.html]
- Asthma and Allergy Foundation of America (aafa.org) & Kids With Food Allergies is a national nonprofit food allergy organization dedicated to fostering optimal health, nutrition, and well-being of children with food allergies by providing education and a caring support community for their families and caregivers. (kidswithfoodallergies.com)
- Allergy & Asthma Network, Mothers of Asthmatics (www.aanma.org)
- Why Risk It? A Canadian food allergy website for teens (www.whyriskit.ca)
### References

- Flokstra-de Blok BM, DunnGalvin A, Vlieg-Boerstra BJ, Oude Elberink JN, Duiverman EJ, Hourihane JO.