



Disordered Eating in Children & Adolescents with PANS

SANE Sweden 2019 PANS Conference

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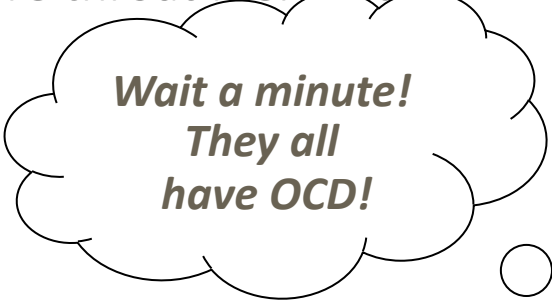
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Overview:

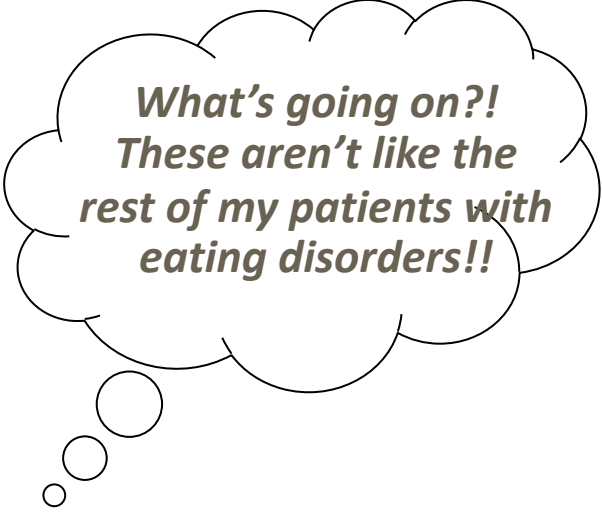
- Abnormal eating behaviors in PANS
- Diagnosing eating disorders in PANS
- Medical problems associated with restricted intake in PANS
- Approach to treating a child with restricted intake and PANS
- Support from family

There are those patients you'll never forget...

- Girl with severe malnutrition, anorexia nervosa:
 - Jumped on and off toilet so many times it broke off the wall
 - Took forever walk along patterned rug in hallway
- Boy with h/o picky eating, treated for an eating disorder, weight restored until...
 - Suddenly stopped eating and drinking
 - Waiting in basement for aliens to bring back his real dad
- Boy referred to Eating Disorders Clinic for severe malnutrition:
 - Wouldn't swallow saliva or take a deep breath because he'd weigh more
- Boy who said he wouldn't eat until we made his sore throat feel better
 - Kept coughing with a tic that wouldn't stop



*Wait a minute!
They all
have OCD!*



*What's going on?!
These aren't like the
rest of my patients with
eating disorders!!*



Disordered Eating in PANS

- Sudden onset of restricted eating is a major diagnostic criteria for PANS
- May restrict food, fluids, or both
- Reasons for sudden change in eating:
 - Difficulty swallowing
 - Sensory alteration/hypersensitivity
 - Fear of contamination/poisoning
 - Fear of choking or vomiting
 - Ritualistic eating behaviors

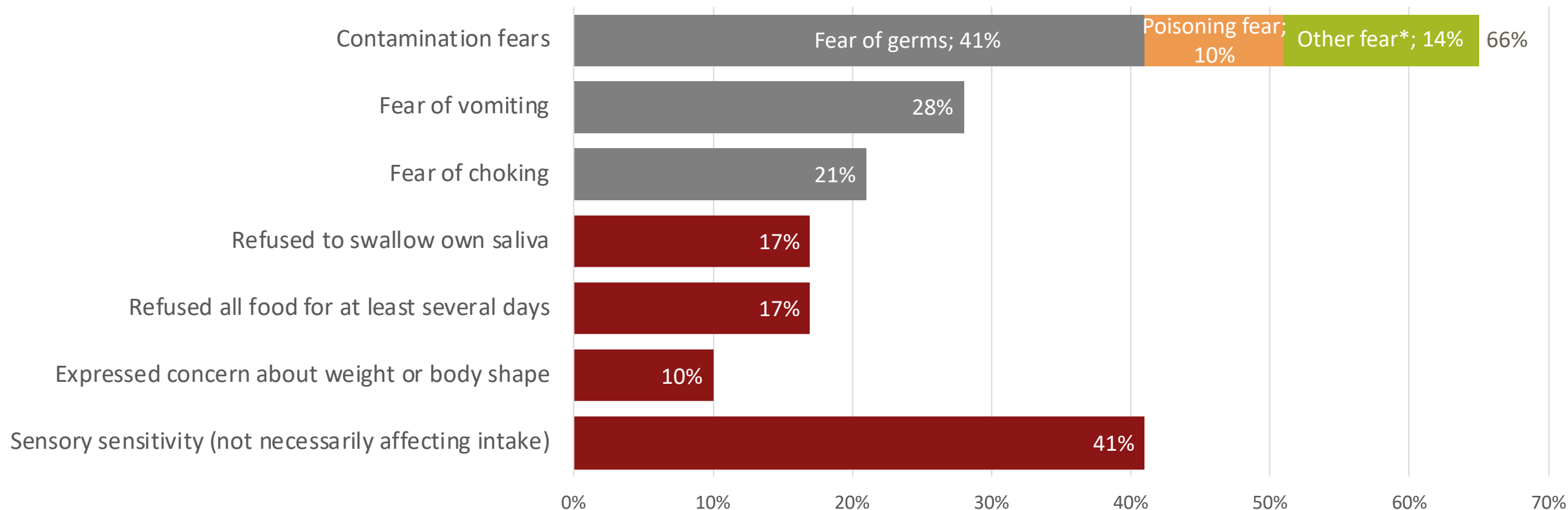


Reasons for Food Restriction in PANS

- 2 studies of disordered eating in children and adolescents seen in clinic for PANS
 - Toufexis, Hommer, Gerardi, et al. (2015)
 - Stanford study (Kapphahn, Peet, Chan, Frankovich, preliminary data 2019)
- Toufexis et al. (2015):
 - Study population: 29 patients with PANS, new abrupt onset of eating restriction or food avoidance
 - Age 5-12 yo (mean 9 yo)
 - 69% male
 - All children had OCD sx

Disordered Eating in PANS/PANDAS: Reasons for Food Restriction (Toufexis et al., 2015)

Percentage of Children with Concern



Disordered Eating in Stanford PANS Clinic (Preliminary data)



- Stanford Population:
 - Consecutive patients presenting to Stanford PANS clinic (9/12 – 6/19)
 - Ages 4-18 yo
 - Meet criteria for PANS
 - Patients excluded if time interval between symptom onset and clinic visit > 5 years, or declined research
 - Study population: 213 patients
 - Age of OCD onset: 9 ± 3 yo
 - Age at first clinic visit: 10 ± 3.5 yo
 - 61% male, Non-Hispanic white 77%
 - **47% had eating restriction at initial presentation at PANS Clinic**



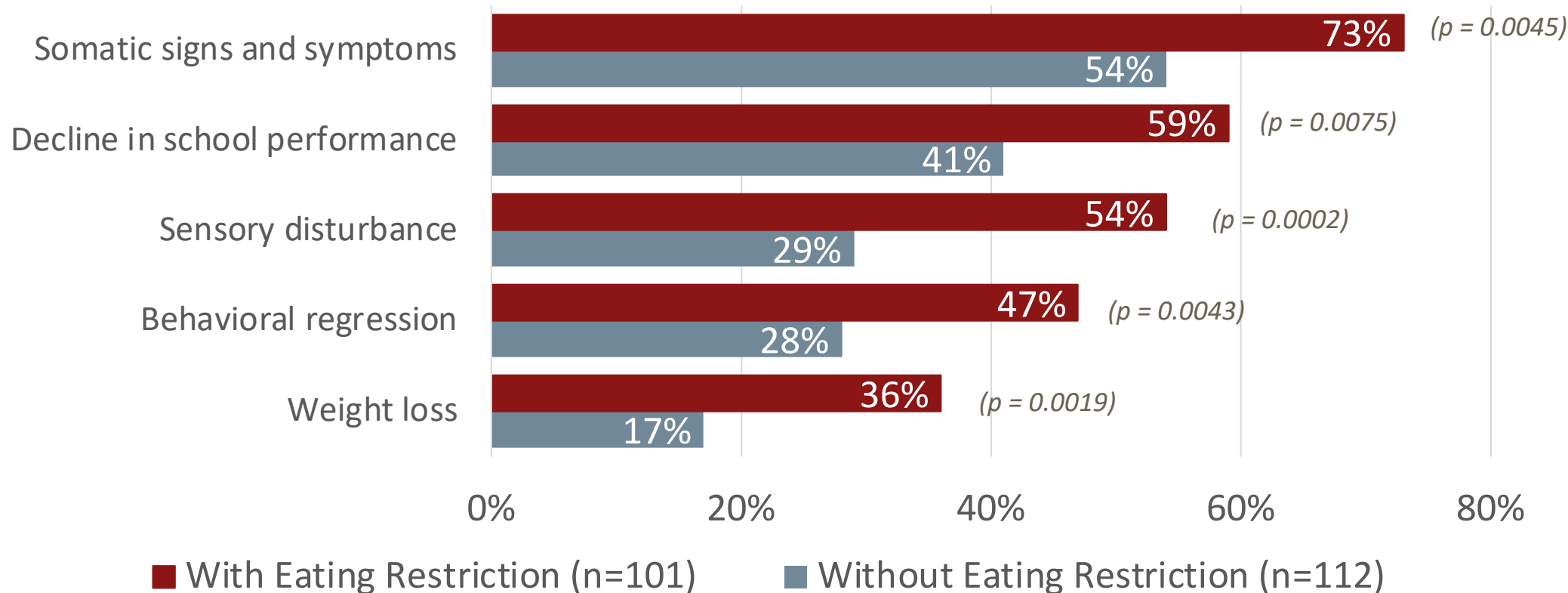
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Preliminary data compiled and analyzed by:
Cynthia Kappahn, Brianna Peet, Avis Chan, Jennifer Frankovich, 2019

Disordered Eating in Stanford PANS Clinic (Preliminary data)



Symptoms in PANS patients with and without restricted eating



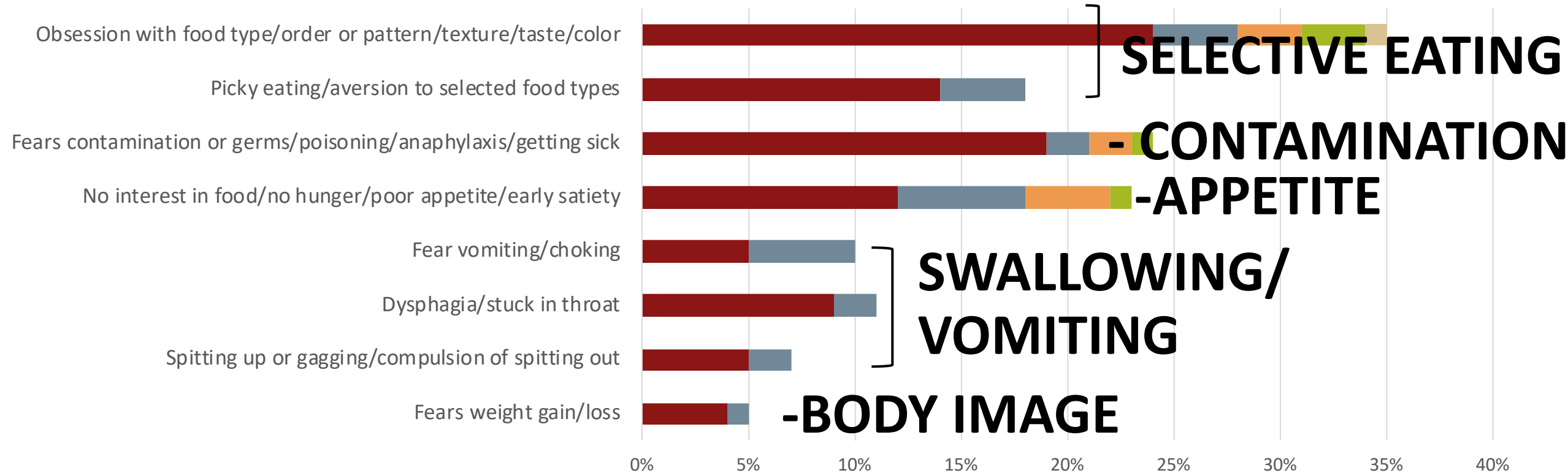
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Reasons for Food Restriction in Stanford PANS Study Cohort (Preliminary data)



Reasons for Food Restriction in Stanford PANS Study Cohort



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Would Food Restriction in PANS Meet Criteria for an Eating Disorder Diagnosis?

MAYBE!

If so, Avoidant Restrictive Food Intake Disorder (ARFID) most likely diagnosis

Anorexia Nervosa also possible

Occasionally excessive eating occurs with PANS,

but unlikely to meet criteria for Binge Eating Disorder (BED)

Would Food Restriction in PANS Meet Criteria for ARFID?



Avoidant Restrictive Food Intake Disorder (ARFID)

- Newly recognized type of eating disorder, included in 2013 version of psychiatric Diagnostic and Statistical Manual, 5th Edition (DSM-5)
- Adolescent medicine physicians and psychiatrists/psychologists working to find optimal treatments for ARFID
- Compared to other eating disorders, patients with ARFID:
 - Younger
 - Higher percentage males (though majority still female)
 - More anxious
 - More likely to have other medical problems

Would Food Restriction in PANS Meet Criteria for ARFID?

ARFID characterized by:

- Persistent failure to meet appropriate nutritional and/or energy needs with at least one of the following:
 - Significant weight loss (or lack of expected gain)
 - Significant nutritional deficiency
 - Dependence on oral nutritional supplements or tube feeding
 - Marked interference with psychosocial functioning
- **NO** disturbance in body image
- Eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. **When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.**



Would Food Restriction in PANS Meet Criteria for Another Eating Disorder?

Less commonly, may meet criteria for Anorexia Nervosa (AN):

- Restriction of energy intake relative to requirements, leading to significant weight loss and/or low body weight
- Intense fear of gaining weight or becoming fat

Why does it matter if an eating disorder can be diagnosed in a child with PANS?

- Evidence-based interventions have been developed to treat specific types of eating disorders
- Children and adolescents may present for assessment of an eating disorder, when PANS is underlying issue

**Even if abnormal eating in PANS not diagnosed as an eating disorder,
may still be a significant problem!**

Risk of Medical Complications from Disordered Eating in PANS

- Risk of medical instability increases with any of these factors:
 - More extreme restriction of food or fluids
 - Prolonged restriction of food or fluids
 - Larger proportion of weight lost
 - More rapid weight loss

Assessing for Medical Complications of Restricted Intake in PANS

- If significant restriction of food or fluids, a medical provider should assess and follow:
 - Physical signs of malnutrition/dehydration
 - Weight trends
 - Vital signs, including:
 - Orthostatic pulse and blood pressure (lying down, then standing up)
 - Temperature
 - Electrolytes, including phosphorus and magnesium
 - Initially, an Electrocardiogram (EKG) should be checked as well

Medical Complications of Restricted Intake

- Restriction of food and/or fluid can affect all organs
- Changes in heart rate, blood pressure, and temperature can be due to malnutrition, dehydration, weight loss, and/or vomiting
- Orthostatic pulse increase or blood pressure drop is common
- **Normal or overweight children & adolescents may develop same medical complications as those who are underweight!**

Restricted Food Intake → Hibernation Response

- Body adjusts to conserve energy when nutrition is inadequate
 - Low heart rate
 - Low temperature
 - Low blood pressure
- Survival mode
 - Blood flow primarily to heart / brain
 - Other organs neglected
 - Cool hands / feet
 - Growth/development/reproduction put on hold!



Restricted Fluid Intake → Dehydration

Dehydration can cause inadequate blood flow to all organs

- Brain – dizziness, fainting
- Heart/Circulation – rapid heart rate, low blood pressure, collapse
- Kidneys – damage, failure
- Liver – damage, failure
- If not reversed, dehydration can cause shock, coma, death

Approach to Child with Restricted Intake and PANS

- Seek expert care for PANS symptoms and disordered eating
 - Team may include medical provider, psychiatrist/psychologist, dietitian, occupational therapist
 - If symptoms significant, may need care from 2 teams of experts: PANS and Eating Disorders
- If severely restricting intake or becomes medically unstable, may require hospitalization for medical complications
- Treat infection/inflammation, using expanding evidence base to guide interventions
- If obsessions or compulsions interfere with eating:
 - Psychiatric medications may help
 - If significantly malnourished, medication may not be as effective until the child has restored weight



Approach to Child with Restricted Intake and PANS

- Relaxation/biofeedback interventions, especially if anxious, nauseous, or afraid of choking/vomiting
 - Posture, breathing, relaxation
 - Other interventions for nausea:
 - Acupressure points
 - Anti-nausea electrical stimulation wrist bands
 - Aromatherapy
- Swallowing difficulties: Children often tuck chin in, makes swallowing more difficult
 - Encourage relaxed shoulders and jaw, shift head forward to neutral position
- Behavior modification plan with specific goals and rewards may help

Approach to Feeding Child with Restricted Intake and PANS

Approach to feeding:

- Be flexible in types of foods or fluids provided
- “Not eating is not an option” (but it is OK to drink your food!)
- Liquid nutritional supplements may be helpful (oral or nasogastric feeding)
- May need intravenous IV fluids, if dehydrated and not drinking
- Rarely, total parenteral nutrition (TPN) if unable to eat or drink for prolonged time
- Continuously reassess opportunities to expand and adjust what’s offered
 - Rapidly shifting symptoms
 - Be ready to adapt and change



Approach to Feeding Child with Restricted Intake and PANS

For food or fluid aversions, balance accommodation with exposure

- If highly anxious or compulsive, exposure and response prevention approach may help
 - Start with safe foods, using liquid nutritional supplements if needed
 - Progress to gradual exposure to foods or situations that cause anxiety or fear, within support framework encouraging incremental progress toward expanded diet and increased intake
- If disordered eating patterns continue even after acute PANS flare, pursue evidence-based therapy for treatment of eating disorders (Lock 2015)

Approach to Child with Restricted Intake and PANS

- Family involvement is very valuable
 - Families often know preferred foods and drinks
 - Children may need extensive encouragement and support to eat and drink
 - Separation anxiety may make it difficult to be away from family members

Approach to Child with Restricted Intake and PANS

- Principles of family-based therapy (FBT) are useful in treating abnormal eating during and after acute PANS episode
 - Empower parents to be in charge of meals for child
 - Externalize illness – don't blame child, just the illness
 - Pragmatic approach to getting in enough nutrition to gain weight:
 - Don't need to know why – Just need to eat!
- Burden on caregivers can be extensive in PANS, parents need self-care as well!



References

- PANS specific resources:
 - Thienemann M, Murphy T, Leckman J, Shaw R, Williams K, Kapphahn C, Frankovich J, Geller D, Bernstein G, Chang K, Elia J, Swedo S. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part I-Psychiatric and Behavioral Interventions. *J Child Adolescent Psychopharmacol*. 2017 Sep;27(7):566-573.
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- Eating Disorder specific resources:
 - Kapphahn CJ, Derenne J. Avoidant/Restrictive Food Intake Disorder in Children and Adolescents. *Adolescent Medicine State of the Art Reviews*. 2018, Fall;29(2):260–278.
 - Lock J. An update on evidence-based psychosocial treatments for eating disorders in children and adolescents. *J Clin Child Adolescent Psychol* 44:707–721, 2015.
 - Golden NH, Katzman DK, Sawyer SM, Ornstein RM, Rome ES, Garber AK, Kohn M, Kreipe RE. Update on the medical management of eating disorders in adolescents. *J Adolescent Health*. 2015 Apr;56(4):370-5.
 - Society for Adolescent Health and Medicine, Golden NH, Katzman DK, Sawyer SM, Ornstein RM, Rome ES, Garber AK, Kohn M, Kreipe RE. Position Paper of the Society for Adolescent Health and Medicine: Medical management of restrictive eating disorders in adolescents and young adults. *J Adolescent Health*. 2015;56:121-5.

