Beyond the Basics: Medical Topics Important for Special Populations with Eating Disorders

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Objectives:
By the end of the presentation, attendees will:
1. Feel more confident managing a variety of outpatient presentations medically, and communicating with patients, families, and other providers accordingly
2. Recognize when a patient may be appropriate for a palliative care approach
3. Have a stronger understanding of the unmeasurable medical problems experienced by those with eating disorders

Purging
Cassie

- Cassie is a 24 year old cis-gender female with bulimia nervosa
- She binges and purges for a few hours, four days a week (with rinsing)
- Escalating use of laxatives (now using 8 senna a day)
- Distressed that every time she reduces her laxatives, or has a day where she only binges and purges once, her weight shoots up 5 lbs
- Her cheeks swell painfully on days she doesn't vomit
- She's sure she's “not sick,” because her body weight is “normal.”

Types of purging

- About 50% of patients vomit only
- 25% vomit and abuse laxatives
- Fewer than 10% vomit & use laxatives & use diuretics
- Fewer than 5% use diuretics or laxatives only

Rinsing

- Drinking water after purging and then purging up the water to “rinse” the stomach of any further kcals missed
- Use of cold water can cause hypothermia
- Patients can feel extremely cold, with particularly white/cold hands and feet
- Hypothermia can kill
Diuretics

• Strongest are loop diuretics
• Lasix (name)
• Causes excretion of salt and water from the kidneys
• Can lead to kidney failure, profound volume depletion, contraction metabolic alkalosis, hypokalemia
• Severe Pseudo-Bartter syndrome

Laxatives

• Good guys (not typically harmful): Miralax, milk of magnesia, magnesium citrate, colace
• Bad guys (when overused): Senna/Senokot, Bisacodyl, Dulcolax

Laxatives

• Use is highly prevalent in those who purge: 14-75%

Laxatives

• Don’t be fooled by the natural labels…

Traditional!
Smooth!
Wildflowers!
Organic!

Laxatives

• Risk for permanent colon damage
  – Atonic colon can in severe cases lead to cathartic colon
  – Inflammation, smooth muscle changes, and damage of the myenteric and Auerbach’s nerve plexi result in permanent colonic damage and refractory constipation

Mehler PS, Rylander M. Bulimia Nervosa - medical complications. J Eat Disord. 2015 Apr 3;3:12

Laxatives

• Laxative abuse can lead to kidney stones and compromised pancreatic function


Laxatives

- Stop laxatives, don’t taper
- No physiologic benefit to the tapering of stimulant laxatives, but there is risk
- Each dose of laxative may bring the patient closer to permanent colonic dysfunction.


Purging

- Number of purging behaviors correlates with psychiatric comorbidity, PTSD, victimization, alcohol use disorders

Brewerton TD, Dansky BS, O’Neil PM, Kilpatrick DG. The number of divergent purging behaviors is associated with histories of trauma, PTSD, and comorbidity in a national sample of women. Eat Disord. 2015;23(5):422-9

Why the rebound edema?

Secondary hyperaldosteronism

Pseudo-Bartter syndrome

- Key points to treat
  1. Stop purging
  2. Slowly rehydrate
  3. Treat the hormone over-production until body down-regulates
     Spironolactone 25 mg daily for 2 weeks if mild
     For those with laxative abuse, much harder task. May need 50-100 mg a day and a slow taper over 6 weeks. Will still see weight surge.

Parotid hypertrophy

- From repeated vomiting
- May be permanent

Acute sialadenosis

- Bilateral acute swelling of parotid glands usually appearing three days after cessation of purging by vomiting
Lemon drop protocol

- Sugar free lemon drops every few hours
- Ibuprofen (weight-adjusted dosing) 3-4 times a day
- Warm compresses

Cassie: Case Resolution

- In the outpatient setting, she contracts not to purge
  - Maybe once a week b/p, no laxatives
  - Stays off the scale (body will still change with rehydration)
  - Oral potassium 20 mEq tid, checking potassium levels weekly
  - Spironolactone 50 mg a day for 3-4 weeks, then 25 mg a day for 2 weeks
  - Lemondrops, warm compresses to cheeks
  - No salt restriction, but maybe max 2-3 L fluids/day
Aidan

- Aidan is a 29 year old cis-gender male with anorexia nervosa who has been in multiple rounds of residential treatment
- He now has a job he likes in a community where he feels connected
- In relapse, he restricts calories (1000/day) and exercises excessively
- He seeks out a team because he is determined not to have to leave his outpatient life again

Starting kcals

- Used to start too low, 600-1000 kcal a day
  - “Prevent refeeding syndrome. Start low, go slow.”
- That’s wrong

Starting kcals

- We now know that the underfeeding syndrome is more prevalent and more dangerous to patients with acute malnutrition
What's the underfeeding syndrome?
- Giving patients too few calories to start out, keeping organs acutely malnourished despite being in a higher level of care
- Brains remain starved and thus rigid, irrational, anxious, and paranoid longer
- GI, cardiac, skin, bone marrow, liver, and overall metabolic systems remain starved and malfunctioning
- A little nutrition boosts the metabolism beyond calorific input, causing ongoing weight loss while in treatment

Instead, start no lower than 1600 calories a day, and increase by 400-500 kcal/week

“But:"
- I've only been eating 1000 calories a day at home!
- I thought you said your care was individualized!
- I get full after four bites!
- You're going to make me gain 10 pounds overnight!
Starting kcals

• Offer compassion, and hold space for the fear, and:
  – Starting calories higher will only boost your metabolism that much faster. Believe it or not, that’s the main thing 1600 calories does. We’ll be chasing your fast metabolism for the next couple increases, before we can start helping you actually restore weight
  – Hanging around in starvation “no man’s land” will prolong your misery, not ease you in to treatment
  – This is standard of care and good science, and that’s what I owe you. Not collusion with your anorexia

Starting kcals

• Does the literature support this as being the safest and best approach? Yes. Unanimously. (Typically performed in higher LOC settings with lower BMIs)

Evidence

  – 215 patients average 15.3 years old (5.8-23.2y); 64% AN, 18% atypical anorexia, 6% BN, 5% purging disorder, 4% ARFID, 3% UFED
  – LOS was 11 days. Initial kcals 1466, discharge kcals 3800
  – Phos supplementation for refeeding lows in 14% of inpatients; full-threshold refeeding syndrome did not occur.
Evidence

  – 1500 kcal initial. Average kcals at 14 days was 3600. Calorie increases made in 500 kcal increments
  – The macronutrient composition 50–60 % carbohydrate, 20–30 % fat, and 15–20 % protein
  – Mean admission BMI 15.9 (11.9-20.6 kg/m2), weight gain 1.4 kg/week
  – 47% incidence of phos <3 mg/dL, checked twice weekly

Evidence

  – 6 UK hospitals, 10-16 years with a BMI <78%
  – Randomized to 1200 vs 500 kcal/day starting
  – Higher kcal pts gained more, no differences in phos
  – Only admit BMI and WBC predicted low phos

Evidence

  – Inpatients on a higher initial kcal level gained more weight and had a 30% lower incidence of bedrest than those started on lower kcals
Refeeding syndrome

- Refeeding syndrome is a term broadly used to describe any symptom of edema (not related to cessation of purging/Pseudo-Bartter syndrome) or low phosphorus level in someone receiving nutritional rehabilitation.
- *Very* few patients with AN get full-blown refeeding syndrome, which actually refers to a medical emergency of volume overload and cellular breakdown from critically low phosphorus.
- **Key to preventing it is watching for it and treating early.**

Refeeding syndrome

- **Low phosphorous can be dangerous...or deadly**
  - Full-blown refeeding syndrome
    - Respiratory failure
    - Red and white blood cell dysfunction
    - Muscle breakdown
    - Seizures
    - Congestive heart failure
    - Cardiac arrest

Phos supplementation

- Like most electrolytes (except magnesium), phos is better given by mouth
  - Check phosphorus level weekly
  - Whatever oral preparation is cost effective is fine
  - Give 3x/day for any phos <3 mg/dL, until appears to be holding above 3 and then taper off
  - Send for IV phos if persistently below 3 mg/dL on maximum oral phos (2 packets tid)...have hospital hang IV Kphos or NaPhos q6h round the clock
  - Can cause diarrhea, so adjust bowel regimen & educate
**Thiamine**

- Thiamine (B1 vitamin) 200 mg a day for 10 days
  - Prevents Wernicke-Korsakoff syndrome
  - When starved brains once again get glucose, they can rapidly use up B1 vitamin and develop a short term confused/incontinent/ataxic syndrome, which can progress to permanent dementia characterized by confabulation
  - Rare, but why risk it? Cheap and harmless vitamin.

**Zinc**

- Zinc is involved in over 300 human enzymes
- Deficiency (mild to severe) associated with numerous findings: severe height restriction, skin/hair deficiency, poor immune state, low testosterone, anemia, cognitive decline
- Level B evidence to supplement zinc in AN (why test?)
- Recommend empiric treatment with Zinc Gluconate lozenges 15 mg daily for 30 days but no more (or blocks copper absorption)


**Aidan: Case Resolution**

- He gets an RD and a therapist who are ED experts
- RD starts him at 1600 kcal/day, increased by 500 kcal weekly with good monitoring
- Given thiamine for 2 weeks, zinc for a month
- Encouraged to start mindful movement as soon as he’s clearly restoring at least 1 lb a week consistently (ie not restricted from movement)
Christy

- 36 year old female with eating disorder since age 14 since, AN-BP for last 5 years (predominantly laxative abuse)
- In and out of treatment countless times
- Each relapse is worse, and happens faster, than the one before
- Fully weight restored several times (i.e. not a patient who serially flees treatment early)

Christy

- Comes to ACUTE for the first time in Nov 2010 at 68 lbs (30.8 kg), 5'2" (157.5 cm), stays 2 weeks, discharges at 73 lbs (33.1 kg) to residential center
- Stays in residential care for 2 months, discharged at 104 lbs (47.2 kg)
- Right after leaving res, relapses
Christy

- Re-presents to ACUTE 9/2011 at 63 lbs (28.6 kg): very weak, falling, difficulty swallowing, severely ill, severely dehydrated
- On the night of admission, says she made a mistake, not ready for treatment, wants to leave AMA
- Agrees to stay 1 week
- Leaves 6 days later AMA
  - Psychiatry consult/decision making evaluation undertaken
  - Has capacity
  - Palliative care option raised
  - Long talk with parents

Christy

- Patient signs a DNR/I order with parents present, with PCP
- No hospice service in Virginia, her home state, will accept anorexia nervosa as a terminal diagnosis. Her PCP rejects calls to support her comfort and fires her.

Christy

- In 3/2012 I get this email: “I know this is my decision and I could choose to continue to suffer, but I am in so much pain physically I am not sure how much more I can take. I still walk with a cane and my legs work some of the time. I am unable to really bend over without being in pain, and I can’t bend my knees all the way. Basically if I fall or end up on the ground, I have to call someone to get up. My current weight as a few days ago is 50 lbs (22.7 kg) and I am on about 35-50 laxatives a day. I don't throw my food up. Do you have room at the hospital for me?”
Christy

- 3/2012 admits to ACUTE at 52.7 lbs (23.9 kg), 48% IBW, profoundly dehydrated. Critically ill, multi-organ failure, cognitive slowing, dysgeusia, asks for a nasogastric tube at admission because of bad taste in mouth.
- Within one week begins to talk of leaving ACUTE AMA again. Not suicidal.
- Deeply ambivalent about getting recovered, being recovered, and staying recovered.

Christy

- 3 weeks later, body weight is 70 lbs (31.8 kg) with some persistent edema
- She says she has to leave AMA and cannot do more treatment
- She has parents, a sister, and nephews near her VA home and arranges GI follow-up
- Extensive conversations ensue to try and convince her to stay. She understands the risks of leaving and doesn't want to die but doesn't feel she can tolerate the process of recovery again.
- Family closely updated

Christy

- 9/2012 tells ACUTE that hospice still not totally comfortable with anorexia nervosa as a terminal diagnosis.
- Has a hospital bed and oxygen at home. Living with parents now.
- Lets us know she's 39 lbs (17.6 kg), can't move, has bedsores. Wants to come to ACUTE “to take the edge off” but doesn’t plan on a full recovery.
- Clearly can't fly commercially, so we urge local hospital and from there, air ambulance – Wondering though whether this is futile
Christy

- She chooses to remain at home
- Passes away in November…2 months after she wrote that she was 39 lbs

Questions

- Should we have taken her rights and forced her on a short term certification to an eating disorder program in CO?
  - Cerfs can't cross state lines
- Was this a good, dignified death?
- Did she and her family get the support they needed in her final 6 months of life?
What do the terms even mean?

- Common misconception that palliative care means “giving up”
- **Palliative care** is its own specialty dedicated to easing physical and emotional symptoms and avoiding aggressive treatments unlikely to improve outcome
  - Quality of life and symptom management are key
- **Hospice care** is provided at the end of life, aiming to ameliorate symptoms and avoid prolonging the dying process

Big Picture

- Concepts like “never giving up” and “fighting this to the end” emerge from people's personal, cultural, familial, and religious roots
- This is a controversial topic, one that can stimulate a lot of conversation and personal feelings

Let me be clear

- Palliative care is NEVER appropriate in adolescents or young adults for their eating disorder
- Eating disorders resist diagnosis and treatment due to ego syntonicity: by no means is every patient who struggles with motivation eligible for a palliative or harm reduction approach!
Palliative Care Prolongs Life

- Studies have found that palliative care prolongs life in patients with cancer, compared with medical treatment alone

Sick patient refuses needed care

- Over 30 years old, recent full treatment without sustained improvement?
- Harm reduction effective?
- Keep on working with team?
- Still willing to work toward recovery with out-patient team?
- Civil commitment necessary?
- Has decision making capacity (medical)?
- Needs higher LOC in mental health setting against will and greatly disabled?
- Guardianship considered?
- YES
- NO

Always try motivation

- Clinicians with real eating disorder expertise
- Give it all you’ve got
**Harm reduction**

- For older patients with more chronic course who can't bear idea/reality of full recovery
- Set treatment goals below those for full recovery, that both allow a quality of life described/imagined by the patient and are more palatable to the patient (e.g., weight goals)

**Harm reduction**

- Always appropriate to allow patient to establish unique goals and values, but…
- For adolescents and those early on in disease, full weight restoration and multi-disciplinary care that embraces the family of origin are most appropriate, not harm-reduction

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**Capacity due to medical problems**

- **Capacity**: The ability to understand, appreciate, and manipulate information and form rational decisions
  - This determination is made by a physician or psychologist
  - Up to 25% of psychiatric consultations in hospitals are for the purposes of assessing capacity, or ability to make one's own medical decisions

Guardianship

- Capacity evaluations often undertaken when patients refuse treatment that physicians think is rational (but this is part of self-determination)

- Standard evaluation for capacity
  - Ability to make a choice
  - Ability to understand information
    - Do they understand the current medical situation and natural course of disease process?
  - Ability to understand consequences of a choice
  - Ability to manipulate information rationally
    - Do they understand the proposed treatment, risks and benefits of it, and alternatives?

Capacity in AN

- Individual’s ability to:
  - Understand information regarding what will happen to the body as it continues to receive inadequate food, or as a person continues to purge
  - Appreciate the consequences: that death will eventually occur, but it can take a substantial amount of time with a great deal of suffering in the meantime
  - Reason through the information needed to make this decision: do they have the supports from family and providers in the outpatient setting to make this feasible?
  - Communicate their choice consistently: lots of discussion must be had, and a consistent and firm decision must be seen, not waffling/having emotional outbursts and splitting the team or family members over this.

Capacity in AN

- Provider:
  - Be non-assumptive (moving away from “just eat,” “just try one more time,” “just go to treatment again”)
  - Recognize that suffering of the mind might be as real and painful as that of the physical body
Civil commitments: mental health side

- Grave disability/civil commitments center around mental health diagnoses
- Options vary by state. Colorado has strong mental health laws more likely to take autonomy in favor of saving lives

When is commitment not right?

- Patients with:
  - Repeated elopements
  - Prolonged need for involuntary tube feedings (persistent inability to take in food)
  - Multiple previous treatment programs
  - Older age
  - Patient who meets criteria for a harm reduction model, palliative care, or hospice care (Westmoreland, 2016)

Framework for palliative care in AN

- Is the patient 30 or above? OR, if in their 20s, have they been sick without meaningful remittance of disease since childhood?
- Have they completed the gold standard of care for AN (full weight restoration) recently, and not experienced relief of the AN thoughts/distortions?
- Have they received high quality eating disorder specific mental health care in the recent past?
- Do they have capacity to make medical decisions?
Severe Persistent Mental Illness

- SPMI: multiple comorbidities and higher-than-average mortality rates
- Swiss Academy of Medical Sciences guidelines on palliative care specify several groups of psychiatric patients:
  - Psychiatric disorders with chronic course/frequent relapses
  - Palliative approach does not primarily aim at fighting the disease but at optimal management of the symptoms and disability.
  - Quality of life can often be improved and suicide risk can be reduced
  - Can take place in addition to curative or disorder-specific treatments
  - They name three diseases specifically: Therapy-refractory depression, severe schizophrenia, and severe anorexia (Trachsel et al, 2016)

Palliative psychiatry

- Features of palliative psychiatry
  - Provides support in coping with and accepting of distressing mental symptoms
  - Affirms life but acknowledges that SPMI can be incurable
  - Intends neither to hasten nor to postpone death
  - Team approach integrates the physical, psychological, social, and spiritual aspects of patient care.
  - Offers a support system for patients and families
  - Will enhance quality of life and may also positively influence the course of the SPMI

Arguments against?

- Mass General study started in 1987
- Females with AN or BN assessed at 9 and 20-25 years of follow-up
- At 9 year follow-up, 31% of patients with AN and 68% of patients with BN recovered
- At 22 year follow-up, 63% of patients with AN and 68% of patients with BN recovered
- Half of those with AN who had not recovered by 9 years progressed to recovery at 22 years
- Early recovery associated with long-term recovery in AN, but not in BN
- Authors specifically argued against palliative care in AN given ongoing recovery

My response

• …but that leaves 36% of patients with AN who still hadn’t recovered after 22 years
• Some of those may still be seeking care and recovery, which is great
• But for those who are suffering deeply, they deserve palliative care

Understandable magical thinking

• If I keep fighting for my loved one/patient and “never give up,” then:
  – There’s a greater chance for recovery, even if she’s never responded well to past treatments
  – I won’t have any responsibility/role in her death if she does die
  – I’m staying true to my religious/cultural/personal beliefs about mental illness and mortality risk
  – I’ll know in my heart we “tried everything”

Some responses (with compassion)

• It’s not primarily about the family member/treatment team member, it’s about the experience and suffering of an individual with a dreadful mental illness that also has physical symptoms
• One may never “be ready” to change the focus of care/permit the option of not requiring engagement in higher levels of care or invasive treatment.
  – Seek one’s own therapy about the feelings that come up, not ongoing imposition of low-success likelihood, high-harm treatments.
Criteria for palliation

• There is no magic number (e.g., number of times hospitalized, years with disorder, medications tried, or expected days until death)
• It's the whole story of each patient that helps guide clinicians

What this isn’t

“So you want to die?”

(Maybe the most common and unkindest reaction of a consulting team)

Options and offerings

• Supportive therapy
• Medications for anxiety and depression
• Agreement not to force treatment against pt's will
• Spiritual support, art therapy; massage (touch remains a vital human need)
• Restructuring of family roles out of “policing” and “mandating,” moving towards spending as much good time together as possible
• Intensive support of the family, who may not feel comfortable with the terminal diagnosis
• Open-ended offering of a higher level of care if desired (but in highly sensitive patients, avoid reopening grief/guilt around a death viewed by many as a “choice”)
• Team may have to do a lot of convincing/educating of outpatient teams and even family members
And then eventually, hospice…

- As ever, supportive enumeration of what to expect
  - It can take a long time to die of malnutrition
- Medical equipment in the home, if desired, when self-care cannot be performed
  - Bed, skin care, ADLs, treatment of anxiety, physical pain, nausea
- Ongoing family support

Our responsibility

- Every person with a potentially fatal illness deserves to have a compassionate, educated talk about the possibility of death
- My patients feel deeply relieved when this is brought up and discussed openly, not just as a threat.
- Because it’s not as if they haven’t thought about it. A lot.

References

Unmeasurable Medical Problems
Postural Orthostatic Tachycardia Syndrome (POTS), mast cell dysfunction

Case: Meena
- Meena is a 29 year old female with atypical anorexia nervosa. She restricts calories without b/p, has a history of overexercise, and weighs 135 lbs (61.2 kg) at 5'4" (162.6 cm) tall.
- She has a history of fleeting skin rashes, "mini allergic reactions" to foods, comprised of mild tongue swelling or bumps in her mouth, belly pain after eating, a sense of flushing or low grade fevers randomly during the week, and frequent sinus issues.
- In the last year, she's developed a racing heart rate with standing, a sense of flushing, rage, and also GI distress with diarrhea after standing for 15 minutes, and has passed out a couple times.
- Relatively small tasks exhaust her

Oh those unmeasurable symptoms
- Often dismissed by medical system as “pan positive review of symptoms (a feminist issue...it's not hysteria, people)"
- Not necessarily DUE to an eating disorder, but can be found in those with EDs...at risk physiology or psychology? Mind body connection
Postural Orthostatic Tachycardia Syndrome (POTS)

- Chronic (>6 mo) postural intolerance, with tachycardia upon standing
  - Pathophysiology thought due to an excessive sympathetic response to pooling of blood on standing, many mechanisms proposed
  - Dx: Rise in heart rate of greater than 30 beats/min upon rising from lying down, or
  - HR >120 after 10 min on a tilt table at 60-70 degrees


POTS

- 1893, first case series in Civil War soldiers
- 1993 formally defined as POTS
- Rule out other etiologies, briefly
- Can be truly debilitating
- Typically in patients with high mind-body connection (somatic patients)
- Hard to treat
- AI etiology? Onset can follow an infection


POTS: not just the heart

- Common associated symptoms include:
  - Chronic pain
  - Fatigue
  - Joint hypermobility
  - Sleep disturbances
  - Headache
  - Anxiety
  - Depression
  - Inattention
  - Nausea
  - Gastroparesis
  - Various functional gastrointestinal complaints

- Ouch. Much harder to treat
POTS, three phenotypes

- Hyperadrenergic POTS ("Hyper-POTS")
  - Excessive serum norepinephrine (and epinephrine & dopamine) levels with standing, cause unclear
  - Might be a mutation in norepinephrine transporter gene
  - Patients experience intense flushing, bouts of rage, bouts of sudden-onset diarrhea, that are postural
  - High angiotensin II levels (worse with lower body mass) and impairment of nitric-oxide mediated vasodilation
  - Mast cell activation can cause hyper-POTS (more soon)
  - • AVOID B-Blockers in these patients!
  - • Common to see elevated heart rate (upright and recumbent), elevated blood pressure, pallor, exaggerated tremors, anxiety, and cold, sweaty extremities
  - • Methylxanthine, clonidine patch, and mast cell treatment can help

Neuropathic POTS

- Associated with partial sympathetic denervation of the lower body, causing impaired vasoconstriction in the lower extremities
- An arteriolar vasoconstriction deficit, not a venous pooling issue
- Up to 54% have this type
- Lower resting heart rates, less anxiety/depression, more acrocyanosis
- Midodrine promotes vasoconstriction and can help this subtype particularly

Hypovolemic POTS

- Usually, low volume (dehydration or anemia) triggers increase in renin-angiotensin-aldosterone system, but does not in these patients
  - They have inappropriately low levels of plasma renin activity and aldosterone and substantially elevated levels of angiotensin II
  - Treatment often involves volume expansion

Heyer GL. Postural Tachycardia Syndrome: Diagnosis and Management in Adolescents and Young Adults. Pediatr Ann. 2017 Apr 1;46(4):e145-e154
**POTS treatment**

- Start with volume expansion...salt and fluid by mouth (urine should be clear after first morning void)
- IV hydration NOT chronically and only in the context of intercurrent serious illness/volume depletion
- Exercise (except in those with concurrent chronic fatigue), eg recumbent bike, PT
- Good sleep

**Incremental outpatient progress**

- Set expectations, and be prepared to bear witness patiently to a highly impacted quality of life
- Remind patients that treatments will be tried, evaluated, and reconsidered if not effective
- Use creativity and curiosity, and stay up on the literature
- Symptoms can get better, especially as the whole person gets better (eg from an ED)
- Felt to be a complex psychophysiological disorder, with possible similarities to migraine

**Mast Cell Activation & association**

- Mast Cell Activation
  - Fevers, rashes, allergies...
  - Mast cells inappropriately release their histamine granules, and patients describe increasingly severe allergic reactions to medicines and foods
  - Watch for ED symptoms to be confused with MCA symptoms, but don't jump to attribute all food issues to ED
  - In severe cases, sunlight can trigger edema, confusion, rash
Incremental outpatient progress

- For mast cell activation, mast cell stabilizers:
  - Gastrocrom (oral cromolyn) 10 ml PO QID can markedly improve MCA symptoms -or-
  - Ketotifen 1 mg PO bid (compound pharmacy) is equally effective, capsule form and only twice a day
  - Also ranitidine, famotidine, or Zyrtec (histamine blockers)

Chronic fatigue syndrome

- Can try Modafinil 100 mg a day
- Highly impairing
- No guarantees that ED recovery will fix CFS, but relapse will absolutely worsen/prolong it

Meena: Case Resolution

- Multidisciplinary care of her atypical AN
- Patient education (diagnose, empower, even though these don’t have blood tests)
- Good POTS treatment: methyldopa 250 mg bid, good volume expansion, exercise incrementally if tolerated. Try Modafinil
- Good MCA treatment: ketotifen 1 mg PO bid, *no low histamine diet*
More Unmeasurables

Irritable bowel syndrome, some BED-related thoughts

Case: Janet

- Janet is a 42 year old executive who has been in a larger body her whole life. Her past is strewn with yo-yo diets and shaming from family and medical professionals.
- Several times a week, she restricts all day and then binges until uncomfortable, body and soul
- She has always had a sensitive stomach, and she notes that she gets diarrhea, bloating, and cramping multiple times a week, worse when stressed
- She has no medical problems and works out with a trainer twice a week, but progressive right knee pain has started to impede her activity.
- Janet goes to an orthopedic surgeon who barely looks at her x-ray before telling her she should go on a diet and lose weight. He tells her that “no one will operate on you in the future unless you lose 50 pounds.”

BED

- Stigma
  - Doctors are the biggest culprit after family, more than classmates, members of community, friends
  - Weight discrimination occurs more frequently than gender or age discrimination
- Not all who are in larger bodies have BED
- Many with BED avoid seeing doctors because of shame/weight-focused discourse
Some “radical” concepts

- Dieting doesn’t work
  - 95% of weight lost through dieting is regained
- Terms like “people in larger bodies” rather than “overweight/obese” reduce shame
- “Health At Every Size” (HAES)
  - Accept/respect the natural diversity of body sizes and shapes
  - Eat in a flexible manner that values pleasure and honors internal hunger cues
  - Move, within ability, for joy and to become more physically vital

HAES

HAES philosophy is absolutely compatible with good medical care

- Weight is never checked
- Weight loss is never a primary outcome/goal
- Aim is to optimize the individual's relationship with nutrition, movement within ability, and support great mental health care
- Beyond that…manage medical/surgical problems

Top medical complication of BED?

You have to lose 50 pounds before I'll do this surgery.
Mortality outcomes

• Erroneous equation of thinness and health
• Study of 29,000 diverse males and females found that reduced exercise capacity was a powerful predictor of mortality, while BMI was of limited importance
• Veterans Exercise Testing Study showed that the lowest death rates of 12,000 middle aged veterans were observed in the “obese men with a high exercise capacity”
• The act of engaging in regular aerobic exercise and/or resistance training causes life-prolonging changes in a number of cardiovascular risk factors, independent of any change in body weight

Knee surgery outcomes

• 12% of a cohort of 11,000 patients undergoing knee replacement surgery lost 5% of body weight in the year prior to surgery. With regards to postoperative infection and hospital readmission, they had identical outcomes to those who did not lose weight.

• Another study noted that presenting to surgery malnourished from taking in too few calories and breaking down body tissue (i.e. losing weight) may itself cause poor wound healing and infection…the very complications weight loss is supposed to prevent.
Knee surgery outcomes

- A study of almost 78,000 patients undergoing knee replacements showed that “morbid obesity” was not independently associated with most surgical complications. Rather, a low blood albumin level (a protein in the blood that can correlate with inflammation as well as poor nutrition) was associated with increased death rates and other complications.

The evidence is plentiful


Irritable bowel syndrome

- Irritable Bowel Syndrome (IBS)
  - Constipation, diarrheal, or mixed subtypes
  - Mind body connection
  - Incremental, individualized approach with expectation setting
  - Holistic approach
- Different from IBD
  - Inflammatory bowel disease
  - Crohn’s and ulcerative colitis
IBS: Rome III criteria

• Recurrent abdominal pain or discomfort at least 3 days/month in the last 3 months associated with two or more of the following:
  – Improvement with defecation
  – Onset associated with a change in frequency of stool
  – Onset associated with a change in form (appearance) of stool

IBS

• Be sophisticated in your choice of meds
  – Constipation subtype:
    • Amitiza (lubiprostone) 8 or 24 mcg PO bid w/ meals
    • Linzess (linaclotide) 145 or 280 mcg PO daily more than 30 min before 1st meal
    • Trulance (plecanitide) 3 mg PO weekly to daily depending on effect
  – Diarrheal subtype:
    • Cholestyramine 1 packet before meals absorbs bile (watch timing)
    • Bentyl (dicyclomine) 10 or 20 mg PO QID
    • Levbid (hyoscyamine) 0.125 or 0.25 mg PO TID-QID prn
    – Not proven in the setting of concurrent malnutrition

Beyond “It’s just IBS”

• Meds, whole-person care, and mindfulness aren’t enough. The symptoms persist. Now what?
Introducing the pelvic floor muscles

- They hold up uterus, bladder, and bowel
- Function and sensation in rectum, vagina, and urethra have everything to do with the pelvic floor

Pelvic floor dysfunction

- Rome III symptoms of pelvic dyssynergia:
  - Having to strain to pass a stool
  - Feeling unable to empty the rectum
  - Having difficulty relaxing to evacuate the stool
- Other related symptoms: needing to self-disimpact, stool incontinence, abdominal distension
  
  

What can go wrong with the pelvic floor?

- Chronic tension, anxiety, drive to keep stomach held in → overall hypertonicity (high tone) of pelvic floor muscles
  - Nothing gets through easily, gas or stool
  - Cycles of dieting/muscle mass loss, compounded by IBS challenges or pregnancy and childbirth, can leave some muscles stronger than others
    - One may tense while another relaxes
    - Matters for pelvic pain eg with intercourse, and bowel function
- Overall weakness of the pelvic floor
How is it diagnosed?

- Anorectal manometry is one way
- A skilled pelvic floor physical therapist can also do a detailed exam, both internal and external, and establish diagnoses and plans of care

Distention and pelvic floor dysfunction

- Patients with functional constipation have 2x incidence of bloating/distention compared with general population
- By contrast, those with IBS-C have a 14x incidence!!
- Impaired gas transit may be responsible for bloating/distension in IBS pts²

Pelvic floor dysfunction

- So what causes impaired gas transit?
  - Pelvic floor dysfunction!
- Patients with abdominal distension exhibited
  - a higher resting anal sphincter pressure
  - a higher maximum anal sphincter squeeze pressure
  - a prolonged balloon expulsion time


Pelvic floor dysfunction treatment

- Physical therapy and biofeedback are highly effective in reducing pelvic pain, dyspareunia (pain with penetrative intercourse), urinary incontinence, constipation, and diarrhea and stool incontinence
- Obvious warning for patients who have experienced sexual trauma or are extremely modest…this is not a hands-off experience

SIBO

- **Small Intestine Bacterial Overgrowth**
  - Increase in more than 100,000 CFU/ml in proximal jejunal fluid
  - Prevalence of SIBO approximately 56% among patients with irritable bowel syndrome (IBS)


- Manifestations range from enteropathy causing severe malabsorption simulating celiac disease to mild symptoms that overlap with IBS
- Lactose breath testing most common test
  - But requires dietary restriction not appropriate for some patients with eating disorders
- Can disrupt epithelial tight junctions, increasing small intestine paracellular permeability, translocation of endotoxin, and induction of proinflammatory cytokines
SIBO treatment

- Well-done RCT showed that use of 2 herbal remedies (eg FC Cidal and Disbiocide) for 4 weeks are non-inferior to rifaximin for SIBO eradication
  - Herbal remedies may disrupt the normal gut microflora less than rifaximin
  - Carry a lower risk of inducing C Diff colitis

SIBO treatment

- Also: Atrantil 2 caps tid until improvement (3 weeks) then 2 caps daily for maintenance
  - Less evidence, but reasonable scientific theory and used by solid Western physicians
  - Can be used with FC Cidal and Dysbiocide
  - Watch for worsening around week 2, possibly reflecting bacterial die-off

Probiotics

- Generally aren’t really ready for prime time, but…I still recommend them in patients after SIBO treatment
Treatment

- Always: a Health At Every Size (HAES) approach
  - Focusing on relationship with food, ability to meet body’s energy needs, and experience within body, not body shape and size
  - There is no need to weigh patients (unless underweight, monitoring restoration), EVER
  - You cannot tell a person's health by looking at them, or measuring their body weight and height

Janet: Case Resolution

- Janet sees a new doctor who believes in a HAES approach and introduces her to this idea
  - Doctor locates her privilege as being a part of an oppressor class for years of people of size
- She diagnoses Janet with BED and refers her to a therapist and RD who also follow HAES
- Pelvic floor therapy referral made, SIBO treated, probiotic started, regular nutrition pursued, tummy feels better

Orthorexia & Athletes
Carla

- 32 year old married cis-gender female was an elite road biker in her 20s
- Three years ago when her sister developed an autoimmune disease, she started researching how food influences health
- She was quickly convinced of the dangers of sugar and became a vegan, “clean” eater
- Her husband misses their date nights, and she’s become more irritable at his requests for her to eat more “normally.” She socializes far less than before
- Her weight is 120 lbs (54.4 kg) at 5’5” (165 cm), and she runs and does yoga every day

Orthorexia

“An unhealthy obsession with eating healthy food”
- Steven Bratman

- www.orthorexia.com
- Not in DSM 5

Orthorexia

Criterion A. Obsessive focus on “healthy” eating, as defined by a dietary theory or set of beliefs whose specific details may vary
- Marked by exaggerated emotional distress in relationship to food choices perceived as unhealthy
- Weight loss may ensue, but this is conceptualized as an aspect of ideal health rather than as the primary goal
Orthorexia

Criterion B. The compulsive behavior and mental preoccupation becomes clinically impairing by any of the following:

• Malnutrition, severe weight loss or other medical complications from restricted diet
• Intrapersonal distress or impairment of social, academic or vocational functioning secondary to beliefs or behaviors about healthy diet.
• Positive body image, self-worth, identity and/or satisfaction excessively dependent on compliance with self-defined “healthy” eating behavior


• Can lead to life-threatening malnutrition


Food

• Regardless of sport, modern day concepts of “healthy eating” permeate social awareness
• Some principles are sound
• Many others veer into pseudo-science
  – Promote associations between categories of nutrition and health/disease states that have no bearing on reality
Now more than ever…

Athletes are susceptible to food messages

- Hard working, not afraid of pain, willing to suffer for improved results
- Want the best for their bodies
- Always looking for the “edge”
- Trust coaching relationships that may work great on the field/road/stage but may not serve them well with nutritional recommendations
  - We need to empower athletes to request that nutritional recommendations come from experts (sports or eating disorder nutritionist)…typically not doctors, trainers, coaches
  - Requesting this expertise isn’t being “un-coachable”
Public Service Announcement

- The best “edge” is almost certainly obtained through attention to:
  - Hydration
  - SLEEP/recovery time
  - Good nutrition
  - Attention to mental health and emotional needs
- …without these to recharge/heal body and mind, training and race/performance strategy will be much less effective

The problem

- To honor the high performance vehicle that is the self & to optimize performance, athletes can apply stringent criteria to their food intake that can lead to malnourishment, medical issues, and mental illness…anything but healthy and optimal
- But size/shape/leanness/muscularity still over-valued

Example… “clean” eating

CLEAN EATING
Beautiful, fresh foods are great, and…

- Human bodies are beautifully designed to make effective use of an extraordinarily broad variety of nutrients and thrive!
- Think of different cultures, geographies
- “Clean eating” would have us believe anything else sullies the temple of our body

Fertility & Pregnancy

(Carla, continued)

Fertility

- Carla has never lost her regular menstrual cycle, but she comes to clinic asking for fertility assistance after 10 months of unsuccessful attempts
  - Will you start her on fertility treatments?
  - Will you recommend she gain weight and relax food rules and exercise first?
Fertility. No pressure.

Fertility

• Topics
  – Carla (the thin woman who wants to conceive)
  – How eating disorders affect fertility
  – How eating disorders influence pregnancy outcomes
  – How pregnancy influences eating disorder outcomes

The data differ

• Population studies
  – A large number of people in the community agree to be interviewed across a range of topics
  – For instance, all pregnant women in the medical system in a city answer questionnaires about medical and psychological history/current practices, including about eating disorder symptoms

• Eating disorder programs follow patients over time for health outcomes
  – Patients had more severe eating disorders than those surveyed from community, so results likely to reflect that
Fertility

- Netherlands-based population study with 9000 total women
  - Relative to women w/o psychiatric d/o, women with BN had increased OR 2.3 of having undergone fertility treatment
  - Patients with AN had half the fertility rate of controls, but in 55% of patients with AN who did get pregnant, it was a surprise pregnancy
  - “Eggs happen”


Fertility

- Women attending a private fertility clinic
  - Up to 20% met criteria for current eating disorders
  - Not one had told her reproductive endocrinologist
  - We are missing women with EDs who present for fertility problems!


Doctors (as usual) lack training

- 84% of Aus/NZ clinicians in fertility clinics agreed important to screen for eating disorders, but only 35% routinely did so
- 9% said their clinics had practice guidelines for management of EDs
- 14% felt satisfied with their level of training in EDs, 38% felt they could recognize an ED, and 92% felt they needed further education and clinical guidelines*
- Gynecologists in the US feel they lack adequate training too**

Great review article

- Anyone wanting a terrific summary of the recent literature can look no further than this article
  - Note that many questions remain, and many studies (on mental health/pregnancy outcomes/birth outcomes/fertility rates) still contradict each other

“When I’m recovered…

..will I be able to get pregnant?”

YES

- ...to the extent that “yes” applies to any woman, because fertility is a mysterious thing
**ED influence on pregnancy outcomes**

- 2300 patients seen over 15 years at Helsinki eating disorder program (inpatient admission, sicker)
  - IUGR (small babies at birth) well established risk in AN
  - In those with AN, pregnancy rate <50% of control group
  - Overall pregnancy and childbirth rates in all eating disorders lower than in controls
  - Highest rates of induced abortion were in those with BN (23% of pregnancies)
  - Highest rates of miscarriage were in those with Binge Eating Disorder (BED), 47% of pregnancies (17% of controls)
  - Infertility treatment in 7.2% of ED pts vs 4.5% controls


**Pregnancy influence on ED outcomes**

- Swedish study, 5200 women admitted during life for anorexia nervosa
  - The 63% of women who remained nulliparous accounted for 80% of deaths in the cohort.
  - Childbearing in AN decreased mortality >60%


**Pregnancy influence on ED outcomes**

- Norwegian Mother and Child Cohort Study
  - First large scale population based study on peripartum effect on eating disorders
  - Pre-pregnancy, incidence of AN 0.1%, of BN 0.9%, of BED 3.5%
  - Women with ED gain more weight during pregnancy, worry more about size and shape, and have higher rates of postpartum depression
  - Eating disorder symptoms may remit during pregnancy
  - At 18 and 36 months postpartum, remission rates for AN were 50% and 59%. For BN were 39% and 38%

Carla: Case resolution

- For Carla, we will recommend a multidisciplinary team to work on her food rules, evaluate her medical malnutrition, and support her psyche
- We will recommend no invasive fertility work (although she can keep trying the old-fashioned way) until she has gained some weight, eased way back on exercise, and improved nutritional intake
- Recommend birth control until patients are truly recovered from their ED

Coming late 2018, my first book

SICK ENOUGH
A Guide to the Medical Complications of Eating Disorders
(Routledge)

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