



Anita Catlin, DNSc, FNP, FAAN  
The Pediatric Anorexia Patient Who Refuses Care  
July 17, 2010, 10:45 AM- 12:15 PM

Thank you Kaiser Permanente for Guidelines

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- watchANOREXIA\_files

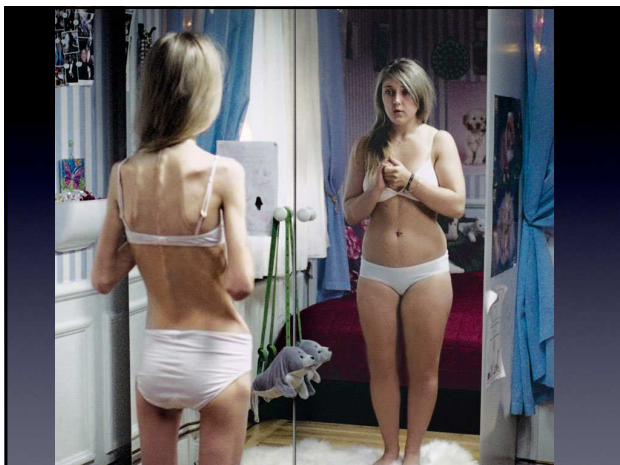
## OBJECTIVES

- Define needs of hospitalized teen with anorexia
- Describe how model of care changes at 17 years and 364 days
- Examine practice protocols for ethical content
- Review legal parameters
- Define needs of nurses who care for those patients
- Palliative Care Discussion

## DISCLOSURE

- **ETHICIST AND RESEARCHER**
- This issue became mine as the chair of a hospital ethics committee
- Nurses were not in agreement on the coercive measures that need to be taken in this diagnosis
- Physicians were not in agreement on reason for admission and treatment while in the hospital
- One protocol used at 17 and completely different protocol at 18

### BENEFIT AND BURDEN



## ANOREXIA NERVOSA



- **STATISTICS**
- How many people have it?
- What ages?
- Does anorexia cause death?

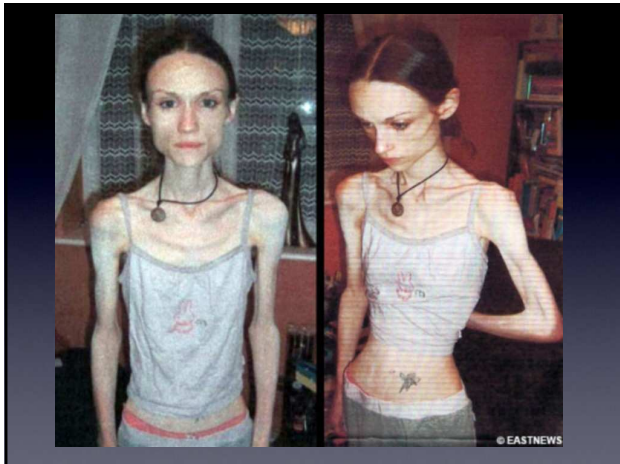


## NUMBERS

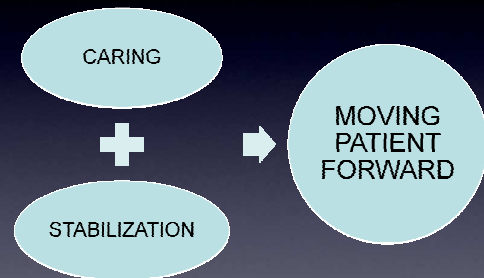
- Occurrence has increased over last 20 years
- 90-95% of teens who have it are females
- 1% of female adolescents have anorexia
- Average onset is 17
- Usually diagnosed in the teens or twenties
- Very rarely diagnosed after the age of 40

## DOES ANOREXIA CAUSE DEATH?

- Up to 20% will die if untreated
- 2-3% will die with treatment
- Mortality rates of anorexia are the highest of any mental health disorder
- Even with treatment, only 60% make a full recovery



## TWO PRONGED MODEL OF CARE



## MODEL OF CARE

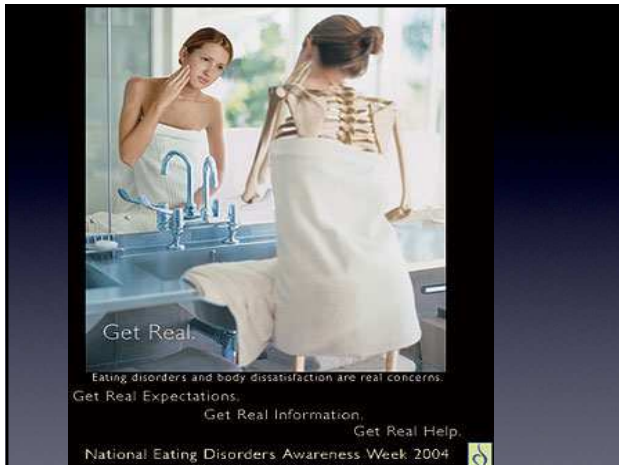
CONSISTANCY IN TREATMENT MODEL IS ESSENTIAL

- There have been nurses who looked at this in a punishment model "You need to eat right now or ..."
- There are those who do not understand the level of psychopathology: "Why don't they just eat?"
- There are those who demean: "All my other patients have real illnesses that they did not choose, you are *choosing* to be sick."
- Treating the patient's *suffering* must be the first prong of the model
- The level of suffering is rated as one of the highest, identity loss, inability to change the situation around them
- Opportunity for essence of nursing: "I am here for you"

## MEDICAL STABILIZATION



- Regardless of reason for admission, refeeding is necessary
- Service agreement between pediatric or adult hospitalists and psychiatry
- Cannot treat medically without treating underlying starvation



## MEDICAL STABILIZATION

- Cardiac arrhythmia, bradycardia, or syncope
- Bradycardia with heart rate less than 50 in daytime, less than 40 at night
- Postural tachycardia with > 20 BPM differential
- Hypotension with systolic blood pressure 90 mmHg or less
- Postural hypertension of > 10 mmHg differential
- Hypothermia with temperature < 96 degrees
- Dehydration/severe electrolyte abnormalities

## MEDICAL STABILIZATION

- Weight less than 75% of expected weight
- Acute starvation – inability to maintain a predetermined minimum nutritional level, or a rapidly falling weight toward that level at which it is known to cause any of the criteria listed on previous slide in an individual patient
- Refusal to eat or drink
- Suicide risk

## PLAN OF CARE

- Environment of Care
- Activities
- Monitoring
- Weighing procedure
- Intake and Output
- Baseline labs, EKG, etc
- Activity
- Mealtime Supervision
- Behavioral Expectations
- **Complete pediatric and adult plans of care available from [calin@sonoma.edu](mailto:calin@sonoma.edu)**
- Nutrition Plan of Care
- Determination and Provision of Calories
- Meal Services
- Menu Selection
- Calorie Calculation
- Multidisciplinary Consultation
- 1. Nutrition Consult
- 2. Psychiatric Consultation
- 3. Social Services Consult

## DECISION MAKING - ANOREXIC TEENS

- At 17 and under, parents have the right to consent for teen's treatment
- There are many directed orders without the teen's consent such as:
  - Strict bed rest with bedside commode
  - Lock bathroom door; no bathroom privileges
  - Remove all potential receptacles: bags, backpacks, trash can, linen hamper, vases, cups
  - Search belongings; remove any sharp objects, meds/pills, gum, any literature promoting weight loss or body image distortion.

- **No cell phones or computers**
- **Hospital telephone use to immediate family only**
- **Sponge bath only**
- **Bed rest activity only: TV, reading, games, homework, journaling, music**
- **Visitation by immediate family only**



## DIRECTED MEAL SUPERVISION

- Enforce no visitation during meal/snack time, and for 30 minutes after meals
- Place patient in a visible area outside of the room, or in bed, with continuous staff supervision during meals & 30 minutes after meals, during snacks & 15 minutes after snacks
- Remove meal trays after 30 minutes and snack trays after 15 minutes
- No television, music or reading during meal/snack times



## ENTERAL FEEDING

- Based on the total of unconsumed calories from each meal/snack, the patient will be given the equivalent volume of standard 1 calorie per one milliliter liquid nutritional supplement to drink at the end of the day
- If the patient refuses, a nasogastric tube will be placed and the supplement will be delivered at the rate of 25 mls/hour to a maximum of 60 mls/hour



## ENTERAL FEEDING

Can be source of conflict

- To physicians:
  - I must provide this therapy to save a life
- To nurses:
  - I am being asked to initiate a treatment without consent from the patient, and in fact, direct refusal
  - I may need to restrain the patient to do this



## AMERICAN ACADEMY OF PEDIATRICS POLICY ON ASSENT

Pediatrics 1995, 95, 314-317.

- Asks physicians to obtain developmentally appropriate assent of child to all treatment activities
- Feels teens must be agreeable to care
- States that coercion is to be a last resort
- Only if proposed intervention cannot be deferred without substantial risk
- Court can be involved if mature teen does not agree with parental consent

## TEEN WHO REFUSES TO COMPLY WITH TREATMENT OR IS NOW 18 YEARS OF AGE

- Teen at 18 is now consider an adult
- Treatment shift takes place
- Directive orders for care remain the same (bed rest, locked bathroom, no exercise, monitored meals, no cell phone, go through belongings)
- What is to be done when these activities are not agreed to and the nurse must use coercive manner?



## Case Study

Marla, 20, was admitted for 4<sup>th</sup> hospitalization in 2 years. Refused to stay in bed, doing laps around nurses station, drinking gallons of water in bathroom

- One consult: Nurses came to ethics committee asking: Are we to tackle her at night when she is doing laps? Are we to call security? Do we have to lock the door to the bathroom? I do not feel right going through her purse, although when I did, there were many laxative pills in there. And whose property are those pills? Do I return them upon discharge?
- Another consult: Psychiatry came to ethics committee: Medical model is treating cardiac dysfunction and anemia only

## COERCION IN FEEDING

- Research review 14 articles; 4 books
- There is a 50% chance of recovery
- There is a 50% chance that coercion is helpful
- No randomized control trials in compulsory treatment outcomes ever done
- Several long term outcome studies found no difference in mortality whether patient was force fed or not force fed

## PATIENT REFUSAL OF CARE

Traditionally, advocacy asks that we make certain patient understands risks to refusal

- If refusal is not life threatening, we usually respect this
- If refusal imminently jeopardizes patient's life, need to go up chain of command
- Suggest involvement of the ethics committee or patient care ombudsman
- Suggest involvement of the courts to deliver care against expressed refusal of a child or an adult

## COERCION IN TREATMENT

- Unfortunately, California 5150 Code to detain patient in psychiatric center does not allow for any medical intervention, only psychiatric intervention
- California Probate Code Section 810-813 lengthy document which delineates legal requires for lack of capacity, which should be based on evidence of a deficit in one or more of the person's mental functions, including a *lack* of:
  - Ability to understand and appreciate quantities
  - Ability to reason using abstract concepts
  - Ability to plan, organize, and carry out actions in one's own rational self-interest
  - Ability to reason logically

## COMPETENCY

- Competency is determined by court of law
- Under the United States Constitution, Americans are given the benefit of the doubt that they are competent, and the burden of proof lies upon the local county to prove to the magistrate that one is not able to make decisions for oneself
- The rights of an individual are very cherished and hard to remove, especially in California
- In California it is a one year process; with several levels of investigation, chance of success limited

## EXAMS FOR COMPETENCE

- The Patient Competency Rating Scale (Hart, 2000)
- Mini Mental Exam (Folstein, 1975)
- MacArthur Competence Assessment Tool for Treatment (Grisso, 1998)
- Note: Exam may show 100% competence but patient may have 0% capacity
- The courts say a competent patient can refuse treatment even if "neither sensible, rational or well considered, or even for no reason at all" except when patient *lacks capacity*

## CAPACITY



- A patient with capacity is one who:
  - (a) can hear information,
  - (b) believes the information, and
  - (c) can weigh the information in the balance and arrive at a choice

## CAPACITY

Capacity means patient “appreciates the nature of the situation and appreciates that this applies to him/her.”

Goes beyond the individual treatment decision and to the wider belief system of the patient

Incapacitated patient has a considerable distortion of reality-- A salient belief that is *fixed and false and firmly* held may be reason to judge as lacking in capacity

## California Health and Safety Code Section 1418.8

- To make determination regarding capacity, the physician shall interview the patient, review the patient's medical records, and consult with nursing or facility staff, as appropriate, and family members and friends of the resident, if any have been identified
- Shall conduct an interdisciplinary team review of the prescribed medical intervention prior to the administration of the medical intervention...which includes a patient representative
- Must evaluate the type of medical intervention to be used in the resident's care, including its probable frequency and duration; the probable impact on the resident's condition, with and without the use of the medical intervention; reasonable alternative medical interventions considered or utilized and reasons for not using

## ● American Nurses Association Code of Ethics Provision 1.4

- Respect for human dignity requires the recognition of specific patient rights, particularly, the right of self-determination
- Self-determination, also known as autonomy, is the philosophical basis for informed consent in healthcare
- Patients have the moral and legal right to determine what will be done with their own person; to be given accurate, complete, and understandable information in a manner that facilitates an informed judgement; to be assisted with weighing the benefits, burdens, and available options in their treatment, including the choice of no treatment; to accept, refuse, or terminate treatment without deceit, undue influence, duress, coercion, or penalty; to be given needed support throughout the decision-making and treatment process.

## CALIFORNIA BOARD OF REGISTERED NURSING Penal Code Sections 240- 248 Assault and battery

- An assault is an unlawful attempt, coupled with a present ability, to commit a violent injury on the person of another.
- A battery is any willful and unlawful use of force or violence upon the person of another
- Punishable by both fine and imprisonment
- Special circumstances
  - in elders
  - in touching intimate parts of body

## BATTERY

- Battery in nursing might be considered unauthorized touching or failure to obtain informed consent prior to treatment.
- In *Roberson v Provident House* (576 So 2nd 992 [La 1991]), a nurse inserted a catheter following a physician's PRN Foley order. Patient told nurse not to do this. Nurse convicted of assault and battery.
- In *Duncan v Scottsdale Medical*, a nurse was charged with battery by giving an injection of fentanyl to a patient despite a direct, verbal refusal.
- A threat to do something without doing it can still constitute a charge of assault
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## SUPPORT FOR NURSING STAFF

- Cannot be simply told to overrule patient care refusal as a doctor's order or protocol
- Must consider pediatric assent
- Must consider adult consent
- Must consider risk to nursing license
- Have the right to conscientiously object
- Balance risk and benefit; this condition is potentially fatal

## ESSENTIAL SUPPORT FOR NURSING STAFF

- Must have clearly documented lack of patient capacity if directed measures will overrule patient wishes
- Must have leadership and peer support caring for patients with complex psychosocial issues
- Must have access to facilitated debriefing after difficult patient care situations



## PALLIATIVE CARE

- Literature suggests that when a pattern of unrelenting eating disorder complications continues over time, that a transition to palliative care efforts may be the appropriate model of care



- Applebaum P., Rumpf T. "Civil Commitment of the Anorexic Patient." *General Hospital Psychiatry* 20. (1998): 225-230.
- Carney T., Tait D., Saunders D., Touyz S., Beaumont P. "Institutional options in management of coercion in anorexia treatment: The antipodean experiment?" *International Journal of Law and Psychiatry* 26. (2003): 647-675.
- Carney T., Tait D., Touyz S., Ingvarson M., Saunders D., Wakefield A. "Therapeutic Advantages of the Different Forms of Legal Coercion." *Managing Anorexia Nervosa*. (2001) 81-91.
- Carney T., Wakefield A., Tait D., Touyz S. "Reflections on Coercion in the Treatment of Severe Anorexia Nervosa." *Isr J Psychiatry Relat Sci* 43. (2006): 159-165.
- Gans M., Gunn W. "End stage anorexia: Criteria for competence to refuse treatment." *International Journal of Law and Psychiatry* 26. (2003): 677-695.
- Giordano S. "Anorexia Nervosa and Refusal of Life-Saving Interventions." *Understanding Eating Disorders*. (2005): 235-253
- Lopez, A., Yager, J. & Feinstein, RE. (2010). Medical futility and psychiatry: Palliative care and hospice as a last resort in the treatment of refractory anorexia. *International Journal of Eating Disorders* 43 (4), 372-377.

- MacDonald C. "Treatment Resistance in Anorexia Nervosa and the Pervasiveness of Ethics in Clinical Decision making." *Can J Psychiatry* 47. (2002): 267-270.
- Melamed Y., Mester R., Margolin J., Kajian M. "Involuntary treatment of anorexia nervosa." *International Journal of Law and Psychiatry* 26. (2003): 617-626.
- Simon J. "Refusal of Care: The Physician-Patient Relationship and Decisionmaking Capacity." *American College of Emergency Physicians* 50. (2007): 456-461.
- Tan, JAO., Hope T., Stewart A., Fitzpatrick R. "Competence to make treatment decisions in anorexia nervosa: thinking processes and values." *National Institutes of Health* 13. (2006): 267-282.
- Tan, JAO., Hope T., Stewart A., Fitzpatrick R. "Control and compulsory treatment in anorexia nervosa: The views of patients and parents." *International Journal of Law and Psychiatry* 26. (2003): 627-645.
- Thiels C. "Forced treatment of patients with anorexia." *Current Opinion on Psychiatry* 21. (2008): 495-498.
- Wong J., Clare I., Gunn M., Holland A. "Capacity to make health care decisions: its importance in clinical practice." *Cambridge University Press* 29. (1999): 437-446.