Disclosures + Conflict of Interest

I have no disclosure. I have no fiscal interest in any of the laboratory or medical device products discussed today.

Presentation Outline

- Introduction
- Brief overview eating disorders in children and adolescents
- Case presentations
- Advances in the Field
- Levels of care and referrals
- Coordination of care
- Q & A
Eating Disorders Epidemiology

- Primarily affecting young women; yet 5-10% are male
- **Peak onset**: adolescence – more than 90% diagnosed before age of 25 years
- Incidence among adults – relatively stable in last 50 years
- In U.S., prevalence of anorexia nervosa is 0.5% making it the third most chronic disease in adolescence (after obesity and asthma)

Etiology

- Multi-factorial disorder
- **Genetics**: a female relative of a patient with clinical EDO is 4x as likely to have BN, 10x likely to have AN vs those with negative family history
- Genetics: twin studies (equivalent environment assumption) for AN – estimated heritability of 58% to 76%
- Environment: socio-cultural theories

DSM V and “new” diagnoses

- Broadened inclusion criteria for anorexia nervosa and bulimia nervosa: removed amenorrhea as criteria, body image distortion is included but not required for AN
- Binge eating disorder
- EDNOS: no longer used
- Avoidant/restrictive food intake disorder (ARFID)
- Other eating disorders: **selective eating** and **food phobia** – still not recognized
- Dilemma of atypical presentations

Eating Disorders in Children

- Amenorrhea missing
- Constant motion
- Failure to gain
**Physiological sequelae**

- **Electrolyte disturbances** from restricting, purging or refeeding syndrome.
- **Cardiac complications**: arrhythmias, syncope and/or cardiac arrest.
- **GI**: enlarged salivary glands, delayed gastric emptying, esophagitis, esophageal tear from purging, constipation, diarrhea (from laxative abuse).
- **Renal insufficiency**.

**Endocrine**:
- amenorrhea, thyroid dysfunction, hypoglycemia, osteopenia, osteoporosis (and associated stress fractures).
- **Bone marrow suppression**: anemia, leukopenia.
- **Neurological**: seizures due to electrolyte disturbances, brain starvation and impaired cognitive function.
- To name few.

**Physiological sequelae**

**CASE 1**

Elsa: 13 yo female
- Presented with acute weight loss over the last 5 months.
- **Restrictive eating**.
- Became a vegetarian 4 months ago.
- Calorie count (eats about 500 calories/day).
- Now wants to become a chef and reads cookbooks.

**Meal Plan**

- **Breakfast**: Oatmeal or often skips.
- **Lunch**: Skips.
- **Snack**: “Whatever” or “an egg”.
- **Dinner**: Cooked by patient or parents.
  - Last night: steamed vegetables.
  - Typically a salad without dressing & vegetables.
REDS

Rating of Eating Disorder Severity (REDS)\(^1\) - validated semi-structured questionnaire administered by MD → score of 37, moderate severity


Medical History

Past Medical history

Unremarkable

Gyn history

Menarche at 10 yo, now amenorrheic (3 months prior to presentation)

Family Medical history

Mother was adopted, recently met birthmother who has likely EDO, dx with pancreatic cancer (hospice care with family)

Physical Exam

Vital signs:

- Pulse: 48 BPM (supine), 88 BPM (standing)
- Blood Pressure: P 94/70 (supine), 88/68 (standing)
- Weight 96.8 lbs. Highest premorbid weight 132 lbs
- Thin, atrophic breast tanner stage IV, predominant lanugo, extremities cold to touch

Growth Chart

CASE 1 (cont.)
Diagnoses

- Anorexia nervosa, restricting subtype
- Amenorrhea, secondary
- Bradycardia
- Orthostatic hypotension

Treatment Course

ROUND 1
- Admitted at Randall Children's Hospital for medical stabilization
- Partial Hospitalization Program for 8 weeks
- Transition to IOP
- Graduated back to new Primary Care Provider.

One month later......

Elsa experienced weight loss and oligomenorrhea

ROUND 2
- Readmitted to Partial Hospitalization Program
- Then Intensive Outpatient Program
- Graduated back to Primary Care Provider.

Questions

- If you were seeing this patient - what would be your next recommendation?

Using individual biology to set goal weights
Never use “100 lbs for 5’ and 5 lbs for each subsequent inch” or similar rules of thumb.

The necessary tools:
- Must include physical exam
- Should include growth chart
- Premorbid weights are critical. Ask yourself: at what weight did he/she function well? NOT what should he/she weigh?

Take note!
There is no weight low enough to satisfy anorexia; down that path lies madness.

Tanner Stages
<table>
<thead>
<tr>
<th>Tanner I</th>
<th>Tanner II &amp; III</th>
<th>Tanner IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>This child is prepubertal; no one menstruates at this stage</td>
<td>These are peak height growth velocity stages Weight suppression is especially harmful here Goal weight is a fast moving target</td>
<td>If a girl has no period at this stage she probably needs to gain more weight Height growth will now slow down and stop</td>
</tr>
</tbody>
</table>

**Stages of development critical to weight goals**

**Metabolic Testing:**

“state not weight”

**We stumbled across a troubling problem:**

Despite clear weight restoration, a cohort of girls (all Tanner III-IV/III-IV) did not resume menstruating or initiate menarche.

**What was happening?**
Individualizing care

- Learning from our patients
- Small cohort despite weight restoration did not resume menses
- In collaboration with a colleague specializing in sports medicine - we are now focusing beyond sex hormone suppression
- Leptin suppression → causes of leptin suppression - such as excessive movement, lack of sleep, or post prandial hypoglycemia

CASE 1 (cont.)

Consult with Dr Emily Cooper

CASE 1 (cont.)

She pointed to leptin and its permissive effect on the LH surge needed for ovulation

We looked at leptin in weight-restored girls with no menses.

It was low.

So what suppresses leptin?

3 THINGS:

1. Even short lived fasting / dieting (with or without weight loss)
2. Exercise
3. Post-prandial hypoglycemia (verbal report, Dr. Cooper)
Could it be Hypoglycemia?

- Our kids were eating on meal plan + not exercising.
- We were skeptical. But we decided to check.
- We worked with the hospital lab to order 30, 60, 90 minute glucose AND insulin following a defined and balanced breakfast.
- As leptin levels (and other labs) may show diurnal variation, ALL of our labs are early morning fasting.

Our Findings

Startling post-prandial hypoglycemia

- Some were dropping within the first 30 minutes, some later
- Occasionally a patient was symptomatic (headaches, tired, sweats), but mostly they were asymptomatic
- Some had critically low values (in the 30’s-40’s!!!) -- surprised us!

Metabolic Labs

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<th>2/21</th>
<th>3/15</th>
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<tbody>
<tr>
<td>Cortisol</td>
<td>21.8</td>
<td>9.3</td>
<td>8</td>
</tr>
<tr>
<td>LH</td>
<td>0.2</td>
<td>&lt;0.1</td>
<td>5.8</td>
</tr>
<tr>
<td>FSH - Follicle Stimulating Hormone</td>
<td>2.4</td>
<td>4</td>
<td>3.8</td>
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<tr>
<td>Estradiol 17-B</td>
<td>26</td>
<td>26</td>
<td>125</td>
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<tr>
<td>Testosterone</td>
<td>34</td>
<td></td>
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<tr>
<td>TSH</td>
<td>3.257</td>
<td>2.633</td>
<td>2.361</td>
</tr>
<tr>
<td>T3 Total</td>
<td>37 (L)</td>
<td>84</td>
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<td>Free T4</td>
<td>0.87</td>
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<tr>
<td>C3 Complement</td>
<td>68 (L)</td>
<td>91</td>
<td>104</td>
</tr>
<tr>
<td>Insulin Fasting Lvl</td>
<td>1.8 (L)</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>ACTH</td>
<td>6</td>
<td>11</td>
<td></td>
</tr>
<tr>
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<td>3.6</td>
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<tr>
<td>Zinc</td>
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<td>109</td>
<td>108</td>
</tr>
<tr>
<td>Leptin</td>
<td>0.4</td>
<td>1</td>
<td>3.3</td>
</tr>
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“Our patients are our teachers”
But sometimes, important colleagues teach us too.
Many thanks to Dr Emily Cooper for her inspiration and teaching about metabolic labs.

Clinical Pearls: Anorexia Nervosa

- Weight loss OR lack of weight gain in children clearly NEEDS to be addressed – even with the current epidemic of obesity
- What is “ideal body weight”? – particularly in pre-pubertal children
- Higher body weight child can also be diagnosed with AN
- The extremes: by the time of referral, most either had a very expensive work-up, or were asked to return in 3 months!
- Misdiagnosis or under-diagnosis can lead to severe sequelae – both temporary AND permanent

Clinical Pearls: Physiological vs Psychological remission

- Without weight restoration + resumption of menses - cannot achieve physiological remission
- Without physiological remission > cannot achieve psychological remission:
  - serotonin + memory function + estrogen modulating 5HT2 receptors in cerebral cortex + limbic system

CASE 1 (cont.)

Ben: 11 yo male
From Sutherlin, OR, self referred by parents
- Onset of weight loss - 10 months ago at beginning of last football season
- Followed by increased sadness and social withdrawal
- Was eating smaller amounts of food
- Noted to be “scratching his stomach” after each meal and complaining of fullness
- Shared with parents “something telling me that I am fat”
- Saw PCP who discussed healthy diet and “RTC in 3 months” despite weight loss

CASE 2
Meal Plan

- **Breakfast**: A small bowl of cereal with 2% milk.
- **Lunch**: Parents pack him a half of PBJ sandwich and a fruit. Admits that to skip lunches at school.
- **Snack**: Refused to eat. May a spoonful of PB. Used to have a granola bar or cheese/crackers with brother.
- **Dinner**: Meals cooked by parents. Very small portions of meat which tries to “defat”, minimal grains, and refuses to drink milk, to have any desserts or fast food.

Physical Activity

- Engaged in compulsive/compensatory exercising – 2 to 4 times per day
- Crunches, push-ups, etc
- Alone in his room or bathroom
- Parents hear him and are unable to make him stop

Reel Dx

Eating Disorders in Boys - Kartini has partnered with ReelDx to create online resources to study and treatment of pediatric eating disorders

Body Image Distortion

- Unlike most boys at his age, Ben felt “fat”, guilty after eating any meals, and “hated his body”
- Initially denied comparing his body shape or weight to that of others
- Yet endorsed obsessive thoughts about calorie counting, meal planning and compulsive exercising
**REDS**

Rate of Eating Disorder Severity (REDS) - validated semi-structured questionnaire administered by MD → score of 46, significantly high severity given patient’s age.

*Rating of Eating Disorder Severity Interview for Children: Psychometric Properties and Comparison with EDI-2 Symptom Index*

**Medical History**

**Past History**
- Born via c-section to 30 yo G1 P0 to 1
- s/p tonsillectomy at 12 yo for recurrent streptococcal pharyngitis and “sleep apnea” per parents
- No hospitalizations

**Family History**

- **Mother**  History of depression. Perfectionistic & tidy. No EDO
- **Father**  s/p back surgeries, good health. No EDO
- **Half brother** Depression - ? activated while on fluoxetine
- **Brother**  Healthy
- **PGM**  Alcoholism
- **PGF**  Deceased from brain aneurysm

**Physical Exam**

**Vital Signs**
- Temp: 36.7 C
- Pulse 66 BPM (supine), 77 BPM (standing)
- Blood Pressure 107/65 (supine), 96/53 (standing)
- Weight 65.8 lbs and height 144.4 cm (4 ft 8.8 inches). Highest premorbid weight 79 lbs
- BMI 14.3
- On exam: cachectic appearing, extremities cold to touch, tanner stage I

**Growth chart**
**Questions**

- Where would you refer this patient?
- What level of care does he need?

**Diagnoses**

- Anorexia nervosa, restricting subtype
- Orthostatic hypotension

**Treatment Course**

- Admitted at Randall Children’s Hospital for medical stabilization
- PHP for nearly 10 weeks
- Transition to IOP
- Currently in outpatient

**Clinical Pearls: Anorexia Nervosa and Boys**

- Often under-diagnosed
- Many present with over-exercising
- May or may not complain of body image distortion e.g. wanted to build muscles, improve sports’ performance
- By the time of the referral: usually quite ill, bradycardic, malnourished, often osteopenic or osteoporotic
WHO ARE WE?

Medical & mental health team

53

54

Levels of Care

MEDICALLY STABLE?

YES

NO

Inpatient @ hospital

Inpatient Hospitalization

- Using the American Academy of Pediatrics for inpatient hospitalization
- At a hospital (not a psychiatric ward!)
- Daily physician visits
- Initiation of family therapy
- Parent support group
- Focus is medical stabilization

Inpatient Hospitalization

- Five days a week, currently with 2 long days (8 am to 6 pm, 8 am to 3:30 pm)
- Three separate “units” – Earth, Wind, and Fire!
- Family-based approach
- Structured eating
- Emphasis on mental health (with continued medical supervision)
- Age appropriate
- Includes group therapy, individual therapy, milieu therapy, art therapy, school time, and movement therapy among others
Intensive Outpatient Program

- 5 days per week: 3-5 hours per day in group therapy
- 2 tracks: morning and afternoon tracks. Focus is on returning to school and seamless transition ("softer landing")

Outpatient Program

- Medical visits
- Ongoing family therapy
- Ongoing individual therapy

Family-Based Therapy at Kartini

- Each family is assigned a family therapist and doctor that work with them through all levels of care
- Parents have orientation with their child’s milieu therapist, nutritional counselor, and school teacher
- Weekly family therapy to provide parent education and coaching
  - Siblings and other caregivers are drawn into family therapy when appropriate
  - All caregivers are required to get meal plan training
- Parents meet with the doctor every two weeks and the nurse weekly
- At least weekly check-in with milieu therapist

Family-Based Therapy at Kartini

- Parents are in charge!
  - Kartini meal plan
  - Supervision
  - Activity plan
- Parental alignment with treatment recommendations
- Parent support through classes, groups, and online resources
Coordination of Multidisciplinary Care

Coordination of Care

- Direct communication with providers from the time of referral, throughout treatment and discharge planning
- Weekly treatment/concurrent review to “care team”: weekly summary of patient’s treatment objectives
- Discharge summary at the time of graduation

Beyond our patients’ graduation - providers have access to the Kartini clinical staff
- Online resources - e.g. Dr. O’Toole’s blogs, etc.

Referral

Sources
- PCP → Therapist → Dietician → Parent(s)

Process
- Early recognition + assessment
  - Formal evaluation from specialist identify level of care + related recommendations
    - PHP/IOP/OP
      - Graduate + return to provider(s)


**THANK YOU!**

Any final questions?

You can find us at help@kartiniclinic.com