Collaborative Caring: The Role of Friends and Family in the Recovery of Eating Disorders

Jennifer Moran, Psy.D.
Introductions
Eating Disorders and Substance Abuse

- As many as 50% of people who present with an eating disorder may also struggle with substance abuse
- 35% of people who are in treatment for substance abuse may also have eating problems
- People who binge and purge have higher rates of substance abuse than those who only restrict

(CASA at Columbia University, 2003)
Eating Disorders and Substance Abuse

- Alcohol
  - Used to manage moods
- Stimulants
- Caffeine
  - Used to suppress appetite
- Nicotine
  - Used as a weight loss tool
- Laxatives
- Marijuana
- Diet pills
- Heroin
Eating Disorder Treatment History

- Dr. Louis-Victor Marce (1860) in regards to Anorexia Nervosa:

“This hypochondriacal delirium, then, cannot be advantageously encountered so long as the subjects remain in the midst of their own family and their habitual circle....it is therefore indispensable to...entrust the patients to the care of strangers.”

Charles Laseague (1873)

“The patients should be fed at regular intervals and surrounded by persons who would have moral control over them; relations and friends being generally the worst attendants.”
John A. Ryle, MD. (1936)

- “The first essential, after diagnosis, is to explain to the patient and the parents separately the nature of the disease in the simplest and most direct terms.”

- “Visitors and particularly near relatives who are likely to cause tears or other emotional reactions should be disallowed or strictly “rationed” at first.”
Hilda Bruch (1962)

- Self-starvation is symbolic of a struggle for control, autonomy and self-respect
- Struggle results from mother not recognizing child’s expression of independent needs
- Therapy should focus on challenging erroneous assumptions and attitudes
1980’s-2000’s

- Cognitive Behavioral Therapy (individual)
- Nutritional counseling
- Psychiatric follow-up
- Medical Stabilization
- Family Therapy as needed (Minuchin developed structural interventions for family in 1970’s addressing boundaries, conflict resolution)
1990’s-present

- “Maudsley” method developed at Maudsley Hospital in 1980’s; made popular by Dare, Lock, Le Grange and Agras
- Parents are empowered to re-feed their adolescent; seen as a resource
- Therapist takes agnostic stance
- Family therapy is the central form of treatment for adolescent with anorexia nervosa
Fundamentals of Family Based Treatment

- Phase one: Refeeding the patient

- Goals:
  1. Obtain history of how AN affects the family
  2. Obtain information about family functioning
  3. Family meal (practice refeeding with therapist support)
  4. Help parents take charge of patient’s eating
  5. Mobilize siblings for support
Phase Two

- Maintain parental control until patient shows ability to eat consistently and to gain weight independently
- Return food and weight control to adolescent
- Explore adolescent developmental issues and how it relates to eating disorder
Phase Three

- Review adolescent issues with family to model problem-solving
- Establish that the adolescent-parent relationship no longer needs symptoms as a form of communication
- Termination
Collaborative Caring

“The New Maudsley Method”
Janet Treasure et al.
Lingo

- **Caregiver/carer**: any support person that is in frequent contact with the person who has been diagnosed with an eating disorder (ex: significant other, parents, grandparent, siblings, friends, etc.)

- **Loved One**: the person who has been diagnosed with an eating disorder
Typical Caregiver Experiences

- Frustration
- Anger
- Helplessness
- Shame
- Sadness
- Isolation
Caregiver Needs

- Education
- Support
- Connection to other caregivers
- Skills
- Referrals
- Help finding resources
- Bibliotherapy recommendations
Caregiver Stressors

- Meals with their loved one
- Stigma of an eating disorder....did they cause it? Are they enabling it?
- Cost of treatment
- Unmet needs of caregiver
- Strain on relationship with loved one
- Fear of causing or worsening the disorder
Obstacles...

• Getting them into treatment

• Lack of resources (transportation, insurance, support)

• Confidentiality limits
National Institute for Health and Clinical Excellence (NICE) used literature review to determine best practices

Grade A recommendations: most reliable based on synthesis of all studies
NICE: Anorexia Nervosa

Limitations in studying Anorexia Nervosa

- Dangerous to test some interventions
- Diversity of cases makes it hard to fully assess
- Not all interventions are tailored to AN

No Grade A recommendations made

Grade B: family interventions should be offered to children and adolescents with Anorexia Nervosa
NICE: Bulimia Nervosa

- Grade A: CBT focused on the eating disorder

- Family involvement with adolescents
NICE: Carers

- Entitled to annual assessment of carer’s needs
- Entitled to access information about the health of the person they are caring for
- Try to incorporate families into the treatment process
How?

- Early dialogues between loved one and therapist about importance of caregiver inclusion

- Some information does not need patient consent:
  - Providing caregiver with general information about dx
  - Providing caregiver with a needs assessment
  - Providing caregiver with access to caregiver workshop/support groups
When can caregiver be involved without consent?*

- High risk of harm to self or others
- Patient does not have capacity to choose LOC
- Involvement of the family is the least restrictive option
- Evidence that family communication is good when patient is not ill
- No history of independent living

*things to consider, not necessarily justified
Collaborative Care Workshops

- Ours meet for 90 minutes per week for six weeks
- Could be done as a full-day workshop and cover material all at once
- More didactic than therapeutic in nature... could be led by anyone who is familiar with eating disorders
Benefits

- Collaborative Care Workshop
  - Provides a meaningful relationship with an expert
- Learn specific skills and strategies to use on their own
- May improve relapse rates

- Family/Friends Support Group/Al-Anon
  - Connection with other supporters
  - Does not require patient consent
  - Helps to validate supporter stress
What should be covered?

- Week One: Eating Disorder Basics
- Week Two: Caregiver Self-Care
- Week Three: Communication and Caregiver Style
- Week Four: Stages of Change and Motivational Interviewing
- Week Five: Emotional Regulation and Mindfulness
- Week Six: Cognitive Behavioral Therapy Basics
Eating Disorder Basics

- Review of diagnoses
- Eating Disorders are ego-syntonic
- Eating Disorders can result in serious medical consequences; early intervention is crucial (within first three years of onset ideal)
- May require an average of 5 years of treatment
- Multi-disciplinary approach is best
Spectrum of Eating Disorders
Anorexia Nervosa

- Restriction of energy intake relative to requirements, leading to significantly low body weight in context of age, sex and developmental trajectory

- Intense fear of gaining weight or becoming fat, even though underweight

- Disturbance in experience of weight or shape, undue importance of weight or shape, or denial of seriousness of problem
Subtypes of AN

In past 3 months:

• **Restricting Type:**
  - person does not engage in binge eating or purge behavior

• **Binge Eating/Purging Type:**
  - person regularly engages in binge eating or purging (self-induced vomiting or misuse of laxatives, diuretics, or enemas)
Anorexia Nervosa

- Specify:
  - In partial remission
  - In full remission

Mild: BMI >17
Moderate: BMI 16-16.99
Severe: BMI 15-15.99
Extreme: BMI<15
Bulimia Nervosa

- Recurrent episodes of binge eating
  - Eating a large amount of food given the context
  - An associated sense of loss of control

- Recurrent inappropriate compensatory behavior
  - E.g., purging, fasting, excessive exercise
  - Diuretics and laxatives
BN cont’d

- Binge eating and compensatory behavior occur at least once per week for 3 months

- Self-evaluation is unduly influenced by body shape and weight

- Disturbance does not occur exclusively during episodes of anorexia nervosa
Bulimia Nervosa

• Specify:
  – In partial remission
  – In full remission

Mild: 1-3 purge episodes/week
Moderate: 4-7 purge episodes/week
Severe: 8-13 purge episodes/week
Extreme: 14 or more purge episodes/week
Binge Eating Disorder

- Recurrent episodes of binge eating
- Episodes are associated with 3 or more of the following:
  - Eating more rapidly than normal
  - Eating until uncomfortably full
  - Eating large amounts when not hungry
  - Eating alone because of embarrassment about how much one is eating
  - Feeling disgusted with self, depressed, or guilty after overeating
• Marked distress regarding binge eating

• Binge eating occurs at least one days a week for 3 months

• Binge eating is not associated with regular inappropriate compensatory behavior, and does not occur exclusively in course of AN or BN
Binge Eating Disorder

- Specify
  - In partial remission
  - In full remission

Mild: 1-3 binges/week
Moderate: 4-7 binges/week
Severe: 8-13/week
Extreme: 14 or more/week
What happened to ED, NOS?

- Eating Disorder, Not Otherwise Specified
- Used to be most common eating disorder
- New criteria in DSM-5 hopes to move people in this category to more appropriate diagnostic category
Other Specified Feeding or Eating Disorder

- Symptoms cause significant distress in social, occupational or other important areas
- Does not meet full criteria for other eating disorders
- Clinician records qualifier explaining the specific reason
- EX: Other specified eating disorder, bulimia nervosa of low frequency)
Unspecified Feeding or Eating Disorder

- Clear impairment in major areas (social, occupational, etc.)
- Does not meet full criteria for another eating disorder
- Clinician unable to provide specific reason, possibly because not enough information to make a clear diagnosis
Malnutrition and the Brain

• Brain needs 500 kcal day

• Starvation impairs brain functions, especially cortical regulation

• Decreases in neuroplasticity (new learning); executive function (rumination, attention stuck); emotional regulation (avoidance, excess); social cognition (isolation); and global connection (fragmented; overly detailed)

**Janet Treasure (2011)**
How does this impact care?

• Difficulty in breaking habits, seeing the bigger picture, regulating emotions, understanding others, regulating appetite, etc.

• Until nutrition improves, brain function remains impaired.
Interruption of Brain Maturation

- Mature brain functioning is put on hold.

- Caregivers need to provide support.

- It takes time after weight restoration for maturational changes to re-start.
What makes E.D. unique?

- Typically high-achieving with stellar grades
- Person may still be very involved in community
- Everything appears to be fine except medical condition
- Ego-syntonic: connected with disorder; lack of insight; poor motivation
Externalizing: Who is this “Ed”?
Externalizing

- Venn diagram
- Life Without Ed by Jenni Schaefer and Thom Rutledge
- Anger should be directed at the eating disorder and not the loved one
- Conflict with the eating disorder is not the same as conflict with the loved one
- Family, especially siblings, can help the loved one feel normal and do normal things
- Review treatment goals and expectations
- Review empirically validated treatment options
- Provide referrals to appropriate resources
- Recommend books that they may benefit from
Levels of Care

- Inpatient
- Partial Hospitalization
- Intensive Outpatient
- Outpatient
- Residential Treatment
Inpatient Treatment

- Primarily used for immediate symptom reduction and monitoring
- BMI is less than 17 (automatic)
- Unremitting restricting, exercise compulsion, purging behaviors despite outpatient efforts (SIV 3-4x/day or more; diet pill use; laxative abuse; very restrictive eating; exercising more than 2 hours/day; limited variety of foods)
- Medical Concerns (irregular heart rate; blood in vomit; GI problems; fainting/dizziness; seizures)
- Lack of motivation or unwillingness to decrease symptoms despite severity
Entrance
Dining Area
Nursing Station/Day Area
Partial Hospitalization Program

- 12 hour Day program that includes 3 monitored meals
- Usually a “step-down” from inpatient
- Can be used as an initial level of care for people who are restricting and need to gain weight but are not engaging in compensatory behaviors
- Appropriate for people who are restricting, purging, exercising and need symptom reduction and are not negatively impacted by 12 hour period at night
**Intensive Outpatient Treatment**

- 4 hour program 4 days/week
- One monitored meal in evening
- Useful for those needing to regulate their eating schedule and need moderate level of structure and monitoring by a nutritionist
- Can be useful for someone purging or exercising and needs more than outpatient and is also motivated to improve symptoms
- Used most often as step-down from inpatient/PHP
- Can be useful for “review” for someone at beginning of relapse who has been through treatment before
Outpatient

- Purging is less than 3x/day and shows signs of improving
- Patient is willing to incorporate challenging foods into diet
- Binges are 2-3x/week or less
- Underweight patient is gaining 1 lb/week at a minimum
Residential

- Usually for people who have been in/out of hospitals with minimal success
- Some difficulty with insurance, but can get scholarships at different places
- May be 2-3 month stay
Other considerations

- Medical Leave of Absence (College students)

- Legal Guardianship (to take control of patient’s treatment in extreme situations)

- Spiritual counseling
Week Two: Caregiver Self-Care
Self-Care

- Take a stress level assessment
- Discuss sacrifices made for the loved one
- Participants share frustrations and concerns
- Positive coping strategies and stress management techniques are reviewed
- Discuss importance of creating boundaries and preserving self
Supports for Caregivers

• Family support group
• General support group
• Bibliotherapy
• Caregiver Intensive Workshop
• Therapy: individual/family
Week Three: Communication and Caregiver Styles
Caregiver Styles

• Developed by Janet Treasure et. al.
  – Kangaroo
  – Rhinoceros
  – Ostrich
  – Jellyfish
  – Dolphin
  – St. Bernard
Kangaroo: Too much emotion, too much control
Rhinoceros: too much logic, too little emotion
Ostrich: Too little emotion, too little control
Jellyfish: too much emotion, too little control
Caregiving Ideal
Communication

- Non-Verbal Communication
- Verbal Communication
- Role Plays
Week Four: Stages of Change and Motivational Interviewing
Stages of Change

- Pre-Contemplation
- Contemplation
- Preparation
- Action
- Maintenance
- Recycling/Relapse
Motivational Interviewing

- To change, it must feel IMPORTANT to the person, and they must feel CAPABLE of making the change.

- We want them to verbalize how their current behavior is not consistent with their life goals and values.
Readiness Ruler (Janet Treasure)

How motivated are you? Why this number and not one above/below? How would your friends rate you? Why?

1---2---3---4---5---6---7---8---9---10
Week Five: Emotional Regulation

- Labeling emotions
- How to properly cope with emotions
- Mindfulness skills
- How to role model effective emotional regulation
- How to encourage loved one to share their feelings
Week Six: Cognitive Behavioral Therapy

- Review philosophy of CBT
- Review cognitive distortions
- Practice using thought logs
- Role play helping their loved one challenge an obviously e.d. type of thought/behavior
- Simple behavior modification awareness
Results

• Caregivers feel more empowered

• Caregivers have decreased anxiety and stress

• Loved ones have increased support and may have lower rates of relapse

• Caregivers serve as allies to the treatment team
What if....

• The carer has an eating disorder?

• A: Encourage carer therapy. Encourage boundaries. Encourage family therapy.
What if...

• The carer is tired of the patient?

• A: Help externalize, externalize, externalize. Help carer focus on the PERSON and not the eating disorder.
What if....

• Their loved one just won’t go to treatment?

A: A person does have the right to refuse treatment. Continue to observe, leave the door open, offer support, etc. In extreme circumstances can consider guardianship.
Questions?
Bibliography


Jennifer Moran, Psy.D.
jmoran@sheppardpratt.org