Psychosocial Issues in Food Allergy:
Vital Information for Health Professionals

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The mission of
ALLERGY & ASTHMA NETWORK
Is to end the needless death and suffering due to asthma, allergies and related conditions through outreach, education, advocacy and research.
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Licensed Psychologist

Almost 30 years of experience in clinical practice, psychological research, and teaching
- Practice specializing in treating trauma/PTSD, depression, and anxiety
- Unique experience in helping individuals and their families cope with life-threatening food allergies, and other complex medical issues
- Mother of a college student with multiple food allergies
- For more information: www.dr.giarosenblum.com

Program Outline

- Foundational Food Allergy Knowledge
- Understanding the Burden of Living with Food Allergies
- Coping with Allergic Reactions
- Informed Interventions
Foundational Food Allergy Knowledge

Food Allergy by the Numbers

1 in 12 children have food allergies

$24.8 Billion: Annual cost of food allergy

29% of children with food allergy have asthma

150-200 fatalities/year from food allergy
Top 9 Food Allergens

- Peanuts
- Tree Nuts
- Wheat
- Dairy
- Fish
- Eggs
- Shellfish
- Soy
- Sesame

Basics of Food Allergy

01 Other serious food allergens: Mustard, mollusks (oysters), buckwheat, celery & Lupin

02 Any food allergic reaction can be life threatening

03 Minute amounts of food protein can trigger anaphylaxis

04 Management: Entirely behavioral COMPLETE AVOIDANCE is essential

05 Treatment: Epinephrine FIRST, Epinephrine FAST Call 911

06 Risk of death: Delayed epinephrine Uncontrolled asthma Adolescent & young people
Self-Management of Food Allergy is 100% Behavioral

Maintain Strict Control
- Control all food-related situations
  - Avoid culprit foods and cross-contact between safe foods and allergens
  - Avoid non-food allergen sources (e.g., cosmetics, soaps/lotions, medications/vaccines, craft supplies)

Be a “First Responder”
1. Self-diagnosis of anaphylaxis (via often ambiguous early signs)
   - Self-treatment by injecting epinephrine and obtaining emergency medical attention
2. Carry two epinephrine auto-injectors within arm’s reach always

Practice Continuous Self-Advocacy
- Request accommodations from: Waiters, restaurant managers, caterers, friends, family members, school districts, principals, headmasters, teachers, school nurses, strangers on airplanes, pilots and flight attendants, coaches, teammates, boyfriends, girlfriends, chorus directors, sorority sisters, tutors, Halloween candy giver . . . EVERYONE!

Many Daily Routines of Daily Life Must Change after Diagnosis

Meal Planning
- Family meals, school lunches, snacks
- Travel often means carrying food, contacting restaurants

Food Shopping
- Eliminate allergen from purchases
- Read labels
- Every item, every time

Food Preparation
- Eliminate/Substitute allergens in all recipes
- Prevent cross contact while cooking

Food Serving
- Prevent cross contact when serving
- Separate plates, utensils, wash hands, don’t touch

Food Storage
- Prevent cross contact between allergen and safe foods
- Prevent accidental ingestion of unsafe foods stored at home

Kitchen Clean-up
- Prevent cross contact during and after cooking and eating
- Cracker crumbs, flour dust, or specks of cheese on counter, sponge, or towel can be dangerous
Empathy Builder – Next Grocery Shopping Trip:

Choose a Top 9 Allergen

Plan meals without that allergen
• Commit not to buy any foods containing that allergen
• Read every label on every packaged food you select in its entirety before you put it in your cart

Choose a non-Top 9 Allergen

Select 3 packaged foods.
• Call the manufacturers to ask if that allergen might have cross contact with the food
• Imagine doing that for everything in your pantry

Understanding the Burden of Living with Food Allergies
Food Allergy is a Chronic Stressor

- Unpredictability
- Uncontrollability
- Expectation of a negative outcome – “Sense of threat”
- Uncertainty
- What to do next?!?

Why is Food Allergy So Stressful?

- Pervasiveness of Threat
- High Levels of Daily Vigilance
- High Behavioral Control Demands
- High Social Skills Demands
- Low Social Support/Social Cruelty
- Uncertainty/Lack of Control
- Low Efficacy/High Stakes Emergency Response Demands
Food Allergy Sense of Threat

Subjective fear of death from food allergy

Far outweighs the objective actual probability of death from food allergy

Psychosocial Research in Food Allergy

Burgeoning science of the psychosocial impacts of living with food allergy

Examines:
- General quality of life (QoL)
- Health-related quality of life (HRQoL)
- Food allergy specific quality of life (FAQoL)
- Stress
- Anxiety
- Clinical psychopathology
Mothers and children with food allergy report…

Increased anxiety and stress

Decreased quality of life

What contributes to a greater impact?

Severe allergic reactions/Epi auto-injector use

Multiple food allergies

Comorbid allergic diseases

Low family income

Research Findings

Perceived History of Anaphylaxis

Worse Quality of Life & Anxiety

Higher Subjective Fear of Death

Perception of the food allergy experience influences psychological outcomes
Future Research

01 Coping Styles
02 Predictors of Resiliency
03 Intervention & Prevention
04 Developmental Context
05 Impact of Stress Levels on Immune Function & Allergic Response
06 Longitudinal Impacts of Food Allergy Stress

Coping with Allergic Reactions
Food Allergic Reactions

Food Allergy reactions are typically unexpected / shocking.

Reactions can be highly stressful regardless of severity.

Reactions may be perceived as life-threatening whether they factually are or not.

All involved (patient, caregivers, witnesses) may feel panicky & flustered.

Anxious Caregivers may avoid preparation.

Plan of Action: Problem solving & planning for an allergic reaction are key to effective emergency response.

Unlike other unexpected medical events in food allergy there is a specific & clear plan of action.

A path to safety: Be Prepared for an Allergic Reaction.

Preparation

Safety
Coaching Caregivers – Prepare for an Allergic Reaction

- **Stay Calm**
  - Fight/flight/freeze response impairs executive function
  - Uncertainty leads to hesitation and delayed responding

- **Calm & Effective Response**
  - Preparation
  - Rehearsal

- **Allergy Action Plan**
  - Have a plan that outlines when to give epinephrine, when to call 911

- **Signs of an Allergic Reaction**
  - Is this anxiety? A true allergic reaction? Understand how young children describe an allergic reaction

- **Patient’s Allergens**
  - Know the specific allergens that may trigger an allergic response

- **Proper Use of Epinephrine**
  - Practice using your device
  - Epinephrine FIRST, Epinephrine FAST

### Rehearse Emergency Response

- **“Allergic Reaction Drills”**
  - Home
  - School - Table Top Drills

- **Use imagination, dialogue or role play**

- **Practice communication with the child / patient**

- **Practice using calm demeanor**

- **Rehearse asking for what is needed**
Potential Patient Responses

May feel more upset, worried, stressed
Wide variety of emotions
May last days or weeks
May depend on severity of reaction, but not necessarily

May question adult’s ability to keep them safe
May disrupt family.

May feel guilty, responsible, “bad”
For reaction, their response, cost of care, family disruption

Confidence in allergen avoidance may be shaken

Increased anxious avoidance
Of eating, food, New allergen?

Helplessness, difficulty talking without distress
May avoid, withdraw
May need help processing

Anaphylaxis can include frightening sensory elements
Airway closing, difficulty breathing

Memories may linger and be distressing

Informed Interventions
Cognitive-Behaviorally Informed Interventions

- Psychoeducation
- Problem Solving
- Beliefs & Mindset / Thought Challenging
- Self-Monitoring Skill Building
- Coping Skills
- Other: Acceptance & Commitment Therapy, mindfulness-based Cognitive Theory, Dialectical Behavior Therapy

Psychoeducation: Risk

Unrealistically high estimates of food allergy risk creates anxiety

- Accurate Information about Risks
- Interventions to Improve Emergency Response Efficacy
- Reduced Anxiety

Collaborate with physicians to create hierarchies of risk situations instead of “Safe” vs Unsafe” situations
Skill Building Techniques

- Education
- Role Modeling
- Role Playing
- Rehearsal
- Story-boarding
- Use of Play
- Creative Therapies
  - Art, Writing, Journaling, Blogging, Poetry

Other Approaches

- Self Compassion
- Systems Informed
- Trauma Informed
Family & Systems Informed Goals

01
Shared view of food allergy living
Common language to discuss food allergy

02
Agreed upon health behavior strategies that all endorse & support

03
Strategies for mutual support

04
Appreciation of the meanings that food allergy may have for family members

05
Increased acceptance of family members’ emotions & expression

06
Understanding of family members’ responses to stress & adversity

Brandon

• High School Senior with Nut allergy
• He and parents never received basic food allergy education (that he knows of)
• Angry that parents don’t ever discuss his allergy with him
• Unnecessary food and situational avoidance.
  • Frequently takes Benadryl for imagined reactions
  • Admits this is mostly to quell his anxiety.
• Reports feeling “on edge all the time,” especially around food
• Concerned he can’t tell the difference between anxiety and a reaction

Most recent reaction: cookies friend brought to an after-school meeting
Assumed absence of “contains statement” meant cookies were safe
EMT told him "Good thing you didn't use Epi - they hurt!"

Worries about starting college:
  Having a reaction away from home
  Making friends who won't think he’s "a freak"
  Finding safe food
  Dating
Issues in Brandon’s Case

01 Chronic anxiety
02 Avoidance behavior
03 Lacking or inaccurate food allergy management information
04 Worries about the future
05 Social skills

Kerry

- Mom of 2 children, each with different food allergies
- Feels she is “on it” when it comes to finding safe foods for both kids.
- Packs food “constantly” for school, day trips, weekend trips, vacations, and visits to family, saying, “I never want the kids to miss out… I want them to feel normal.”
- Works part time. Reports being exhausted and concerned that she “can’t keep this up.”
- Tears up immediately when asked about recent allergic reactions. Describes feeling shocked and angry with herself that an allergen slipped through.
  - States that she feels helpless when she thinks about it, so she tries not to
  - Says she has had nightmares about her children’s reactions, even though only one was severe
- Is dreading upcoming Oral Food Challenge
Issues in Kerry’s Case

01 Daily stress & fatigue of food allergy management
02 Concerns about her children’s emotional wellbeing
03 Standards for her own behavior & performance
04 Distress from witnessing children’s allergic reactions

Post Traumatic Stress?

A Home Study Course for Mental Health Professionals
The Mental Health Professional’s Guide to Psychosocial Issues in Food Allergy

Home Study Course

One of a kind program
Designed to enhance health practice
Licensed professionals
Increase competence & confidence in working with food allergy

11 program modules – online learning
Self-paced, on demand learning – complete from the comfort of your home and on your schedule
Printable slides & reference lists

Evidence-based, practice proven
Professional faculty – psychologists, medical doctors
Foundational knowledge – medical & psychosocial
Case studies, appropriate interventions

Why Take This Course?

The food allergy population is growing – more than 30 million patients – a significant number need mental health support

Career Enhancement
New in career? Grow your practice
Mid-career practitioners – Add to your practice
Learn how to serve families with food allergies.

CE offered through NBCC
Earn CE while you learn.

Modules offered:
Food Allergy 101
Foundational Knowledge & Patient Self-Management
Understanding the Burden
Developmental Stages in Food Allergy: Infancy Through the Preschool Years
Developmental Stages in Food Allergy: Elementary & Middle School
Developmental Stages in Food Allergy: Adolescents
Oral Food Challenges & Immunotherapy: Helping Parents Cope
Assessing Psychosocial Issues in Food Allergic Patients
Coping with Allergic Reactions & Oral Food Challenges
Interventions in Food Allergy
Following participation in the Home Study Course, you can apply to be a

FOOD ALLERGY COACH

Certified by Allergy & Asthma Network
Join our list of approved providers

Promotion of Coaching Practice
Can be done locally or remotely
Option to join our HIPAA-compliant telehealth platform for certified coaches

For more information contact us at info@allergyasthamanetwork.org

Join our food allergy community! Make a difference!

QUESTIONS

We’ll get to as many questions as we can!
Next Webinar

COPD Phenotypes

July 26, 2022
4:00 PM ET

Breathe Better Together

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