

PARENTAL FOOD ALLERGY ANXIETY: IMPLICATIONS FOR ORAL IMMUNOTHERAPY (OIT) PROVIDERS

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Research/Importance/Implications

Allergists' Role in Addressing the
Psychosocial Needs of Parents

PART I: LIT REVIEW

- Parental Psychosocial Adjustment to Food Allergies and OIT (with a Focus on Anxiety)
- Impact on Family System/Children
 - Which parents are at risk for unmanageable FAA
 - QoL (Quality of Life) after OIT

PARENTAL PSYCHOSOCIAL ADJUSTMENT TO FA/OIT

Parents of food-allergic children (especially moms) report:

- Increased anxiety, stress and depression
- Decreased QoL as the result of FA management (Feng & Kim, 2018) (Pistiner, 2009)

Mothers

- Poorer QoL and suffer more anxiety and stress than fathers do (Pistiner, 2009).
- Feel alone and unsupported in the responsibility - child's FA management and QoL (Mandell et al., 2005)

Parents identify anxiety as the most burdensome FA-related emotional distress (Westwell-Roper et al., 2021)

39.1% of parents report moderate-extremely severe anxiety. (criteria for study was having a child with medically diagnosed food allergy) (Roberts et al., 2021)

PARENTAL
PSYCHOSOCIAL
ADJUSTMENT TO
FA/OIT
(CONTINUED)

42.3% parents met the clinical cut-off for PTSS, (Roberts et al., 2021)

81.0% of parents reported clinically significant worry, (Roberts et al., 2021)

Mental health issues associated with food allergies are likely underrecognized. (Feng & Kim, 2018)

FOOD ALLERGY
PARENT ANXIETY:
IMPACT ON
CHILDREN AND
THE FAMILY
SYSTEM

(WESTWELL-
ROPER ET AL.,
2021)

Shared experiences of distress in the family system (multi-directional)

Higher parental worry associated with more limitations on kids' activity including social events

Challenges in navigating developmentally appropriate joint responsibility.

FOOD ALLERGY
PARENT ANXIETY:
IMPACT ON
CHILDREN AND
THE FAMILY
SYSTEM

(CONTINUED)

Maternal FAA linked to reduced psychological functioning and QOL in kids (Chow et al., 2015)

Poorer child functioning (by maternal report) was associated with parental **over protection and control**. This results in

- Hypervigilance

- ex. Accompanying child to events past developmental level (Westwell-Roper et al., 2021)

Negatively affects child's health

- parents unable to manage reactions

- avoidance of diagnostic procedures such as OFC

- unnecessary food elimination (even after negative OFC)

- delayed food intro. (Westwell-Roper et al., 2021)

***WHAT PARENTS
ARE AT RISK FOR
FAA***

(ANTECEDENTS)

**(WESTWELL-ROPER
ET AL., 2021)**

Low perceived control

Perceived lack of FA self
management knowledge and
resources

***WHAT PARENTS ARE
AT RISK FOR FAA***

***(CHILD
DEMOGRAPHIC
INFO)***

**(WESTWELL-ROPER ET
AL., 2021)**

Younger age child

Hx of ANA or perceived FA
severity

Multiple food allergies

Hx of OFC- (but reports vary
here)

Milk and/or egg allergy

OIT AND QOL

OIT improved QoL in patients (children and adolescents) and caregivers - most substantial impact was in adolescents. (Opper et al., 2025)

The QoL of food-allergic children improves significantly upon reaching OIT maintenance, with additional improvement 6 months later. (Epstein-Rigbi et al., 2019)

The detrimental effect of OIT on some patients' QOL during up-dosing is reversed upon reaching maintenance. (Epstein-Rigbi et al., 2019)

Children's overall QoL improves after POIT treatment.

- fewer concerns about accidental exposures and severity of reactions
- fewer limitations on dietary choices and social interactions.

(Blackman et al., 2020)

PART II: ALLERGISTS' ROLE IN ADDRESSING THE PSYCHOSOCIAL NEEDS OF PARENTS

Psychological attunement/Language

Acknowledge/validate/normalize

Assess/monitor

Disseminate information

Model Flexibility

Connect to resources

PSYCHOLOGICAL ATTUNEMENT AND LANGUAGE

Your language matters greatly

Your words can be healing and affirming

Your words can be damaging and even traumatic

Case Example

ACKNOWLEDGE/VALIDATE/ NORMALIZE

Acknowledge that FA
does carry a
psychosocial burden
(**Bingemann et al.,
2024**)

Offer praise for their
ability to navigate thus
far

Normalize initial
distress and anxiety
AND help is available
if unmanageable

Normalize initial
adjustment and
restriction AND
readjust and get back
out there

ASSESS/MONITOR (INFORMAL ASSESSMENT)

Ask directly- How are food allergies/OIT impacting your life?

Is there anything you are avoiding that you think may be excessive?

Moms are hiding anxiety oftentimes in office – check on parents

Watch for shoulds and shouldn'ts

Watch for inflexibility. "I have to." "My child will die without OIT." "I can't handle it" "Can't live a normal life."

Perfectionism/all or nothing thinking

Involve children when appropriate- When parental anxiety is very high talk to parent individually

ASSESS/MONITOR (FORMAL ASSESSMENT)

IMPAACT (To et al., 2022) Impairment Measure for Parental Food Allergy-Associated Anxiety and Coping Tools

- excellent internal and external validity

– used to determine parents who are need of further psychological support.

OIT Parental Burden Scale (Maeta et al., 2023) Measures 4 burden subscales:

- adherence to treatment plan
- anxiety about risk
- patient's eating behavior and
- anxiety about treatment effect.

Parent/Caregiver Food Allergy Psychosocial Information (Hubbard, 2022)

<https://www.foodallergycounselor.com>

SOFAA (Dahlsgaard et al., 2022) –FOR CHILDREN Child Parent and Adolescent measures of child food allergy-related anxiety and related anxious avoidance behaviors over the past week.

DISSEMINATE INFORMATION/ EDUCATION

(BINGEMANN ET AL., 2024)

Caregiver misinformation is common

Shift in conceptualization and treatment (delay intro, OIT, Benadryl, biologics as examples) - need for ongoing info

Encourage questions-answer as clearly as possible

Encourage use of certain resources that are evidence based and discourage use of others – social media (Drs. Jones, Kahn, Stukus and Rubin)

Families often have dual educational burden. Themselves and others

Disseminate as much info as possible in writing to everyone. Everyone does not have internet access.

Be available for questions. Have a portal, so they have answers in writing

WHAT INFO DO PARENTS NEED?

(MENTION RAPID GROWTH IN FA KNOWLEDGE)

General action plan

Advisable restriction

Excessive restriction- be direct if unnecessary

Educate-More unnecessary restriction = more anxiety

Use seatbelt analogy for epi

Appropriate vs excessive vigilance

Social events

School plans

What will happen in office if reaction to OFC or OIT updose

What will happen at home if reaction
Detail!

OIT rest period

Circumstances that make reaction more likely in OIT

Realistic expectations for OIT

Length/frequency of OIT/commitment

MODEL AND ENCOURAGE FLEXIBILITY

Modifying interventions and treatment with input from parent and child

Normalize exposure/OIT reactions can happen despite best effort- but it is not a failure- more info and regroup

Emphasize competency not perfection

Encourage questions/brainstorm solutions

Ask about and take parental values into consideration

Collaboration between parent, you and child
Which allergens, schedule, how often updose, when to stay put on dosage

Be clear with info but also acknowledge when you are unsure. Model that being unsure/uncertain does not have to stop life

OFC- not pass/fail- info gathering

CONNECT TO MENTAL HEALTH RESOURCES/ REFER OUT

Psychological support with OIT is underutilized (Trevisonno et al., 2024)

Psychological support is critical in terms of both OIT adherence and success (Trevisonno et al., 2024)

Patients and caregivers may benefit from FA support groups and patient advocacy groups (Bingemann et al., 2024)

Quality of support group is important. Training of mental health practitioners, psychoeducation and evidence-based (Bingemann et al., 2024)

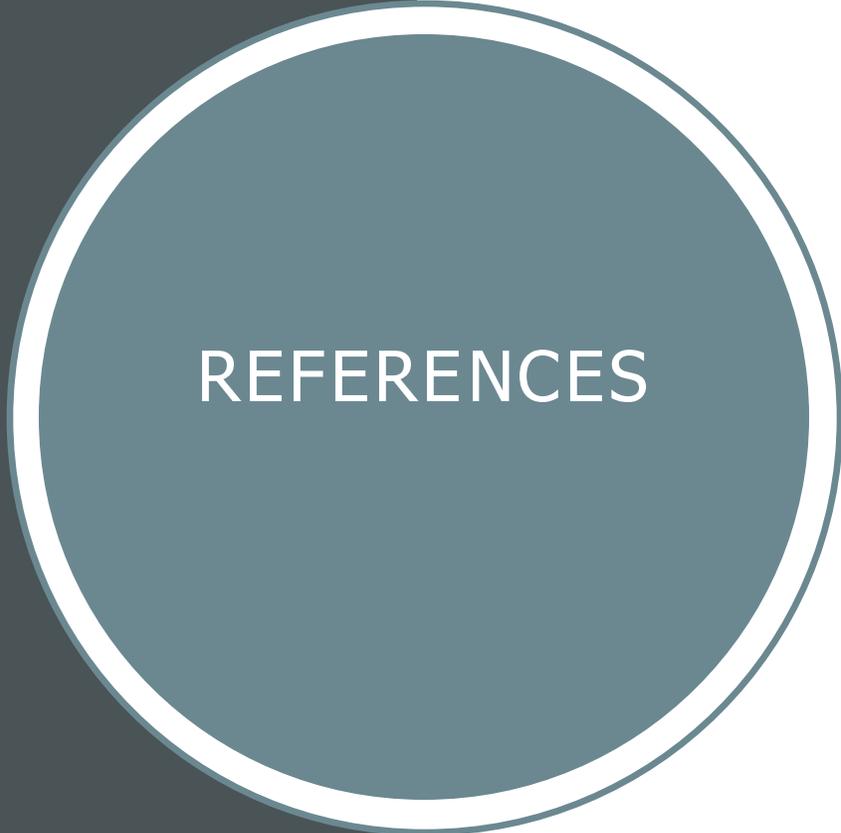
Many resources are disseminating incorrect info- most of it favoring over restriction (Bingemann et al., 2024)

AFAC-(Academy of Food Allergy Counselors) professional therapist network that focuses on food allergies

Foodallergycounseling.org

Paigefreemanphd.com

May Contain Anxiety-
Managing the Overwhelm of
Parenting Children with
Food Allergies (Hubbard,
2025)



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