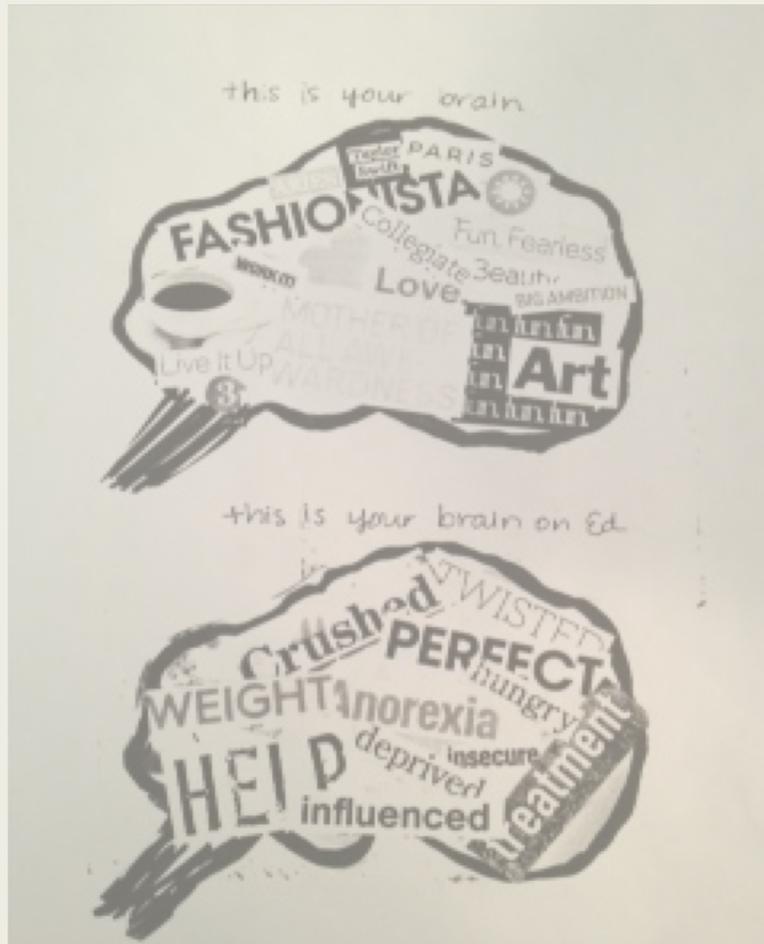


EATING DISORDERS

Christina Tortolani, PhD,
&
Andrea Goldschmidt, PhD

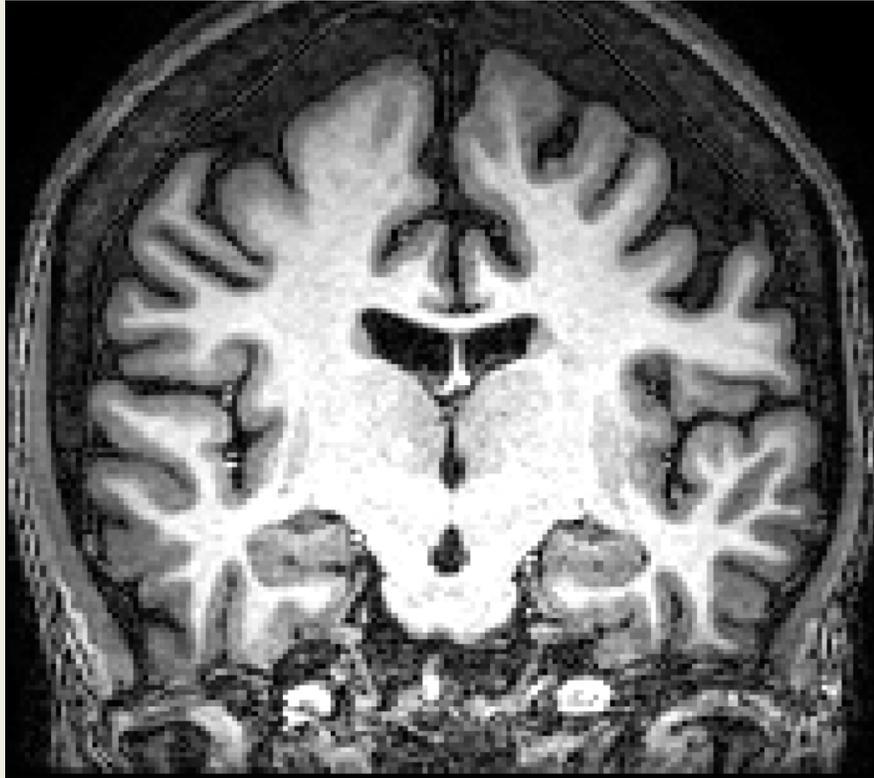


Learning Objectives

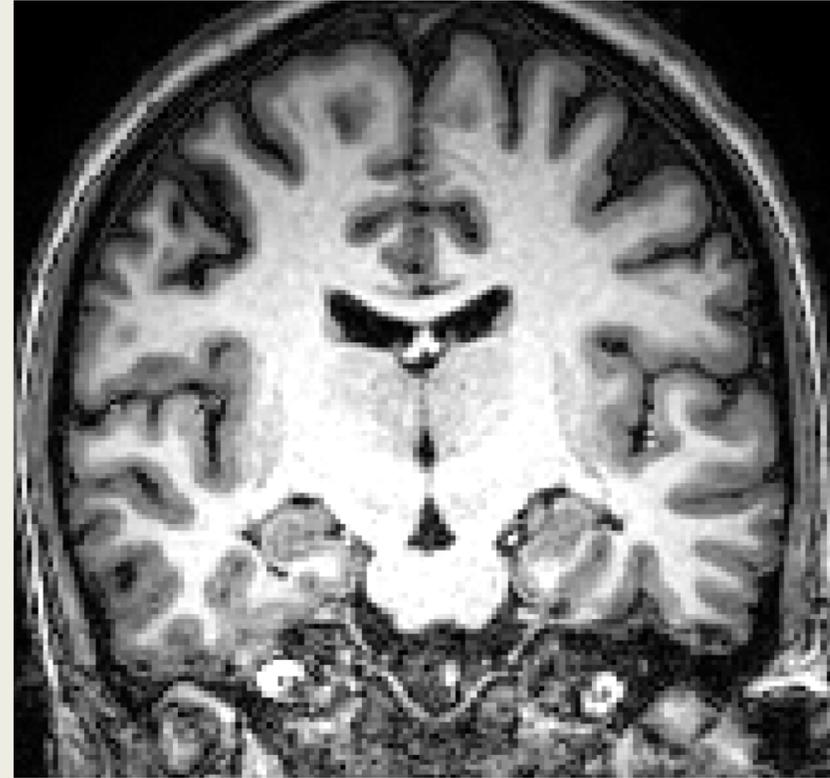


1. Identify assessment strategies for effective and timely recognition of eating disorders within primary care setting.
2. Describe intervention strategies to engage and support families across stages of eating disorder treatment.
 - *FBT informed*
3. Recognize need for team-based care for adolescent eating disorders.
 - *Community resources*
 - *FBT-HB*

What is wrong with the brain when someone has an ED?



29 year-old patient with anorexia



28 year old healthy control

Translation to Function

- Difficulties with executive functioning
 - *Academic, occupational*
- Cognitive integration
 - *lost in details, “not getting the big picture”*
- Impaired decision making
- Diminished social cognition
- Mood disturbance



152; *Psychiatr Res* 2004;127:259-2007;133:976-1006

Psychol Med 2007;37:1075-1084; *IJED* 2008;41:143-266; *Psychol Bul*

Malnourishment messes up the brain

“Starvation brain”

- When someone is ENERGY DEFICIENT, the body starts to go into hibernation to conserve energy (think: Bears in hibernation)
- Minnesota Starvation Study (1940s)
- After a few weeks of seriously reduced diet, the men in the experiment:
 - *Became obsessed with food; its all they thought or talked about*
 - *Often pored over cookery books, images and descriptions of foods*
 - *Became irritable, egocentric and depressed*
 - *Lost their sense of humor and isolated from others*

Science Lesson...

- Eating disorders are treatable
- Our knowledge that the brain is operating differently in eating disorder patients can help families respond with less frustration
 - *it can help to understand that this is not a set of choices or lack of motivation to change.*
- No one, including the patient, is at fault.
- Parents and families need to focus on helping the patient regain their health through normal eating, providing a warm and supportive family environment, and working with a clinical team with the most recent training and expertise.



DIAGNOSIS & ASSESSMENT

*CHANGING THE LANDSCAPE OF EATING DISORDERS MANAGEMENT BY
FACILITATING EARLIER INTERVENTION AND CARE*



A Diverse Array of Clinical Vignettes in Primary Care

- An 11-year-old boy with autism, weight loss, and picky eating
- A 12-year-old girl with body image concerns and questions about dieting
- A 15-year-old boy with obesity, binge episodes, and secretive eating
- A 17-year-old girl with female athlete triad
- A 22-year-old man with Type 1 diabetes, restrictive eating and insulin omission
- A 18-year-old college athlete with anorexia nervosa in remission
- A 20-year-old woman with severe chronic anorexia nervosa and malnutrition

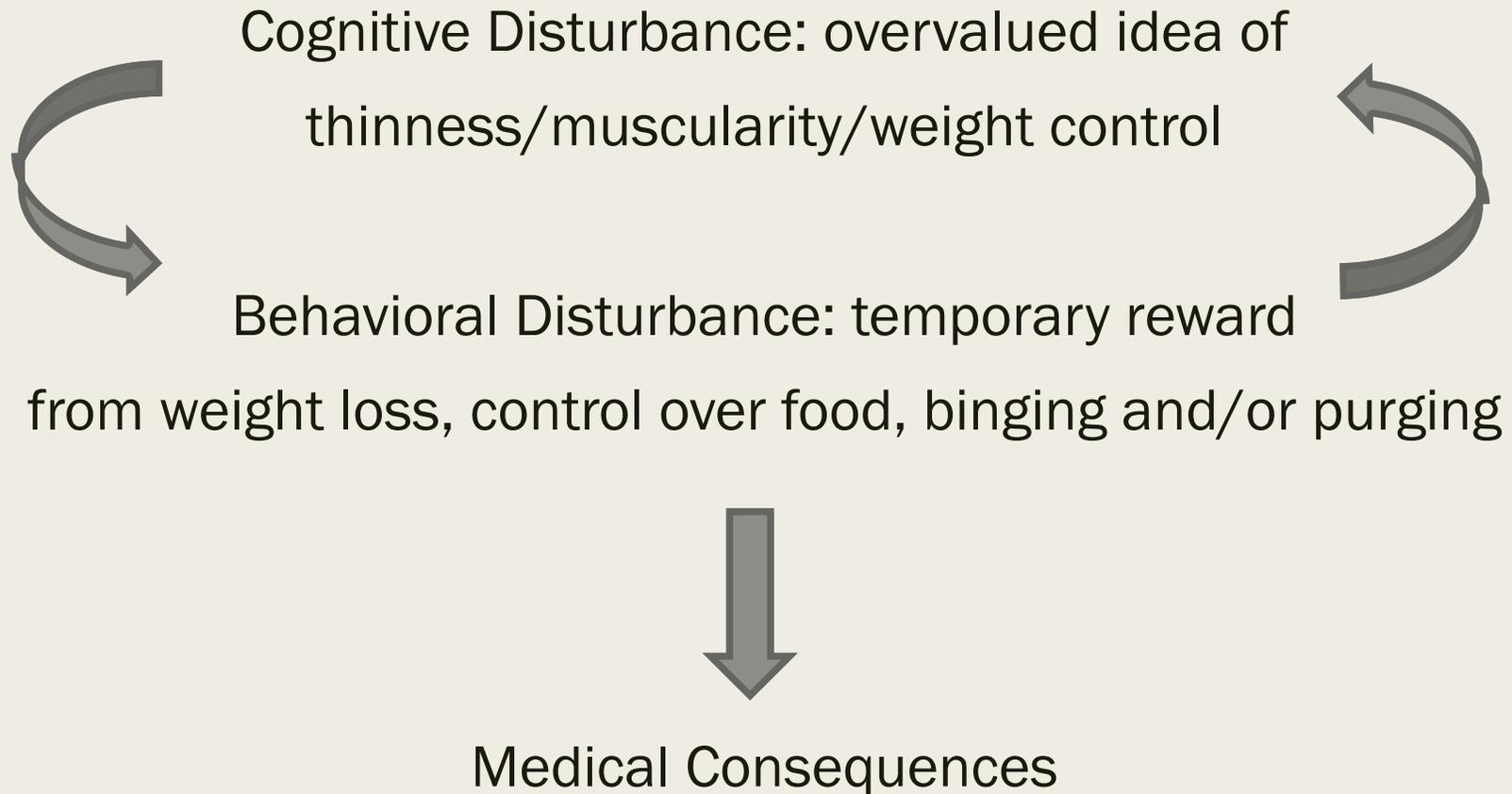
Eating Disorder Diagnosis: *Down the Rabbit Hole*

- AN
- BN
- ARFID
- BED
- OSFED

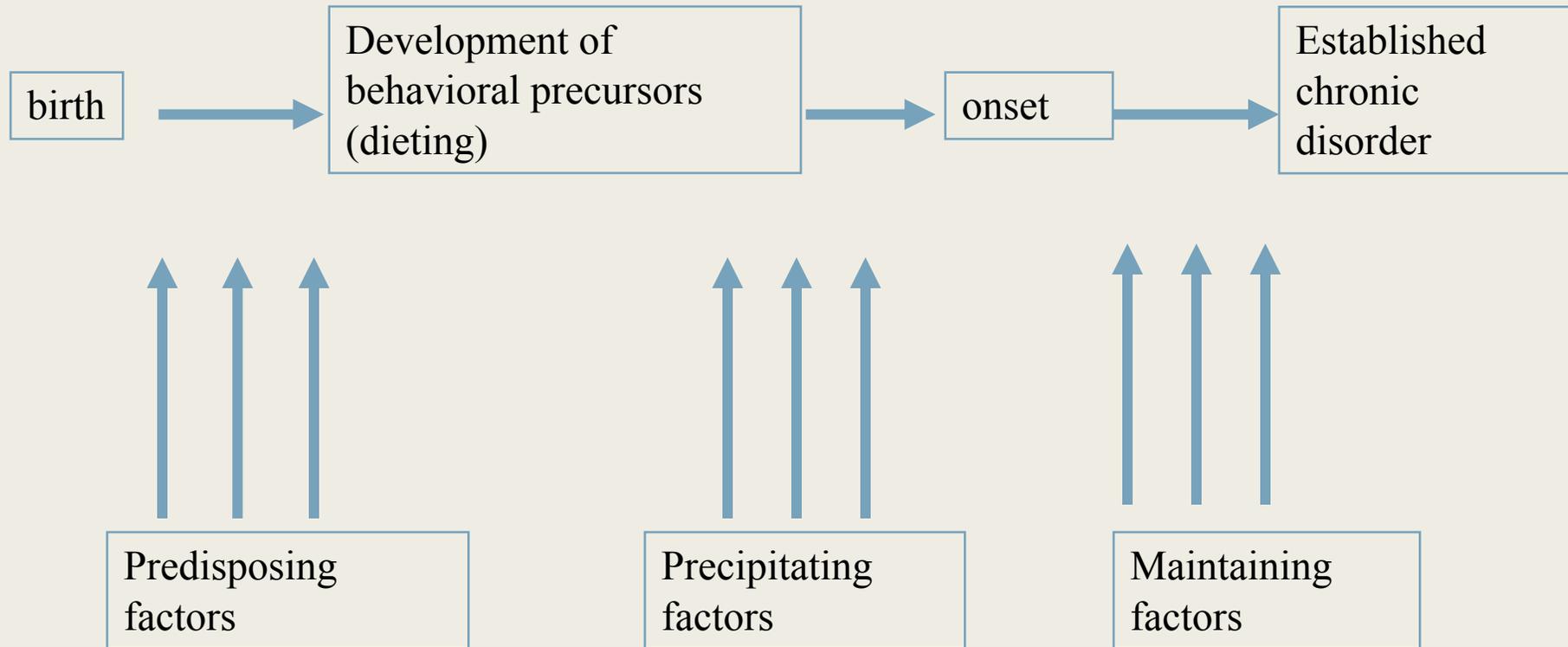
Although an eating disorder diagnosis may feel like a devastating blow to a patient and their family, it is an opportunity to begin a treatment process that can allow your patient to restore their mental and physical health and live a full, successful life

CENTRAL ANXIETY HAS TO DO WITH FOOD & EATING

Vicious Cycle



Development and Maintenance of Eating Disorders: *A perfect storm*



Focus on the “BIG B”

It is because of these **self-sustaining factors** that initial treatment must focus on stopping the eating disorder **BEHAVIOR** rather than exploring predisposing and precipitating factors

Your unique role

- Pediatric providers are uniquely situated for ED assessment
 - *Know the patient*
 - *Know the family*
- Medical providers can greatly impact ED prognosis through:
 - *Early identification*
 - *Care coordination when higher level of support is needed*
 - *Interdisciplinary collaboration*
 - *Close monitoring*
 - *Long-term follow up*



Assessing for an Eating Disorder:

Becoming a detective

- Consider including **feedback** from someone within the support system
- Identify **historical eating patterns**: does the individual have a history of picky eating, overeating, skipping certain meals
- Identify when concerns regarding eating began, with a step-by-step **review of changes in eating behaviors**, including change in types of food, amounts consumed and whether there is concern for skipping meals. Have they become a vegetarian, vegan, cut out grains or dairy? Are there foods that were previously enjoyed that they are no longer eating?

Assessment, continued

Becoming a detective

- Concise current meal plan (“food recall”):

“From the time you get up until the time you go to bed, what do you eat.”

- Be sure to ask if they are eating the same or different meals than those around them, portion sizes, how much of the meals they complete, if they are eating with the family, friends or in their room, etc
- Details about low fat, fat free foods, etc.
- Fluctuation in weight

Assessment, continued

Becoming a detective

- **Calorie counting**, measuring foods
- **Odd food rituals and rules** including temperature of foods, time of day allow self to eat, picking food into small pieces, taking long periods of time to complete, eating in certain order, foods touching
- Any evidence of **binge, purge**, vomiting, laxative, diet pills, diuretics (good opportunity for psycho education)
- **Exercise**: type, amount, aimed at wt loss. Include gym, organized sports, running, etc. What happens if they are injured? Rest days?

Assessment, continued

Becoming a detective

- Body image- comments about appearance/ wt of self and others, body checking
- Shape/size of peers
- Culture of food and dieting in the family and peer circle
- Excessive water/caffeine intake or gum chewing
- Access to online pro-ana/pro-mia websites, calorie counters, fitness apps; “influencers,” esp Tik Tok
- Mood changes/ irritability with food discussions
- Drop in grades/taking longer to complete work

Red flags



■ Developmental:

- *Puberty*
- *Crossing growth percentiles*
- *BMI <17.5 kg/ m²*

■ Medical:

- *Type 1 Diabetes*
- *Cystic Fibrosis*
- *Psychiatric disorders*
- *Syncope*
- *Functional GI disorders*
- *Unexplained electrolyte disturbance*
- *Bradycardia*

■ Familial:

- *First degree relative*

■ Sexuality:

- *Gay males*
- *Straight females*
- *Non-cis-gender individuals*

■ Lifestyle:

- *Activities: aesthetic, weight-based, high visibility*
- *Diet/exercise fads*
- *Transition out of high school/away from home*

Red Flags

- Vegetarian/ vegan
- History of anxiety
- Recent major life change/ transition
- History of high weight
- Growth with weight loss/ no gain
- Feeling dizzy
- Taking more interest in cooking/ types of food they are eating

There's a problem, so now what?

Calling it what it is

- Even if unsure, talk about the ED as a possible diagnosis.
- Be prepared that some families may have difficulty hearing this
- We NEED to be having these conversations
- “I’m concerned for these reasons...”
- “This is what multidisciplinary treatment can look like...”
- Talk next steps
- If things continue to worsen, refer to HEDC

There's a problem, so now what?

Initial treatment plans

- laboratory and other diagnostic and assessment steps
- dietary recommendations
- physical activity guidance
- home-based behavioral management strategies
- guidance regarding engagement with school, work, social media (Sindani, 2016) or other day-to-day activities.

There's a problem, so now what?

At a minimum



- Discuss the severity of malnutrition with patient and parent
 - *Focus on the **medical***
 - *Activity cessation until nutritional changes can be made to support exercise*
 - *First: stop weight loss*
 - *Second: some weight gain likely needed to support physiologic function*
- Referral to a dietitian, therapist
- Very close medical monitoring to ensure engagement with treatment plan

There's a problem, so now what?

Mobilizing for care

- Clear outline of medical concerns
 - *Recommendation to get higher level of care, if needed*
 - *Family wants to “try at home”*
- Very clear statement of imperative for nutritional change
 - *Recommendation for ED-informed RD*
- Care for underlying anxiety
 - *Therapy may not be effective until weight gain has occurred*
- Regular visits
 - *Consider blind weights*
 - *Vitals: HR, BP, and orthostatics*
- Activate support system—parents, school, others



Goals of Treatment

Short Term: *Nutrition First*

- Medical stabilization
- Weight restoration if underweight

Longer-term: *Insight Later*

- Establish/maintain normal eating behaviors
- Cognitive rehab/ REWIRING
- Return to normal developmental trajectory

Framing treatment



- Stigmatize the behavior, not the patient
- Counter demoralization & reduce blame
- Explore pro's/con's of behaviors in patient's life
- Build rapport and reinforce medical message
- Clear message about expectation for recovery
 - *Patient/family must be ready to engage in care to succeed*

Ramsay et al., 1999; McHugh 2000

Team Based Care: *It Takes a Village*

- Primary medical doctor
- Therapist and/or Psychiatrist
- Nutritionist (sometimes)
- Parents/ Caregivers
- Patient



The best outcomes for patients with eating disorders are associated with a collaborative approach by a interdisciplinary team.

As providers, we must talk to each other and to the families. A unified message is essential.

Various levels of care available for treating eating disorders

- Hospitalization
- Inpatient Eating Disorder Program
- Residential Eating Disorder Program
- Partial Hospitalization Program (PHP)
- Intensive Outpatient Program (IOP)
- Outpatient (should include medical, nutrition and psychological/psychiatric)



PARTNERING WITH CAREGIVERS:

*FAMILY BASED INTERVENTION STRATEGIES TO
ENGAGE AND SUPPORT FAMILIES*



Caregiver's Perspective

I don't know what to do

Anxious, overwhelmed, defeated

Am I to blame?

Is this a phase?

Just how do we get her to eat again when she won't let us?

What do I do when he disappears after a meal and I know he is going to throw it up?

I don't understand this illness; isn't the solution straightforward- you eat and that's that?

Adolescent with ED Perspective

I don't have an eating disorder

I don't need help

What's the big deal

I can take care of this myself

"I don't want to eat that. Its going to make me fat

Why are you punishing me? I hate you!

Support parents, set a plan, and guide the family

- WHAT TO DO:

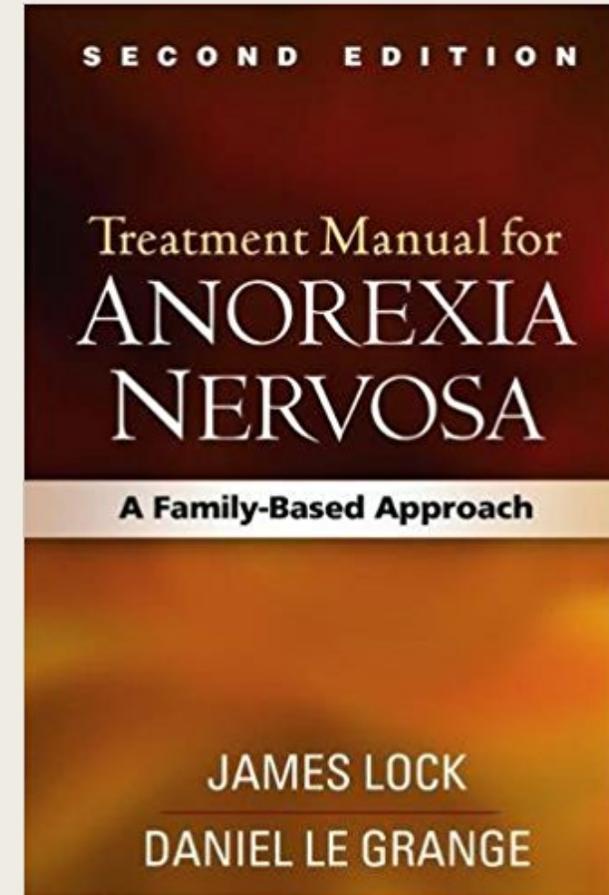
- Act Now
- Get Together
- Focus on How, not Why
- Stay Empowered- 1 step ahead/ take care of self

- HOW TO DO IT:

- Food is medicine
- One bite at a time
- Outsmart/ Outplay

Family Based Therapy

- Randomized controlled trials indicate 70-80% of adolescents with AN do well, when treated early, with weight restoration, normalization of eating-related thoughts and behaviors, and psychosocial functioning
 - *75 - 90% are fully weight recovered at five-year follow-up*



FBT should be first line intervention for adolescents with AN who are medically fit for outpatient treatment

Fundamental Tenets of Family- Based Therapy

- An agnostic view about the cause of AN
- Initial symptom focus (pragmatic)
- Non-authoritarian consultative stance as therapist
- An ability to separate disorder of AN from the adolescent (externalization)
- An emphasis on parental symptom management (empowerment)

CHANGING PARADIGM IN EATING DISORDER TREATMENT OF ADOLESCENT
EATING DISORDERS

Suitability & Context

- Children and adolescents who are *medically stable* with eating disorders
- Outpatient intervention designed to restore weight AND put adolescent “back on track”
- FBT is a team approach
- Brief hospitalizations to resolve medical concerns

Parents are
the experts
of the
family

+

WE are
experts on
the eating
disorder

=

HOW to
parent in
context of
an ED

Three Phases of FBT-AN

Phase I
(Sessions 1-10)

- Parents in charge of weight restoration

Phase II
(Sessions 11-16)

- Parents hand control over eating back to the adolescent

Phase III
(Sessions 17-20)

- Discuss adolescent developmental issues

Food as “medicine”

- FOCUS on behavioral change: the aim is to return food & meals to their normal place
- Food is medicine: as in other illnesses, it is sometimes necessary to take unpleasant medicine
- In order to recover, some med may have objectionable side effects or be difficult to take, but NEED TO do it.
- “MAGIC PLATE”
- Caloric density (snickers vs carrots)
- 3 x 3

REFEEDING IS NOT NORMAL
EATING OR NORMAL PARENTING

Hypothesized Mechanisms

- Exposure to forbidden foods and feared weight gains
- Restructuring of family authorities and coalitions
- Hormonal regulation as a function of weight restoration
- Training parents to identify warning signs and creating a long-term zero tolerance environment for symptom engagement

Parents are necessary

- Included: family is the best resource
- Empowered: parents challenge/ disrupt disordered eating behaviors
- Informed: parents given information about ED as part of therapy (physiological and psychological effects of starvation)
- Prepared: join with the therapist to persistently deal with the illness and figure out how to take it away
- Equipped: therapist guides, doesn't give specific solutions- parents figure out their own mutually agreeable solutions & rediscover their resources/ strengths

Family Goals for FBT

- Family goals
 - *Strengthen bonds between all members*
 - *Understand the disease affects all members*
 - *Reduce anger and guilt*
 - *Encourage all members to support each other*
 - *United front*



Goals for Co-Management of Patient with therapist

- UNITED FRONT AND CONSISTENT MESSAGES
- BEHAVIORAL goals first
- FBT therapists take the lead
- Collaborative weighing in therapeutic environment
- Behavioral experiments; “trial and error”

Rationale for Outpatient FBT Alternatives

- FBT is not accessible to many families
 - *Shortage of providers trained in FBT*
 - *Professional certification in FBT is cost prohibitive*
 - *Treatment is often costly and available only in private practice settings*
- Traditional outpatient treatment may not be feasible
 - *Transportation difficulties*
 - *Conflicting schedules*
 - *Other family commitments*

FBT has not been tested outside of outpatient specialty
settings

Home-based Treatment Models

- Home-based behavioral health treatment is available in 48 out of 50 states
 - *Population is often severely ill, lower income, of racial/ethnic minority status*
 - *Conceptualized as intermediate level of care*
 - *Most providers have limited experiences treating AN, and no experience with FBT*
- Home-based treatment has been applied to several mental health conditions
 - *Learning that occurs in therapy may be more generalizable in naturalistic settings*

Ongoing Partnerships



Gateway Healthcare
Lifespan. Delivering health with care.®



The Providence
CENTER

Healthy minds for healthy lives

- 1) Train and supervise community-based clinicians to deliver home-based FBT to assess feasibility of implementation in novel home environment
- 2) Collect effectiveness data on impact of home-based FBT on patients' weight and eating disorder symptoms

What's Working

- Reduces barriers for families
- Clinicians attend appointments
- Collaborative problem-solving with dietitians
- Emphasis on the family, in the home



Challenges with Implementation

- General barriers to implementing a new approach within existing systems
- Resistance to delivering FBT interventions (e.g., weighing clients)
- Measuring fidelity
- Engaging families many of whom had significant/warranted distrust of state funded healthcare agencies

Future Studies

- R34 to support RCT of FBT-HB vs. Integrative Family Treatment (IFT)
- Training outpatient private practice clinicians in RI to deliver FBT to ensure evidence-based care across all service levels
- Preparing grant to develop email- and text message-based intervention to improve knowledge, competence and attitudes in primary care



Take Home Lessons

- Pediatric providers are uniquely situated for ED assessment
 - *YOU Know the patient and YOU Know the family*
- No one is to blame for an eating disorder
- The eating disorder is separate from your patient (even though it doesn't often seem like it)
- Parents are your best tool in re-feeding
- Treatment team (including family) need to GET TOGETHER/ united front
- Use meal support AND require FOOD IS MEDICINE
- FBT is the most well-established psychological treatment for adolescents with eating disorders
 - *FBT has not been tested outside of outpatient specialty settings*
- Projects aim to implement FBT in community settings and disseminate intervention to multidisciplinary providers
 - *Each family enrolled has presented learning opportunities and challenges*
 - *This is a FEASIBLE and ACCEPTABLE mode of treatment!*

Community resources

- GRANT FUNDED INITIATIVES TO DISSEMINATE EBT FOR EDs in RI
- Lifespan/ Gateway: FBT EOS team
 - *>16 weeks of FBT 2x/week*
 - *DBT 1 session/ week*
- Project HOME
 - *The Providence Center Child & Adolescent Outpatient and EOS teams*
 - *FBT and CBT-E trained*
- Kohl's Cares
 - *Parent ED "Bootcamps;" Parent Support/ Skills Groups*
 - *Clinical supervision in FBT and CBTe to community therapists*

ED Treatment Resources



- **Recommended books for medical providers:** Mehler and Andersen, “Eating Disorders: a Guide to Medical Care and Complications” (2010); Jennifer Gaudiani, “Sick Enough” (2019)
- **Recommended books for providers/care-givers:** Life Without Ed; Brave Girl Eating; Help Your Teenager Beat and Eating Disorder; Sick Enough; How to Nourish Your Child Through an Eating Disorder; Anorexia and other eating disorders: How to help your child eat well and be well
- National Eating Disorder Association (NEDA): <https://www.nationaleatingdisorders.org/>
- Academy for Eating Disorders: <https://www.aedweb.org/>
- Families Empowered and Supporting Treatment of Eating Disorders: <https://www.feast-ed.org>
- **Meal coaching video posted on youtube:** “Eating Disorders Meal Support: Helpful Approaches for Families”
- International Association of Eating Disorder Providers, RI Chapter

Community resources

- laedp (International Association of Eating Disorder Professionals)
 - *RI Chapter hosts 2-3 professional development events / year*
- RI Eating Disorder Collaborative
 - *Monthly Brown Bags on clinical and research topics related to EDs*

Parent Toolkit

- AED's Nine Truths
- F.E.A.S.T. Family Guides
 - *"First 30 Days"*
- Rebecca Peebles Video
- How to Help Your Teen Beat an ED book
- Brave Girl Eating & Feeding Your Anorexic books
- Eva Musby book & website