

# Food Allergy Self-Management among Adolescents

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# Disclosure Slide

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# OBJECTIVES

1. Explain the major tasks of food allergy management
2. Identify challenges to food allergy self-management among adolescents
3. Describe development of a behavioral intervention for adolescents that targets food allergy self-management

# A FOOD ALLERGY PRIMER



# Food Allergy Primer

## How common is food allergy?

- Almost 8% of US children and 11% of US adults
- May be diagnosed in infancy through adulthood

## What are common food allergens?

<b>Peanut</b>	<b>Tree nut</b>
<b>Cow's milk</b>	<b>Egg</b>
<b>Wheat</b>	<b>Soy</b>
<b>Shellfish</b>	<b>Fish</b>
<b>Sesame</b>	



## Are there frequent comorbid conditions?

- Atopic dermatitis, asthma, environmental allergies

## Demographic data show...

- Black and Hispanic/Latinx children are disproportionately affected
- Asian/Black children have higher rates of > 1 food allergy than White children
- Families with lower income spend more on emergency care than families with higher income



- Gupta et al. Prevalence and severity of food allergies among US adults. JAMA Network Open 2019; 2(1):e185630.

- Gupta et al. The public health impact of parent-reported childhood food allergies in the United States. Pediatrics 2018; 142(6):e20181235.

- Mahadavinia et al. Racial differences in food allergy phenotype and health care utilization among US children. J Allergy Clin Immunol Pract. 2017;5:P352-357.E1.

# Food Allergy Primer

## What is food allergy?

- An adverse health effect arising from a specific immune response that occurs reproducibly on exposure to a given food

## Allergic reactions may involve multiple systems

- Skin and mucous membranes
- Gastrointestinal tract
- Respiratory system
- Cardiovascular system



## What is anaphylaxis?

- A multi-systemic allergic reaction that can result in shock and/or death

## How is anaphylaxis treated?

- Prompt administration of epinephrine



# Food Allergy Primer

## How is food allergy diagnosed?

### Food history

Assesses for history of symptoms after ingestion of the allergen

### Skin prick tests

Checks for immediate allergic reaction to specific allergen extract

### Blood tests

Measure the presence of IgE antibodies to specific foods

### Oral food challenges

Stepwise ingestion of the allergen to determine outcome



# Food Allergy Primer

## Daily food allergy management includes:

- Elimination diet
- Identification and treatment of allergic reactions

## Are there other treatments for food allergy?

- Palforzia: Approved by FDA for peanut allergy treatment in children ages 4-17 years in 2020

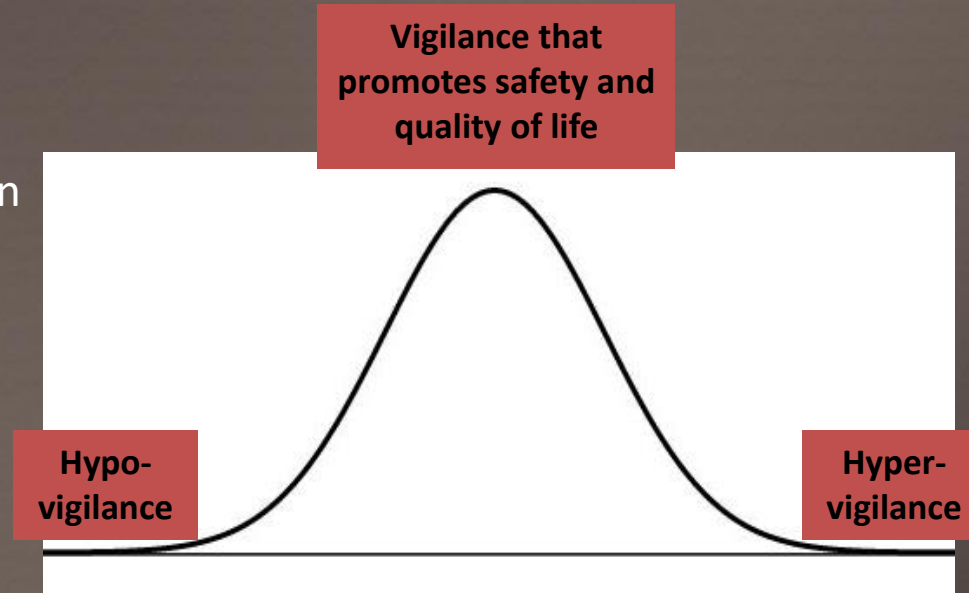


# Food Allergy Primer

## What are common psychosocial concerns?

### Affected children/parents report...

- Increased stress related to daily burden
- Increased anxiety which can lead to avoidance/social isolation
  - Allergen exposure
  - Ability to treat reactions
  - Trusting other caregivers
  - Relationships
  - The future
- Decreased quality of life, especially regarding social activities and diet diversity



# Food Allergy Primer

## How common are allergic reactions?

- 38% > 1 per year
- 13% 1 per year

## Where do allergic reactions occur?

- At home
- Restaurants

## Who is most likely to have a fatal allergic reaction?

- Adolescents and young adults, especially when allergens are unknowingly ingested away from home and treatment is delayed.

## Why do adolescents have allergic reactions?

- Unintentional exposure, mostly by cross contact

## Further, about 10% of exposures are to previously diagnosed allergens

- Had not experienced an allergic reaction in the past
- Were unaware of the risk
- Knew the risk of decided to take the risk
- Did not believe food allergy is serious
- Exposure by bullying (1% of parents, 2% of self-respondents)



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Bock et al. (2001). Fatalities due to anaphylactic reactions to foods. *JACI*, 107(1), 191-193.

Fierstein et al. (2021). Understanding food-related allergic reactions through a US national patient registry. *JACI In Pract*, 9(1), 206-215.

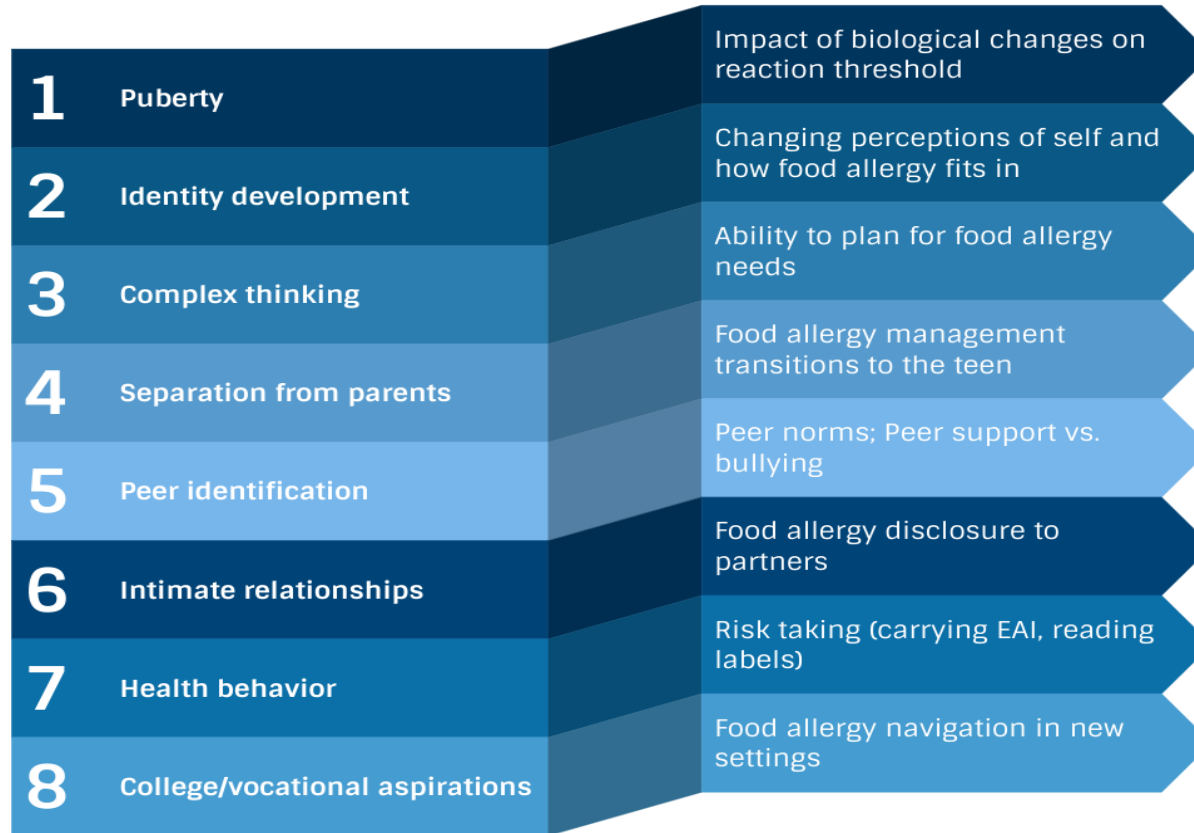
Oriel et al. (2020). Characteristics of food allergic reactions in United States restaurants. *JACI In Pract*, 9(4), 1675-1682.

Warren et al. (2017). Food allergy-related risk-taking and management behaviors among adolescents and young adults. *JACI InPract*, 5(2), 381-390.

# ZOOMING IN ON ADOLESCENCE



# Developmental Tasks and Food Allergy



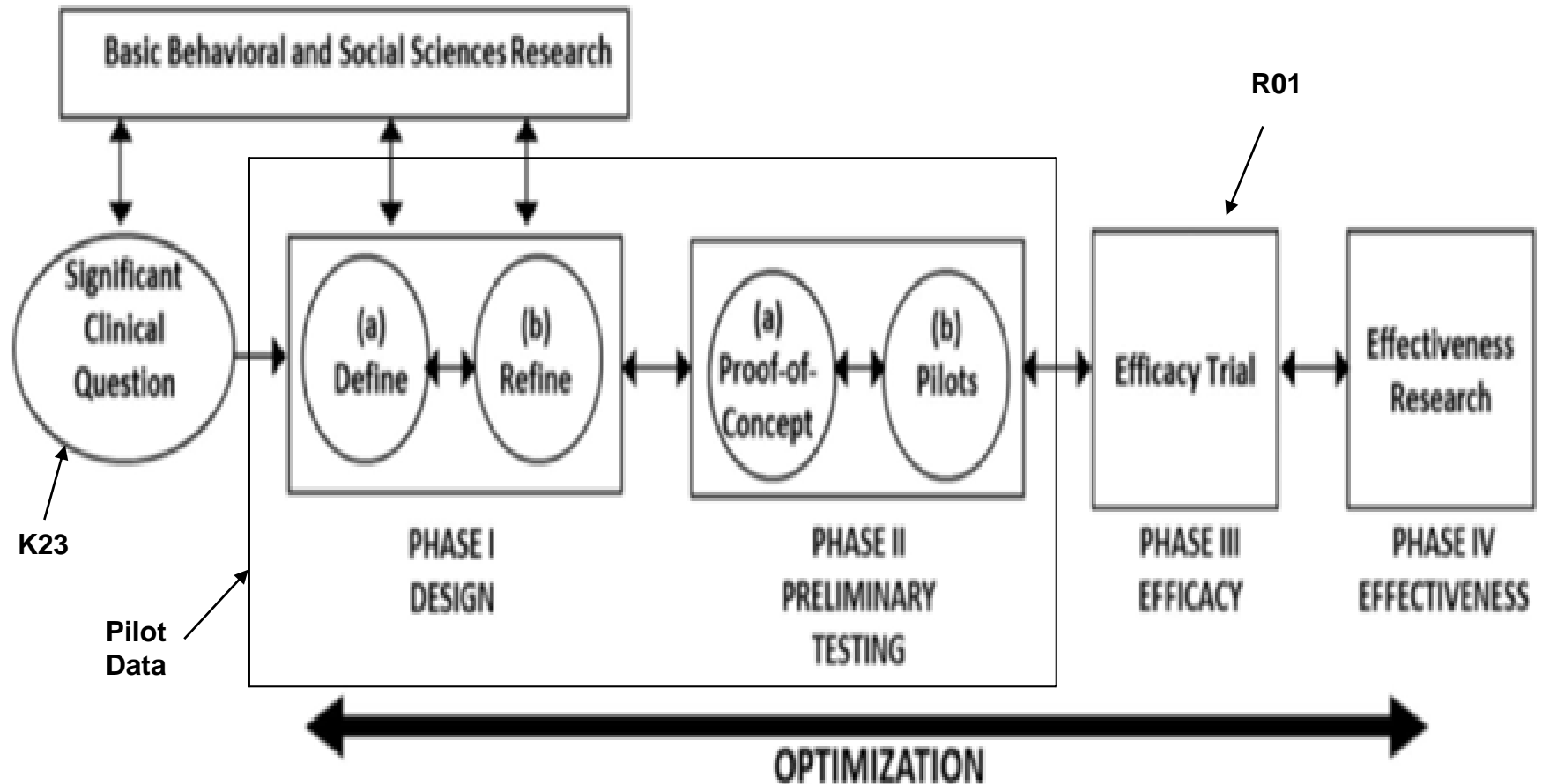
# Challenges with Medical Management

Example: Asthma-- systematic review of facilitators and barriers

	Barriers	Facilitators
Knowledge	Poor knowledge of asthma, treatment, and devices	Severe exacerbation
Lifestyle	Forgetting to take meds; Time constraints; Not waiting to interrupt activities; Inconvenience; Can't avoid triggers	Routines; Cues for remembering meds
Beliefs/Attitudes	Side effects; Beliefs of ineffectiveness or not serious; Denial	Positive attitudes about asthma and meds
Relationships	Unsupportive teachers/school policies; Negativity toward HCPs	Accepting help from others; Support/reminders from peers; Supportive HCPs
Intrapersonal	Apathy; Embarrassment; Lack of assertiveness; Shame; Wanting to "be normal"	Acceptance of asthma
Communication	Withholding info from HCP; Difficulty being honest; Afraid to ask HCP questions; Not paying attention to HCP; Not discussing asthma with others	



# Approach: The ORBIT Model of Behavioral Intervention Development



# THE FOOD ALLERGY MANAGEMENT PROJECT (K23)



## AIMS

1. Evaluate child food allergy-related anxiety, quality of life, and adherence during a 1-year period and their relationships with child biopsychosocial experiences
2. Use qualitative interviews to identify factors that affect food allergy adjustment and adherence

## SAMPLE

- 121 parent child dyads
- Mean age = 11.76 years (Range 10-14 years)
- Gender: 60% male
- Race: 37% Black, 30% White, 12% Multiracial, 6% American Indian, 6% Others
- Ethnicity: 12% Latinx
- All top 9 allergies represented

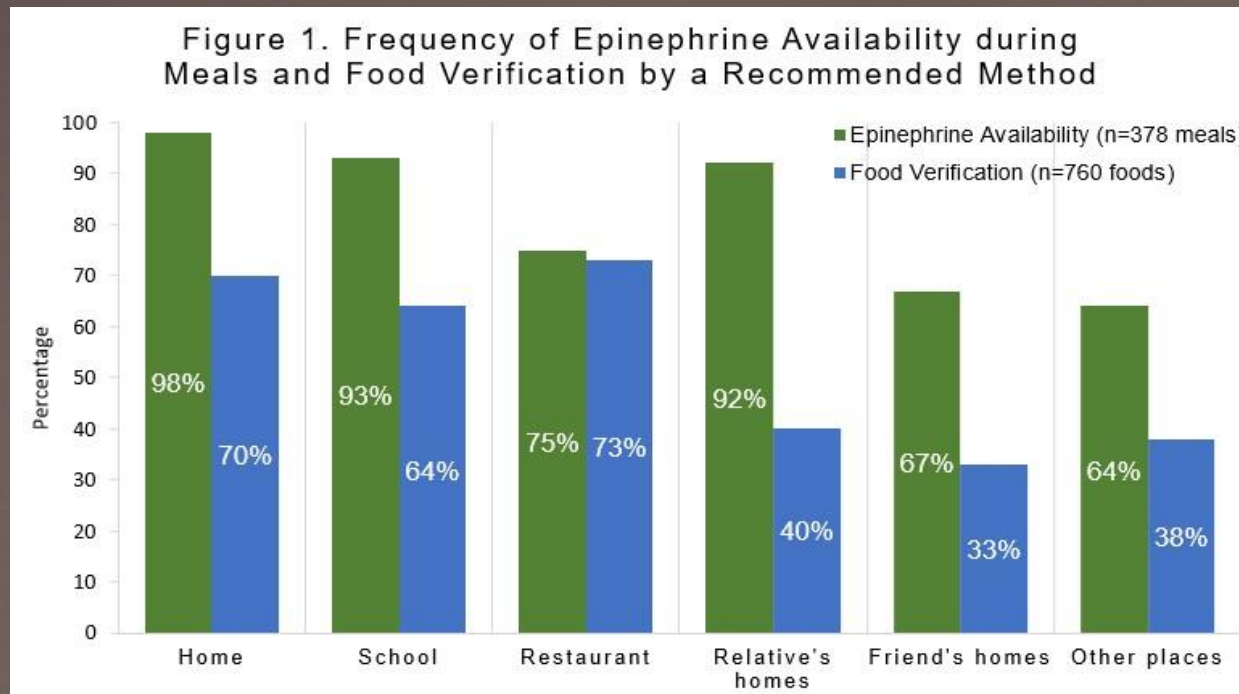
# Food Allergy Self-Management: Allergens



Estimates of how frequently adolescents avoid their allergens vary widely

- Robinson et al. (2019): 85% reported that they “tried” to avoid allergens
- Sampson et al. (2006) and Jones et al. (2015): 20-54% of adolescents acknowledged that they knowingly ate foods with allergens.

FAM Project data: About 35% of the time early adolescents rely on past experience with a food to make decisions about its safety, which is not a reliable or recommended strategy.<sup>22</sup>

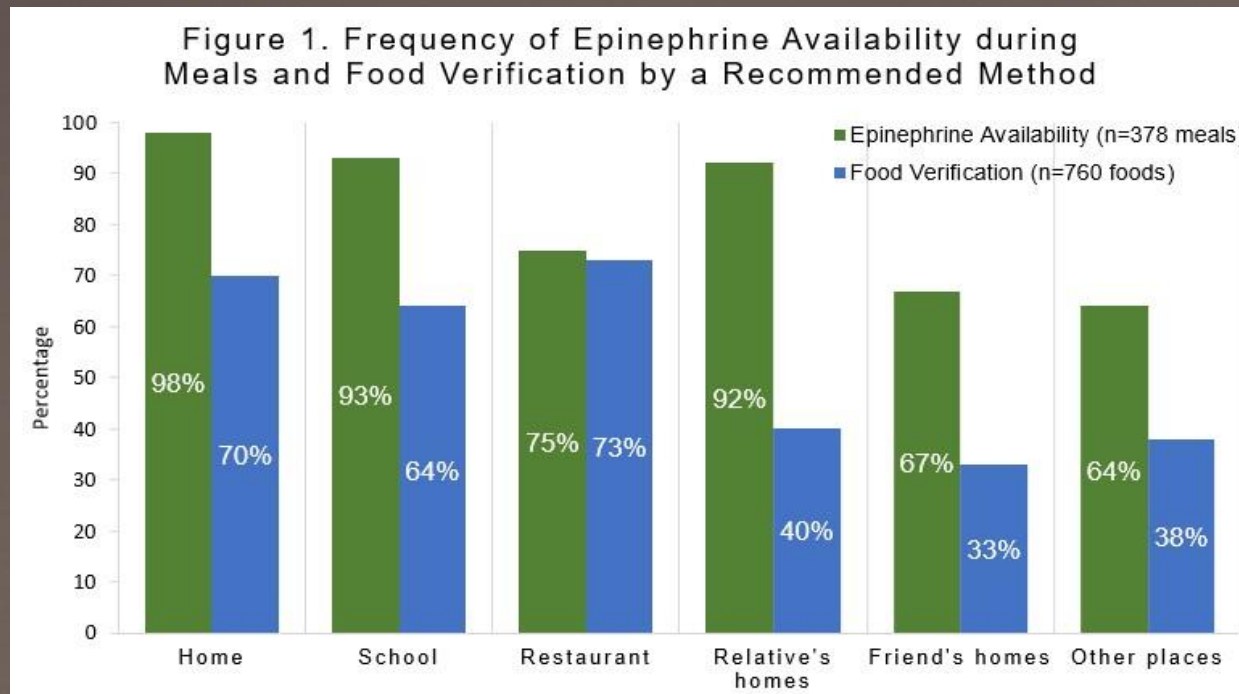


# Food Allergy Self-Management: Epinephrine



Robinson et al. (2015), Shah & Pongracic (2008), and Sampson et al. (2006): Very few adolescents always carry their EAI

FAM Project data: EAI availability is dependent on the location of the meal or snack, with early adolescents being particularly unlikely to have EAI with them when in the homes of friends, restaurants, and other locations such as the car



# Food Allergy Peer Experiences

## Food allergy vigilance conflicts with peer norms

- Carrying epi may depend on how conspicuous auto-injectors are
- Reluctance to appear different (what they are eating, asking questions)

## Food allergy-related bullying

- 1/4 to 1/3 of children have experienced food allergy-related bullying or teasing, mostly at school by classmates
- 2/3 noted continued bullying one year later
- Children who were bullied and their parents reported decreased quality of life, sadness, and embarrassment



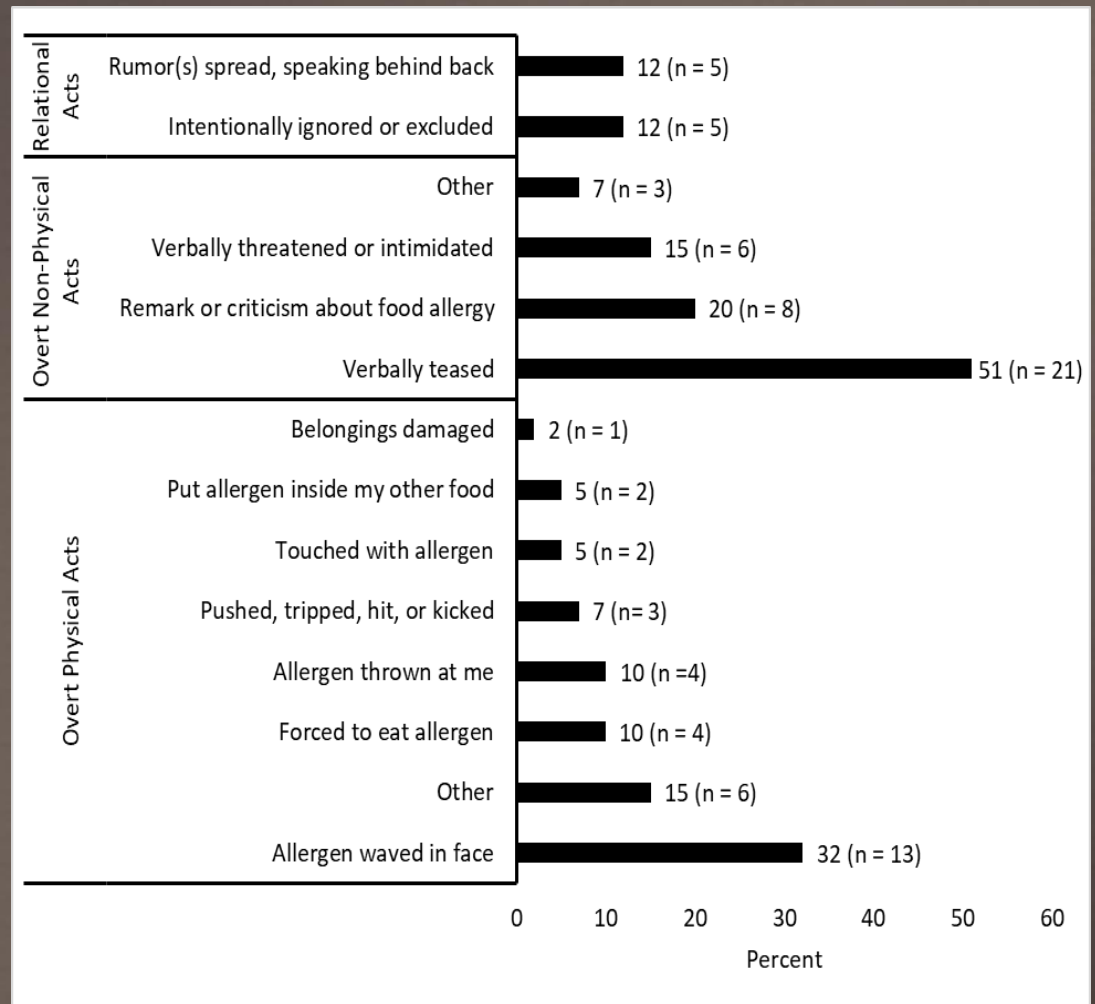
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# Food Allergy Peer Experiences



## FAM Project Data:

- Adolescents: 17% and 31% of reported food allergy-related bullying
- Parents: 12% reported child had been bullied due to food allergy
- By whom? Classmates, teachers and other school staff
- Reasons? Having food allergy, receiving special treatment, not able to be with the group



# FAM Project Qualitative Interviews



## SAMPLE

- 26 adolescents
- M age = 11.92 years
- Gender: 62% male
- Race: 42% Black, 31% White, multiracial, 8% other
- Ethnicity: 12% Latinx
- All top 9 allergens represented



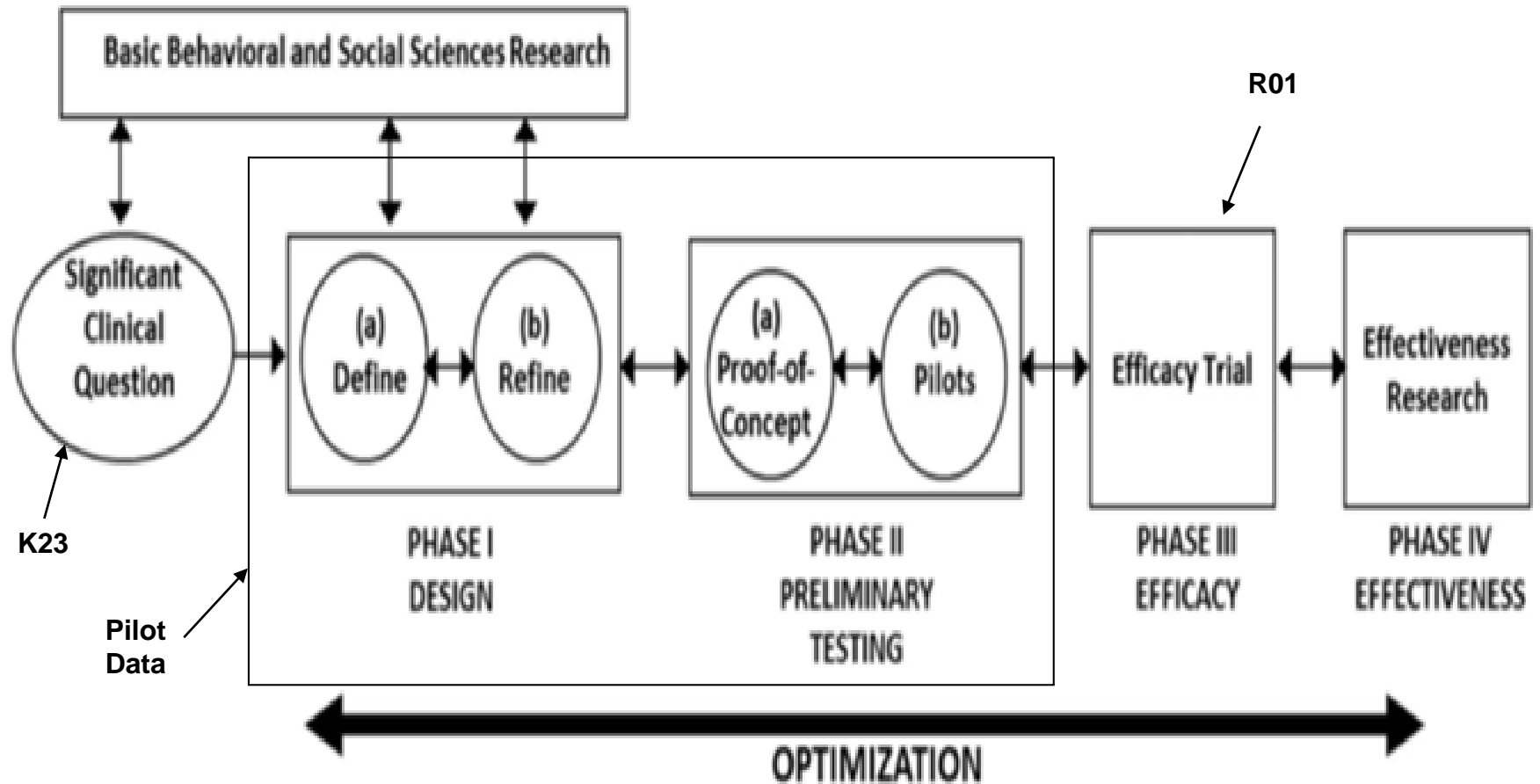
## Emergent themes

- 1) Food allergy is a chronic burden that affects daily life
- 2) Families experience anxiety about food allergy
- 3) Families need to transition food allergy management from parent to child
- 4) Food allergy families need to be prepared
- 5) Food allergy advocacy is frequently necessary
- 6) Social experiences affect the food allergy experience



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# The ORBIT Model of Behavioral Intervention Development



# THE FOOD ALLERGY MASTERY (FAM) PROGRAM



A behavioral intervention for adolescents with food allergy that targets self-management and adjustment should:

-  1. Provide food allergy education
-  2. Bolster stress and anxiety management
-  3. Assist parents in transitioning food allergy management responsibility to the youth
-  4. Teach executive functioning and advocacy skills
-  5. Foster peer support



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# Focus Group and Pilot Study → THE FOOD ALLERGY MASTERY PROGRAM



Session	Topics	Delivery Format	Participant	Content	Behavioral Tasks
1	Orientation; Food allergy education; Transitioning food allergy management responsibility	One-on-one telehealth session	Caregiver & Adolescent	Unique adolescent challenges of food allergy; Parenting an adolescent with food allergy; Shifting food allergy tasks from caregiver to child	Participate in discussion of food allergy medical information; Caregiver modeling/scaffolding of food allergy management
2	Social support from peers with food allergy	Group telehealth session	Adolescent	Network with peers; Receive and provide emotional support; Practical strategies	Be active participant in group telehealth session
3	Food allergy self-management through successful planning and organization	One-on-one telehealth session	Adolescent	Challenges of carrying epinephrine auto-injectors and preparing for meals outside the home; Problem-solving technique	Problem-solve food allergy management difficulties; Practice using a schedule/reminder system
4	Assertiveness training for self-advocacy in social situations	One-on-one telehealth session	Adolescent	Social impact of food allergy; Strategies to self-advocate for safety; Cognitive reframing of peer situations	Role play social situations and situations that involve food outside the home; Make plan for talking with peers, waitresses, etc.
5	Coping/adjusting to food allergy; Anxiety management	One-on-one telehealth session	Adolescent	Emotional impact of food allergy; Relaxation techniques; Cognitive reframing	Reflect on food allergy experiences; Practice breathing and cognitive reframing exercises
6	Food allergy self-efficacy; Putting it all together	One-on-one telehealth session	Caregiver & Adolescent	Balanced integration is hard to achieve; Identifying sources of support; Planning for the future	Participate in discussion about achieving balanced integration of food allergy into daily life; Problem-solve challenging situations

# FAM PROGRAM: SESSION EXAMPLE

## Practicing Identifying Allergens



# Let's Practice Reading Labels!

INGREDIENTS: PRETZEL PIECES (ENRICHED WHEAT FLOUR (FLOUR, NIACIN, REDUCED IRON, THIAMINE MONONITRATE, RIBOFLAVIN, FOLIC ACID), MALT, SALT, SOYBEAN OIL, YEAST), MILK CHOCOLATE FLAVORED COATING (SUGAR, PALM KERNEL OIL, COCOA POWDER, WHOLE MILK SOLIDS, NONFAT DRY MILK, REDUCED MINERAL WHEY POWDER, NATURAL FLAVOR, SALT, SOY LECITHIN), CORN SYRUP, RICE CRISP (RICE FLOUR, SUGAR, BARLEY MALT EXTRACT, SALT), ROLLED OATS, CHICORY ROOT EXTRACT (INULIN), FRUCTOSE, HIGH OLEIC CANOLA OIL, GLYCERIN, CONTAINS LESS THAN 2% OF THE FOLLOWING: SUGAR, WATER, CORN SYRUP SOLIDS, CANOLA OIL (WITH TBHQ AND CITRIC ACID TO PRESERVE FRESHNESS), SOY LECITHIN, CARAMEL COLOR, SALT, HONEY, MOLASSES, BHT (TO PRESERVE FRESHNESS), XANTHAN GUM, DEXTROSE, MAPLE SYRUP, MIXED TOCOPHEROLS, NATURAL FLAVOR, BROWN SUGAR, PEANUT FLOUR, ALMOND FLOUR.  
CONTAINS: WHEAT, MILK, SOY, PEANUT, TREE NUT (ALMOND). MAY CONTAIN: TREE NUT (COCONUT).

enlarged to show texture

TREE NUT (COCONUT).

# FAM PROGRAM: SESSION EXAMPLE

Discussing Food Allergy Management  
Responsibility



# Food Allergy Management Responsibility



## Read labels

- At home
- In the grocery store
- When at a friend/relative's house

## Carry epinephrine auto-injectors/meds

- In school
- When away from home

## Ask about ingredients

- In a restaurant
- When calling a restaurant
- Looking at a menu online
- When at a friend/relative's house
- When calling a manufacturer

## Order/pick up prescriptions

## Cook safe meals

## Carry safe foods

## Teach others

- About food allergy
- About epi



# FAM PROGRAM: SESSION EXAMPLE

## Planning Ahead



# Food Allergy Bag

*What would you put in your food allergy bag?*



# FAM PROGRAM: SESSION EXAMPLE

## Navigating Social Activities



# The DEAR Strategy: Putting It All Together!

## Describe the situation

“You may already know that I have peanut allergy.”

## Express thoughts and feelings

“Sometimes I feel awkward when we’re out celebrating and everyone looks at me when I talk with the waiter.”

## Ask for what you need

“I’d love it if you all keep talking instead of looking at me.”

## Reinforce

“Thanks for understanding and helping me with this.”

# “Off The Mark” Thinking

## Personalization

Jumping to conclusions or assuming the things people say or do are a reaction to you



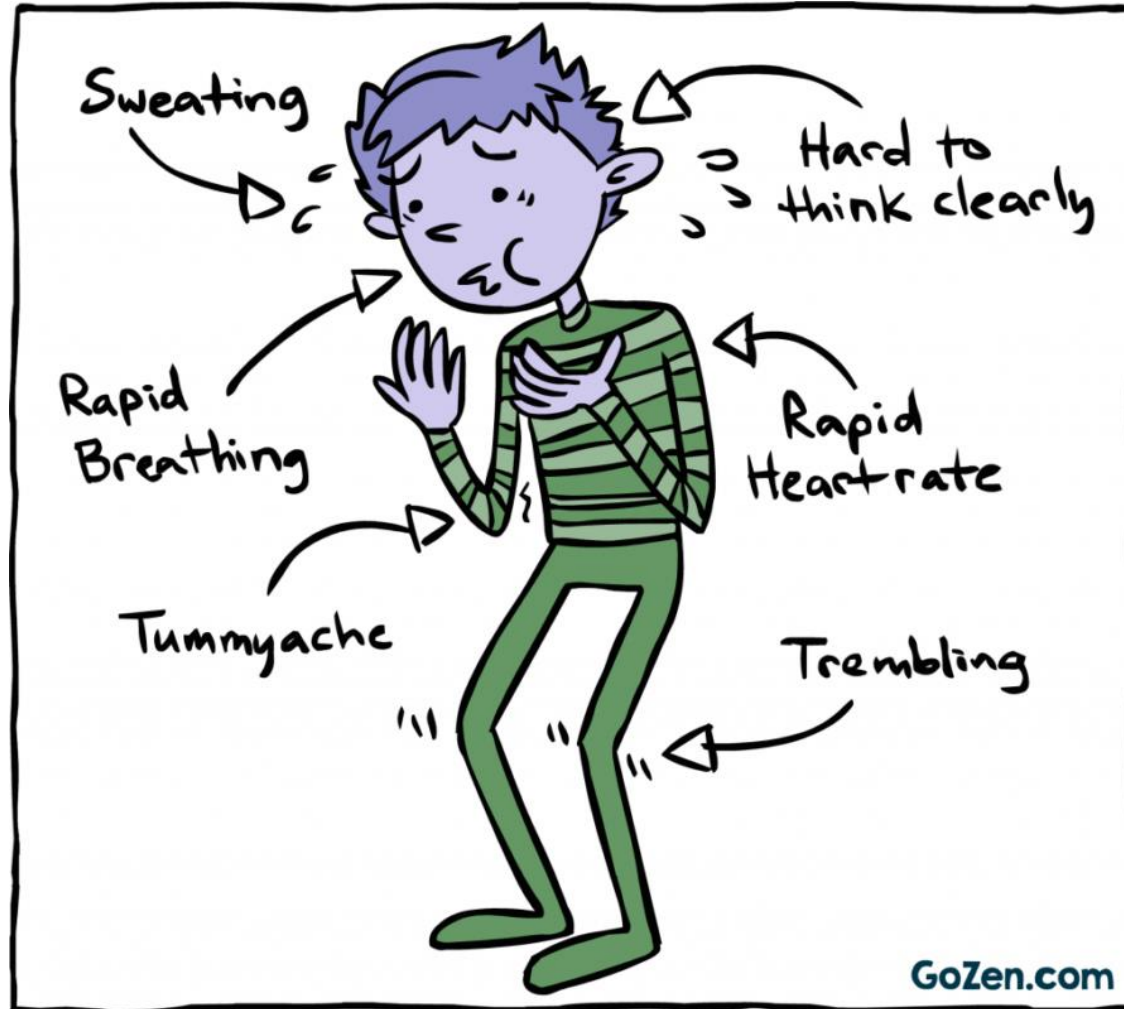
Everyone sees that I'm not eating anything. They must think I'm really weird.

# FAM PROGRAM: SESSION EXAMPLE

## Anxiety and Allergic Reactions

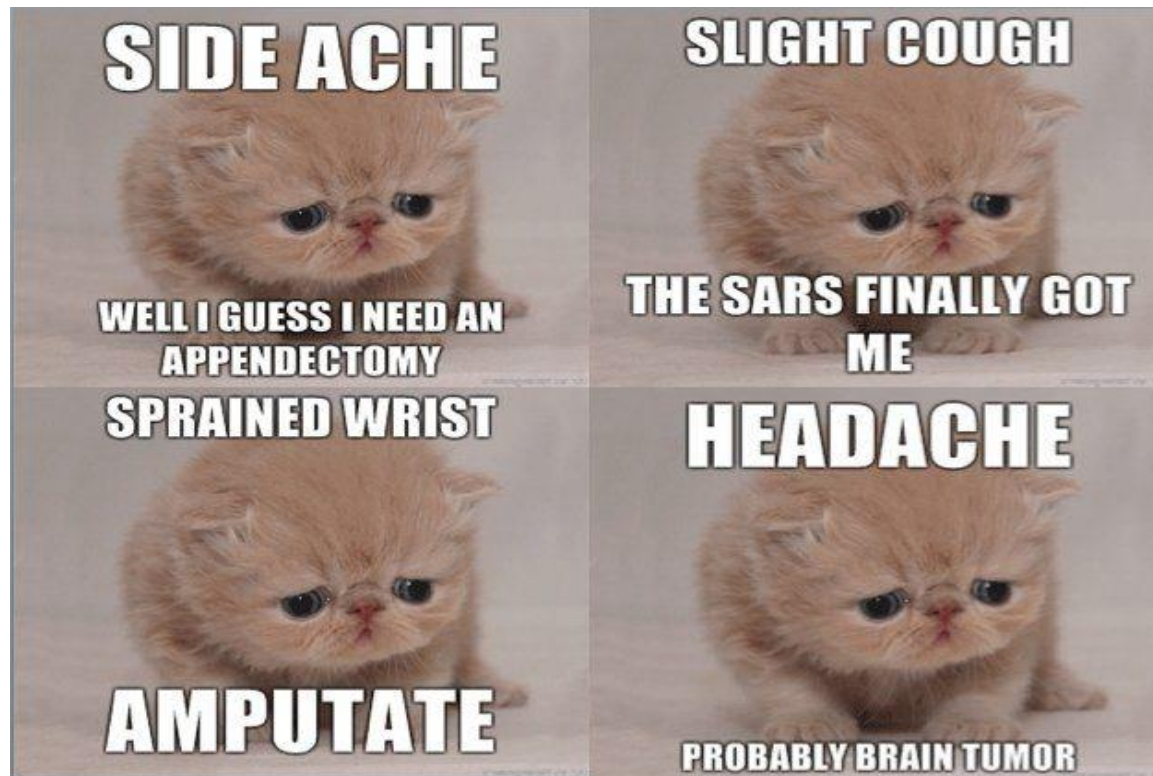


# Anxiety, Your Body, and Allergic Reactions



# Catastrophizing

When you expect that the worst will happen and there's no way you can handle it



# FAM PROGRAM: SESSION EXAMPLE

## Accessing Support



# It Takes a Village!

Ever heard the phrase, it takes a village?

Who is in your village?

How does your village support you?

How do they know what/when you need support?



# Focus Groups



3 2-hour focus groups with 9 early adolescents and 9 primary caregivers

## Content

- Learned about the proposed content of the FAM Program
- Reviewed and discussed the proposed format of the telehealth Zoom platform
- Asked to give opinions regarding the relevance and comprehensiveness of the FAM Program

## Feedback



- Participants believed the content of the sessions was appropriate and relevant
- The focus on food allergy management in social situations and stress and anxiety management were noted as necessary
- Youth and caregivers emphasized that connection with other peers with food allergy would be of interest

# FAM Program Pilot



## METHODS

- Recruited from our food allergy clinics to complete the FAM Program
- Participants completed baseline and follow-up questionnaires regarding food allergy knowledge, social support, and food allergy self-efficacy
- The 6-session FAM Program was conducted via Zoom and program evaluation was obtained by Zoom interview

## SAMPLE

- Eight early adolescents (Mean age=12.4 years; 75% male; 13% White; 13% Hispanic/Latinx) and a primary caregiver (87% mothers) completed all 6 sessions of the FAM Program
- Two additional participants completed at least 1 FAM Program session but dropped out due to time constraints or because they were diagnosed with COVID-19

# FAM Program Pilot Results



Social support increased from baseline to post-intervention

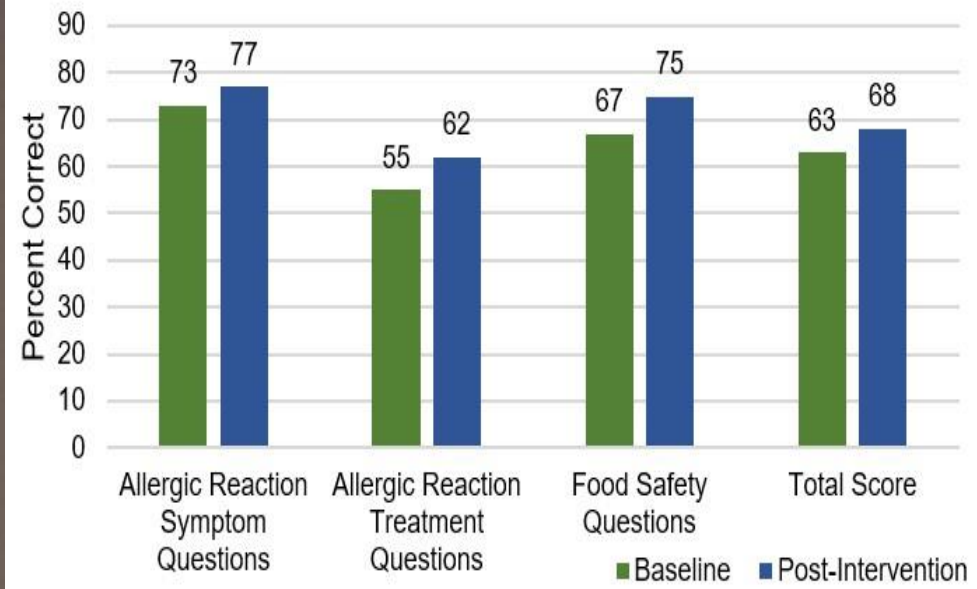
- Mean at Baseline=5.02, SD=1.42; Mean after FAM Program=5.70, SD=0.66, Possible Range=1-7)

Overall food allergy self-efficacy remained stable between baseline and post-intervention

Improvement for self-efficacy regarding recognizing and treating allergic reactions

- Mean at Baseline=70, SD=25; Mean after FAM Program=89, SD=12; Possible range=0-100)

Figure 3. Average Food Allergy Knowledge Test Scores at Baseline and Post-Intervention (N=7)



## Next Steps/Conclusions

- Food allergy management is challenging, especially during adolescence, and treatment options are limited
- There are clearly identifiable domains that should be addressed to help support adolescents as they transition to independent food allergy managers
- The FAM Program is a promising step towards providing this kind of support
- Next Steps: Continued refinement of the FAM Program sessions, potentially Pilot Study #2, grant applications for an RCT, etc.

Thank you!  
Questions? Comments?

