Child & Youth
Mental Health Series

Today's topic:

Just Caring: managing resistance to treatment in adolescent eating disorders

Speaker:

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Date: February 18 2016

CHEO The Le Royal

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Declaration of conflict

Speaker has nothing to disclose with regard to commercial support.

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OBJECTIVES

- To review an approach to assessing, soothing, and managing an agitated patient suffering from an eating disorder.
- To discuss the theory and process of decision making around issues of involuntary admission and compulsory treatment of eating disorders.

A TYPICAL CASE…

- Kelly, a 16-year-old honor student who has AN, comes for a follow-up visit.
- She looks worse than her previous visit to the doctor. She has lost weight and is cold, her hands show acrocyanosis, her breath is ketotic, and her pulse is weak. Her orthostatic vitals are unstable.
- Her parents are in tears and tell how she is hardly eating and constantly complaining that her stomach hurts.
- The physician completes her assessment and explains to Kelly that she is in danger and hospitalization is required. She discusses the reason Kelly is in pain is because she has developed delayed stomach emptying and impaired intestinal motility, which are treatable.
- Kelly listens with increasing despair and interrupts the physician screaming, "You cannot do this to me, I can't miss school . . . besides this is *my* body! I do not want to go to the hospital and you cannot make me!"

WHY DO PATIENTS WITH EATING DISORDERS RESIST TREATMENT?

- Patients with EDs have a strong sense of self-determination which they are reluctant to abandon.
- They feel humiliated at not being able to address their own difficulties.
- As with so many other patients with mental illness, they fear stigmatization.
- They are adversely influenced by the often less than optimistic view regarding the long-term outcome of the disorder.
- Their strong sense of self-determination which is characterized by their asceticism and rigid inflexibility.

WHY DO PATIENTS WITH EATING DISORDERS RESIST TREATMENT?

- Patients with EDs often have a mistrust of interpersonal relationships.
- They are extremely apprehensive about a perceived loss of control.
- Patients with EDs constantly strive to overcome a pervasive feeling of ineffectiveness.
- They are strongly perfectionistic.
- Patients with EDs have been characterized as having distortions in their thinking which have an adverse impact on their conceptual, perceptual and decision-making abilities.
- Patients with AN often report a mood disturbance that may be exacerbated by the physiological and metabolic disturbances that accompany starvation and malnutrition.

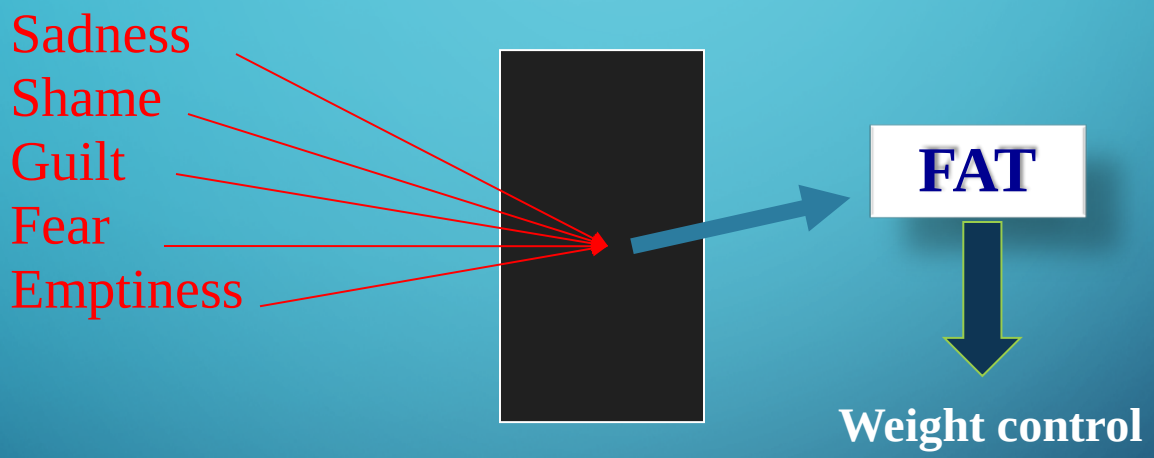
Goldner, E. (1989). Treatment of refusal in anorexia nervosa. *International Journal of Eating Disorders* 8, 297-306.

WHAT IS HAPPENING FOR KELLY IN THIS MOMENT?

EATING DISORDERS ARE MULTIFACETED

- Meaning and Purpose
- Effects of Malnutrition
- Comorbidity

The Power of an Eating Disorder:



Powerless → **Powerful**

Patients need their Eating Disorders

WITHOUT THEIR EATING DISORDER SYMPTOMS PATIENTS FEEL…

- Worried and stressed
- Hopeless and worthless
- Emotions are "out of control"
- Have no identity
- **"Not good enough"**

EFFECTS OF MALNUTRITION

- Ancel Keys Study (1944-45)
- 36 "normal men" with "superior psychobiological stamina"
- 24 weeks of "semi-starvation" followed by 12 weeks of restricted diet → lost ~25% body weight

Keys, A, et al *The Biology of Human Starvation*, University of Minnesota Press, 1950

EFFECTS OF MALNUTRITION

- Cognitive Changes:
  - Impaired concentration
  - Impaired comprehension and judgment
- Emotional Changes:
  - Depression
  - Irritability
  - Anger outbursts
  - Extreme mood swings
  - High levels of anxiety

EFFECTS OF COMORBIDITY

ANOREXIA NERVOSA

- >50% depression
- 50% anxiety disorders (GAD, Social Anxiety or OCD)
- Perfectionism
- 'Cluster C' traits (rigidity, restraint, obsessiveness)

BULIMIA NERVOSA

- >50% depression
- >50% anxiety disorders (GAD, Social Anxiety, PTSD)
- Substance abuse
- 'Cluster B' traits
- Bipolar spectrum disorders

WHAT IS HAPPENING FOR KELLY IN THIS MOMENT?

Threat to eating disorder symptoms

+

effects of starvation

+

effects of comorbidities

=

OVERWHELMED/FRIGHTENED/ANGRY/PANICKED

WHAT CAN HELP?

- Allow her to express herself
- Validate her feelings
- Respond firmly but with kindness/compassion
- Express that you care about her and her wellbeing, that your actions/decisions are coming from a place of caring
- Gently explain the reasons/process/protocols of admission
- Take time to answer questions fully/honestly

Silber, T (2011). Treatment of Anorexia Nervosa against the Patient's Will: Ethical Considerations. Adolesc Med 022; 283–288

THERAPEUTIC MILIEU

- Patients are full of shame, guilt, and self-criticism → assume that others see them in critical and negative light → **need persistent and compassionate positive regard to counteract their self-perception**
- Patients are entwined with their disorder → feel that anger/frustration towards the disorder is anger/frustration directed at them → **need to continuously externalize the disorder**

PHARMACOTHERAPY

- No consensus/best evidence
- Consider risks related to malnutrition (bradycardia, orthostasis, low weight, etc)
- SSRIs (for comorbidities) do not work in the malnourished patient
- Most widely used for anxiety and agitation– atypical antipsychotics (olanzapine) and low dose benzodiazepines (30 min pre-meals)

Couturier, J & Spettigue, W. 2011. Pharmacotherapy for Eating Disorders in Children and Adolescents. In *Eating Disorders in Children and Adolescents*. New York: Guilford Press, pp 402-418

A TYPICAL CASE…

- Kelly is admitted to hospital on the pediatric unit.
- RD recommends non-select menu to minimize the anxiety and guilt Kelly would feel having to consume foods that she has chosen.
- Initially Kelly is able to comply with bed rest and complete all of her nutrition orally.
- On Day 5 of her admission she starts pacing in her room shortly after she completes dinner. Nursing staff and her parents are not successful in redirecting her to bed rest despite her unstable vitals.
- Pediatrician is called for further direction and support, when she comes to talk with Kelly, she screams at the doctor and demands to be discharged.

A TYPICAL CASE…

- The pediatrician talks with Kelly, but is unable to help shift her to agreeing to remain in hospital.
- As the pediatrician attempts to explain the risks to Kelly's health, she screams "I don't care if I die, I would rather be dead than fat". She starts removing the leads for her cardiac monitor and packing her belongings.
- Psychiatry is called to assess whether Kelly should be placed on a Form 3.

REASONS FOR INVOLUNTARY ADMISSION

- Medical instability
- Failure of outpatient treatment resulting in the individual being at risk for death or acute deterioration possibly resulting in death
- Active suicidal ideation and/or plan
- Co-morbid psychiatric illness warranting involuntary treatment independent of the eating disorder

Adapted from Yager, J et al (2006). Practice Guildline for the Treatment of Patients with Eating Disoders. In APA Practice Guidelines, Third Ed.

MEDICAL INSTABILITY

- <75% HBW
- <10% body fat
- Heart rate < 50 beats per min daytime; <45 beats per min nighttime
- Esophageal tears/Hematemesis
- Hypothermia
- Hematemesis
- Arrhythmia
- Syncope
- Systolic pressure < 90 mm Hg
- Orthostatic changes in pulse (>20 beats per min) or blood pressure (>10 mm Hg)
- Temperature < 35.5C
- Serum potassium concentration < 3.2 mmol/L
- Serum chloride concentration < 88 mmol/L

Rosen, D (2010). Identification and Management of Eating Disorders in Children and Adolescents. *Pediatrics*, Volume 126, Number 6; 1240-1253.

MORTALITY IN EATING DISORDERS

Three recent studies:

	AN	BN	EDNOS
Scott et al 2009 (crude mortality rates)	4.0%	3.9%	5.2%
Arcelus et al 2011 (standardized mortality ratio)	5.86	1.93	1.92
Franko et al 2013 (standardized mortality ratio)	4.37	2.33	

Scott J et al. (2009). Increased Mortality in Bulimia Nervosa and other Eating Disorders. Am J Psychiatry, 166:1342-1346

Arcelus J et al. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. Arch of Gen Psychiatry, Jul;68(7):724-31.

Franko D et al (2013). Do Mortality Rates in Eating Disorders Change over Time? A Longitudinal Look at Anorexia Nervosa and Bulimia Nervosa. Am J of Psychiatry 170(8): 917-925.

WHO IS AT THE HIGHEST RISK OF DEATH?

- **Comorbid Alcohol Abuse****
- Low BMI at admission
- Longer duration of illness
- Older age
- Diuretic use
- Poor social adjustment/supports
- Multiple psychiatric and somatic comorbidities

**most frequently reproduced finding

THE UTILITARIAN PERSPECTIVE:

- DOES IT WORK?

- WHAT ARE THE LONG-TERM OUTCOMES?

DOES IT WORK?

- 8 studies of outcome for involuntary treatment

	Group + N	BMI admit	BMI D/C	LOS
Griffiths et al 1997 (AUS)	IT= 15 VT = 73	13.4 14.3	18.1 17.2	14.9 (10.9)* 8.8 (6.0)
Serfaty et al 1998 (UK)	IT = 7 V = 4	11.8 12.0	17.7 16.6	NA
Ramsay et al 1999 (UK)	IT = 81 VT = 81	14.2 14.3	18.7 18.5	16.1 (12.9)* 12.6 (7.6)
Watson et al 2000 (USA)	IT = 66 VT = 331	17.4 18.4	20.5 20.7	8.2 (6.6)* 5.8 (5.1)
Kondo et al 2004 (Japan)	IT = 8 VT = 62	15.3 14.6	NA	30.1 10.0
Laakmann et al 2006 (GER)	IT = 11 VT = 5	11.8 12.1	16.6 18.8	28.1 14.0
Carney et al 2008 (AUS)	IT = 23 VT = 47	13.2 14.0	14.9 15.4	7.4 6.7
Ayton et al 2009 (UK)	IT = 16 VT = 34	16.6 14.2	19.6 18.5	60* 34.6

WHAT ARE THE LONG-TERM OUTCOMES?

- Long term outcomes:
  - All 5 study authors noted that there was no worsening of therapeutic relationship for those admitted involuntarily
  - Ramsay 1999 – 5 yr F/U data on mortality (detained group 12.7%, voluntary group 2.9%)
  - Ayton 2009 – 1 yr F/U data:
    - Mortality - 2/34 voluntary, 0/16 involuntary
    - More likely to have resumed their menstrual cycle
    - Fewer readmissions
    - Better overall functioning

A TYPICAL CASE…

- Given that Kelly's vitals remain unstable and she was expressing feelings of hopelessness, the psychiatrist decides to place her on a Form 3.
- Kelly settles once the option of discharge is taken out of her hands because she no longer has to feel the guilt for having chosen to come into hospital, and being placed on a Form 3 has sent her a strong message about the severity of her illness.
- She resumes consuming all of her nutrition, but struggles with feared foods and chooses to take Ensure to replace a portion of most meals.

A TYPICAL CASE

- On Day 6 of admission Kelly is again becoming more agitated. She ate only a small portion of her lunch meal, and is now refusing the large cup of Ensure that has been given to her for replacement.
- Kelly's vitals have stabilized, and she is off the cardiac monitor.
- In conjunction with parents, the team decide to place Kelly on bedrest until she is able to complete her replacement and resume taking all of her nutrition.

A TYPICAL CASE…

- Kelly was able to take some of the lunch time Ensure and her PM snack by supper time. However, she has struggled all afternoon, and now refuses dinner or any more Ensure.
- The pediatrician is called to assess whether to insert an NGT.
- She talks with Kelly and her parents about this option. Parents agree that it is necessary, but Kelly refuses stating "I have gained so much weight already, you made me fat, I am not putting any more calories into my body!"

A TYPICAL CASE…

- The pediatrician calls the psychiatrist to discuss whether Kelly is competent to make this decision and whether an NGT should be placed against Kelly's will.

CAN ANYTHING BE DONE TO REDUCE THE RISK OF NEED FOR NGT FEEDING?

CAN ANYTHING BE DONE TO REDUCE THE RISK OF NEED FOR NGT?

- Meal Support:
  - Staff/family member sits with the patient throughout the meal or snack.
  - Provide empathy and understanding of the patient's struggle.
  - Encourage the consumption of food and set firm expectations about what must be eaten in a set period of time.
  - Provide distraction by talking about other issues, or by playing interactive games.
  - Discussion of calories, dieting, comments about food, and focus on eating disordered thoughts is discouraged.

DOES MEAL SUPPORT HELP?

- Couturier & Mahmood (2009):
  - Retrospective chart review of 21 adol inpts with AN
  - One yr prior and one yr after implementation of meal support
  - Rate of NGT use significantly decreased (67% vs 11%) with use of meal support

WHAT HAPPENS WHEN THEY REFUSE?

- Two questions:
  - Is the patient competent to make decisions related to medical treatment including NGT feeding?
  - If not competent, should they be fed against their will?

COMPETENCE TO MAKE TREATMENT DECISIONS

- Criteria for Informed Consent:
  - UNDERSTANDS the info provided re dx, tx options, risk/benefit
  - Engages in RATIONAL REASONING based on info provided
  - APPRECIATES the dx and foreseeable consequences of tx decision in PERSONAL CONTEXT
  - Able to MAKE A TREATMENT CHOICE from available options

**Often determined through discussion with patient, can be assessed using MacCAT-T

HOW DOES AN EATING DISORDER AFFECT CAPACITY?

- 1. Cognitive changes associated with acute and chronic starvation (Malnutrition affects the orbitofrontal prefrontal cortex, dorsolateral prefrontal cortex, striatum, and serotonin/dopamine pathways → effect decision making)
- 2. Psychological distortions and phobias are inherent in the diagnosis.
- 3. Deeply rooted ambivalence affects most patients due to inextricable link between recovery and their most feared outcome (weight gain)

MEDICAL DECISION MAKING IN AN

- 35 female adolescents with AN vs 40 healthy controls
- Excluded those taking psychotropic meds or steroids
- Administered MacCAT-T using hypothetical vignettes of MDD and scoliosis + own illness for AN group

Turell, S et al (2011). Consent to Treatment in Adolescents with Anorexia Nervosa. *Int J Eat Disord; 44*:703–707

MEDICAL DECISION MAKING IN AN

- Patients with AN were:
  - Less able to engage in consequential reasoning
  - Less able to generate everyday consequences of their decisions
  - Less able to make logically consistent decisions

Reasoning comparatively worse when related to their own illness

?due to seeing illness as part of their identity → unable to weigh the pros/cons logically

Turell, S et al (2011). Consent to Treatment in Adolescents with Anorexia Nervosa. *Int J Eat Disord; 44*:703–707

IF INCAPABLE - SHOULD PATIENTS BE TREATED AGAINST THEIR WILL?

- Clinical case by case approach
- Options include:
  - NGT remains in place until patient can consume adequate oral nutrition
  - NGT In/Out for each meal
  - Offer oral nutrition vs “break” from oral nutrition

WHAT ARE THE PATIENTS' VIEWS?

- 2 qualitative studies:
  - Guarda et al 2007 – ½ the patients that denied need for treatment at admission converted to acknowledging need for treatment within 2 weeks
  - Tan et al (2003 and 2010)
    - Most reported that treatment was "self evidently" the right thing to do because "no one should be allowed to die from the consequences of AN"
    - Many felt compulsory treatment should be used early in course of illness to prevent chronicity and improve prognosis
    - Many felt that possibility of compulsory treatment allowed them to eat
    - Minority felt that compulsory treatment should be reserved for imminent risk to prevent future treatment avoidance

DOES IT WORK?

DOES IT WORK?

- No studies to guide decision making.
- NICE guidelines and APA guidelines = If risk of death imminent – forced feeding justified.
- If child/adolescent – consider:
  - Adolescents treated early and aggressively have better outcomes.
  - Importance of adequate nutrition for adolescent growth and development.

Bryden et al (2010). The Ontario experience of involuntary treatment of pediatric patients with eating disorders. Int J of Law and Psych, 33; 138-143.

GUIDING PRINCIPLES

- Coercion is not an exercise to preclude psychotherapy – nor does coercion mean that psychotherapy should not be forthcoming.
- Need for involuntary admission and compulsory treatment should be re-evaluated regularly.
- The risk of dying needs to be considered and if high, should lead to involuntary admission/treatment. Factors to consider are severe low weight, suicidality, electrolyte imbalance, cardiac arrhythmia, and comorbid substance use (esp alcohol).

GUIDING PRINCIPLES

- Treatment should be the least restrictive possible and for the shortest possible time. Ultimately, it is going to be the therapeutic relationship and a supportive milieu that will produce the best outcome.
- Every effort needs to be made from the outset to encourage the patient to consume nutrition independently.
- The patient should be treated with dignity and respect recognizing the fragile mental state especially their self-esteem.
- Wherever possible, involve of the family.

QUESTIONS?

Thank you!

for participating in today's

Mental Health Series

Join us next time:

Psychosis in Youth *with* Dr. S. Robertson

Date: Feb 25 from 12-1pm @ the Royal