

PSYCHOLOGICAL CHALLENGES OF OIT

- FAST ANNUAL MEETING 2024
- Paige Freeman, Ph.D.

*Although I often refer to parents in this presentation the principals also apply to adults and children

COMMON FEARS

ANXIETY

**GUIDANCE FOR
ALLERGISTS**

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32. What is the most Common Barrier TO OIT INITIATION?

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WHAT IS THE MOST COMMON
BARRIER TO OIT INITIATION?

(Trevisonno et al., 2024)



A. TASTE
AVERSION



B. FEAR OF
REACTION



C. BOREDOM WITH
FOOD CHOICES

COMMON OIT
FEARS THAT LEAD
TO ANXIETY

General Reaction Fears

Quality of Life Fears

Compliance Fears

Miscellaneous Fears

COMMON OIT FEARS

OIT GENERAL REACTION FEARS

Will there be reactions, how often, and how bad will they be

Death or permanent disability

Competency to ascertain reactions if no signs- only internal symptoms the child doesn't report

Competency to distinguish between a dose reaction vs. e.g., a viral illness or a symptom of a co-occurring allergic disease (e.g., hives, wheezing, congestion)

Competency to treat a reaction

Danger of giving Epi if not having FA reaction

Needle phobia - Epi

Reactions will necessitate quitting OIT

COMMON OIT FEARS

*OIT QUALITY OF
LIFE FEARS*

Ability to live a normal life

Concerns about what activities and meaningful life events will be missed because of dosing/reactions

Can we travel and maintain dosing?

COMMON OIT FEARS

OIT COMPLIANCE

Dose refusal/Food
aversion

Rest period- what
activity is too much

Emotional upset during
dosing/rest period

Dose
measurement/prep

COMMON OIT FEARS

***MISCELLANEOUS
FEARS***

ANA to Xolair

SLIT/OIT in conjunction with Xolair-
which is protective?

Quit OIT and wasted effort

Quit OIT- more allergic?

Being “too much” or “not enough” in
the overall management of both FA
and OIT

FOOD ALLERGY/OIT ANXIETY



AMBIGUITY/UNCERTAINTY



PERCEIVED DANGER



ANXIETY AND AVOIDANCE

FOOD ALLERGY/
OIT ANXIETY

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PERCEIVED DANGER

LOW

HIGH

<u>LOWEST</u> Anxiety	Moderate Anxiety Depends on Circumstance
Moderate Anxiety Depends on Circumstance	<u>HIGHEST</u> Anxiety

Food Allergy Anxiety

AMBIGUITY/UNCERTAINTY

PRE-OIT AMBIGUITY/ UNCERTAINTY

Initial food allergy reactions before Dx (possible trauma)

Diagnosis ambiguity- skin prick, blood work

OFCs

Reaction ambiguity- is it a reaction or some other illness

Trusting others to keep child safe (school, bday parties, relatives' house, etc.)

Vigilance ambiguity

Avoidance ambiguity

Food introduction- uncertainty

Information ambiguity- Social media and internet

Physician ambiguity- across specialties, allergists and inter-office

Food label ambiguity- difficulty of labels and rules

Uncertainty about restaurant safety

Uncertainty of the potential of other children developing food allergy

Potential to develop new food allergy at any time in previously tolerated foods

**OIT AMBIGUITY/
UNCERTAINTY**

INTRODUCES MORE
AMBIGUITY/
UNCERTAINTY WITH THE
HOPE OF MORE
CERTAINTY

All of the previous listed ambiguity/uncertainty

Is OIT the right choice

EoE possibility

How many allergens do we treat at once

Patient specific ideal maintenance dose

Length of treatment

Measuring/preparing correctly

Rest period– what is too much activity

Food Allergy Anxiety

PERCEIVED DANGER

FOOD ALLERGY/
OIT ANXIETY

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PERCEIVED DANGER

LOW

HIGH

<u>LOWEST</u> Anxiety	Moderate Anxiety Depends on Circumstance
Moderate Anxiety Depends on Circumstance	<u>HIGHEST</u> Anxiety

PERCEIVED DANGERS OF FA/OIT

Risk of death

Risk of permanent disability

Incompetency to deal with
reaction

Epi use dangers- esp. if not
ANA or FA reaction

Risk of trauma- both parent
and child

Belief that each reaction makes
FA worse

Food Allergy Anxiety

ANXIETY AND AVOIDANCE

FA/OIT AVOIDANCE CYCLE



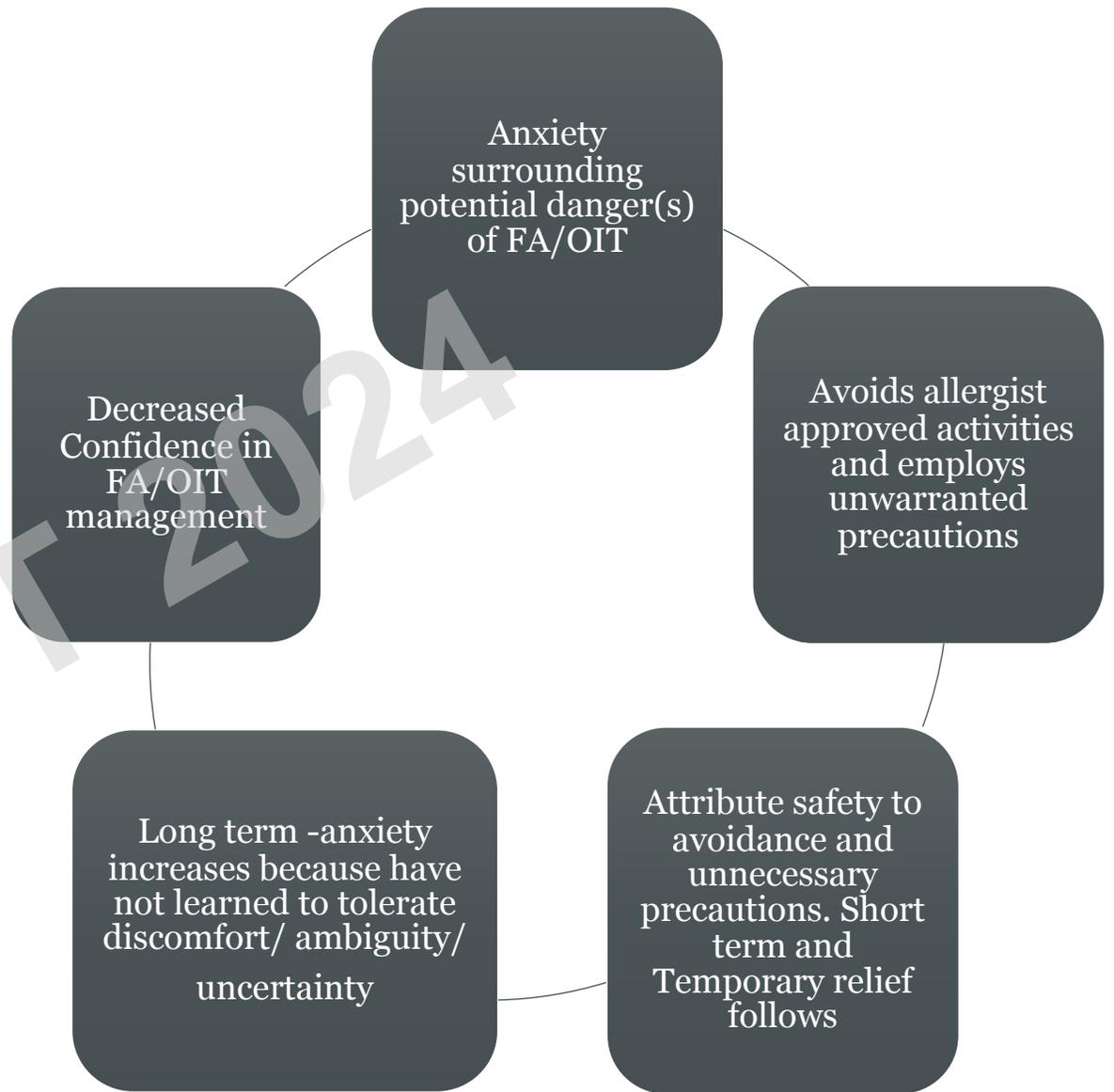
AMBIGUITY/
UNCERTAINTY



PERCEIVED
DANGER



ANXIETY AND
AVOIDANCE



EXAMPLES OF WHAT HIGH ANXIETY FOOD ALLERGY INDIVIDUALS AND FAMILIES AVOID

Food Introduction

Parties

Family gatherings

Holidays

Restaurants

Having more children

Eating at friends' house

Traveling

Possible contaminated surfaces- even after wiped down

Having people to their house

School experiences including field trips

Extracurricular activities

Summer camp

Using same dishes and cookware- even after dishwasher

Mental Distress

EXAMPLES OF HIGH ANXIETY AND OIT SPECIFIC AVOIDANCE AND PRECAUTIONS

Avoid doing physician approved movement during waiting period

Extend rest period beyond recommendations

Avoid emotional upset outside of window

Excessively avoid emotional upset during rest period-emotional monitoring

Avoid travel

Introducing new foods while doing OIT

Excessive handwashing after measuring dose

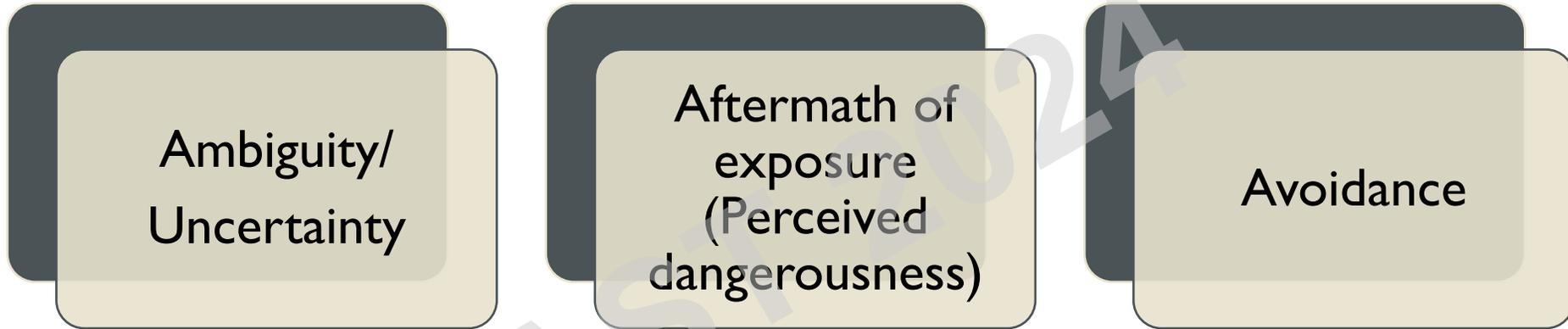
Repeatedly measuring dose beyond usual checking for accuracy

Checking self or child repeatedly and on schedule during rest period for signs of allergic reaction

Wiping OIT area down numerous times when clean

Having designated area for OIT that is not used for anything else and not allowed to touch it outside of OIT

Address the 3 A's



HOW CAN ALLERGISTS HELP WITH
FA/OIT ANXIETY?

HOW ALLERGISTS CAN HELP WITH AMBIGUITY/UNCERTAINTY

Answer questions about fears/precautions as clearly as possible- remember to ask children

Normalize anxiety and the difficulty of managing FA and OIT

Ascertain where they are getting their food allergy/OIT info

Practice using Epi with patients- assess for needle phobia /fear

Clarity surrounding any restrictions/precautions

Consistent messaging across office staff- continuity of provider when possible

Consider orientation to OIT- how to treat symptoms and when to hold or reduce dose, when to contact office

Printed guidebooks with information from orientation

Consider using a portal and/or communication app for questions- permanent record

Discuss labeling- what is necessary for them to avoid- advise when precautions change with OIT

Social media, website, groups, speaking - we need more good sound dissemination of info

HOW ALLERGISTS CAN HELP WITH PERCEIVED DANGER OF FA AND OIT

Talk frankly and clearly about risks- esp. anaphylaxis- High anxiety patients vastly overestimate the risk of death from ANA. Many associate any reaction with death

Be as specific as possible to different types of exposure danger
aerosolized/airborne, contact, cross contamination, ingestion

Seat belt analogy

Normalize OIT reactions-
2019 Stanford study
Symptoms as positive signals

Symptoms as “Positive Signals” (SAPS)

50 OIT participants ages
7-17

Families split into 2
groups- "symptoms as
side effects" and
"symptoms as positive
signals"

Groups received identical
treatment instructions
and had access to the
same resources

SAPS group - mild
reactions as signs that
their child was building
tolerance to the allergen-
treatment is progressing
positively into
desensitization

Uncomfortable symptoms
indicate healing. E.g.,
fever means fighting
infection, inflamed and
itchy cut- wound is
healing. Immunizations

HOW TO HELP WITH PERCEIVED DANGER CONT.

2019 STANFORD STUDY
(HOWE, ET AL., 2019)

RESULTS

Children and parents in
the SAPS group were less
anxious when they had a
reaction/less likely to
contact staff with concerns
about symptoms

Also less likely to skip or
reduce doses because of
symptom-related anxiety:
4 percent missed a dose
compared with 21 percent
in the control group.

HOW ALLERGISTS CAN HELP WITH AVOIDANCE

Ask Questions about Avoidance- what are they avoiding

If level of avoidance is necessary – discuss safe alternative experiences

If level of avoidance is unnecessary – let them know

Model Psychological and Behavioral Flexibility when possible- with dosing and OIT in general- E.g., Reevaluate maintenance dose if necessary

Ask about food introduction for both patient and sibs- emphasize importance

Refer to food allergy therapists

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33. In a recent study surrounding Barriers to OIT, what Percentage of patients who saw a therapist During OIT found it to be very or extremely helpful?

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IN A RECENT STUDY
SURROUNDING BARRIERS TO
OIT, WHAT PERCENTAGE OF
PATIENTS WHO SAW A
THERAPIST DURING OIT FOUND
IT TO BE **VERY** OR **EXTREMELY**
HELPFUL?

(TREVISONNO ET AL., 2024)

A. 15%

B. 32%

C. 59%

IMPORTANCE OF REFERRING TO FOOD ALLERGY THERAPISTS

Familiar with the seriousness of food allergies

Understand unique food allergy stressors

Understand food allergy testing, procedures and medical management (OFC, OIT, SLIT, etc.)

Follow the latest research in allergic disease

Use specific assessment tools relevant to food allergy mental health and know what questions to ask

Well versed in effective food allergy behavioral health treatment

Different treatment modalities- individual, family and group work

Experience working collaboratively with allergists, dieticians and other professionals who work with allergic disease.

Find a food allergy informed therapist at
<https://www.foodallergy counseling.org>

HOW TO HELP FOOD ALLERGY THERAPISTS

ERP (exposure and response prevention) and OIT

Refer sooner rather than later

Answer patient questions

Consult with therapist

HOW CAN FOOD ALLERGY THERAPISTS HELP YOU?



Screen for OIT appropriateness



Encourage and support patients through OIT, food introduction, and OFC's



Help clients to establish or re-connect with OIT commitment and values



After initial establishment of unnecessary restriction, decreased office calls/ visits that center around anxiety



Help patients generate clear and succinct questions to ask during appointments



Increase OIT compliance by decreasing anxiety fusion



Allergist office presentations/consults surrounding psychosocial management of FA/OIT

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