Eating Disorders: Biology, Psychology, Ethics & the Law

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Outline: Health & Ethics

- Brief overview of Eating Disorders among university students
- Discussion of common psychological obstacles to treatment & recovery.
- Application of Ethics literature to clinical care.
Outline: Legal Topics

- Tort Liability: Negligence

- Federal Antidiscrimination Laws:
  - The Americans with Disabilities Act ("ADA")
  - §504 of the Rehabilitation Act ("Rehab Act")
  - Fair Housing Act

- Privacy Laws
  - FERPA
  - HIPAA
  - State Health Record Privacy Laws
Graduate student, 25

- Presents to Student Health after Winter break to establish care.

- Recently left in-patient care AMA with BMI 15, felt “constrained” on the locked unit. Had been in ICU 2 months earlier with life-threatening hepatic failure.

- Isolated from but financially dependent on parents.

- Asserts recovery “will not occur” away from University.

- History of excessive exercise, currently denying. No purging, no medication abuse.
• PE: BP 90/64, HR 48, T 36.3, BMI 13.5

• Cachectic, with cyanotic lips and extremities. Scaphoid abdomen, palpable nontender liver.

• Labs: grossly normal (mild leukopenia and mild hyponatremia)

• Patient leaves before EKG can be done, despite clear instructions. Had to attend a seminar.
The Legal Challenge

Tort Liability: Medical malpractice, wrongful death

Disability Discrimination Suits
Negligence: Recent Suits

University found liable for wrongful death:

* School knew about student’s risk of suicide but did not act to prevent it.

  *Schieszler v. Ferrum College, 2002*

* School participated actively in student’s treatment which was ongoing when she killed herself.

  *Shin v. MIT, 2005*
Recent settlements in favor of student

- Student evicted from campus housing after hospitalization for suicide attempt.
  
  *Doe v. Hunter College*, 2006

- Student withdrawn after he checked himself in to ER for suicidal thoughts.
  
  *Nott v. George Washington University*, 2006
Involuntary Withdrawal Policies

- How do we balance civil liberties and individual rights of self-harming students against the university’s mission/standards and rights of community members?

- How can we ensure self-harming students are afforded due process without being subject to adversarial disciplinary proceedings?

- **Eating Disorders:** Ground Zero in these policy discussions
Eating Disorders are:

- inherited
- disorders of neurochemistry and/or neurocircuitry
- influenced by the environment
- associated with other psychiatric disorders
- associated with high morbidity & mortality
- treatable
Eating disorders

U.S. prevalence (%)

- Anorexia, 0.09
- Bulimia, 1.5
- Binge Eating, 3.5
Binge-Eating Disorder

A. Recurrent episodes of binge eating. Binge eating is:
   1. eating, in a discrete period of time more food than most people would eat under similar circumstances
   2. a sense of lack of control over eating

B. The binge-eating episodes are associated with 3 or more of the following:
   1. eating rapidly
   2. feeling uncomfortably full
   3. eating large amounts of food when not feeling physically hungry
   4. eating alone because of feeling embarrassed by how much one is eating
   5. feeling disgusted with oneself, depressed, or very guilty afterwards
Bulimia Nervosa

A. Recurrent episodes of binge eating, characterized by both:
   1. eating objectively large amounts of food
   2. loss of control
B. Recurrent inappropriate compensatory behavior
C. These behaviors occur > twice a week for at least 3 months
D. Self-evaluation unduly influenced by body weight/shape
E. Does not occur exclusively during Anorexia Nervosa
Anorexia Nervosa

A. **Refusal** to maintain weight at or above a **minimally normal weight** for age & height.

B. Intense fear of gaining weight or becoming fat.

C. Disturbance in the way one’s body weight or shape is experienced; self-evaluation unduly influenced by weight or shape; or denial of seriousness of current low weight.

D. In post-menarchal females, amenorrhea.
Student Statistics

- 91% of surveyed college women diet
- 95% of those who have eating disorders are between the ages of 12 and 25
- 43% report onset of ED between 16 - 20
- AN is the 3rd most common chronic illness among adolescents.
- 25% of college-aged women engage in bingeing & purging to manage their weight.
Are Eating Disorders Protected Disabilities?

**ADA**: Applies to both public and private institutions:

* Title II applies to public colleges and universities
* Title III applies to private entities that are “places of public accommodation,” including private colleges and universities

**Rehab Act**: Applies to any institution receiving federal assistance, which includes nearly all public and private colleges and universities.
Disability Defined

The ADA has a three-part definition of disability that is based on the definition under the Rehab Act. An individual with a disability is a person who:

1. Has a physical or mental impairment that substantially limits one or more major life activities.

2. Has a record of such an impairment.

3. Is regarded as having such an impairment.
“Major Life Activities”

• (A) In general

• For purposes of paragraph (1), major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.

• (B) Major bodily functions

• For purposes of paragraph (1), a major life activity also includes the operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.

42 USC § 12102(2)
“Regarded As”

• For purposes of paragraph (1)(C):

• (A) An individual meets the requirement of “being regarded as having such an impairment” if the individual establishes that he or she has been subjected to an action prohibited under this chapter because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity.

• (B) Paragraph (1)(C) shall not apply to impairments that are transitory and minor. A transitory impairment is an impairment with an actual or expected duration of **6 months or less**.
Construction of “disability”

- The definition of “disability” in paragraph (1) shall be construed in accordance with the following:

- (A) The definition of disability in this chapter shall be construed in favor of broad coverage of individuals under this chapter, to the maximum extent permitted by the terms of this chapter.

- (B) The term “substantially limits” shall be interpreted consistently with the findings and purposes of the ADA Amendments Act of 2008.

- (C) An impairment that substantially limits one major life activity need not limit other major life activities in order to be considered a disability.

- (D) An impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active.
Mental health conditions, including eating disorders and depression, constitute disabilities protected under the ADA and Section 504 as they limit a student’s ability to participate in the major life activity of learning.

So a university that takes adverse action against a student as a result of conduct caused by a mental health condition may be deemed to have discriminated against a qualified individual even if that action is intended to protect the student.
Explaining the ADA (before)

Once an institution has found that a student’s conduct poses a “direct threat” to the safety of that student or others, the student is no longer a “qualified individual” under Section 504 and the student may lawfully be withdrawn from the college or university.

If the university is sued for disability discrimination, it may then present the results of its “direct threat” test as an affirmative defense in court.
Applying the Direct Threat Test *(before)*

Adverse action, i.e. involuntary medical withdrawal, may be appropriate when…

1. Student conduct poses “significant risk” of harm to self or others; and
2. *Individualized* inquiry and *objective* assessment;
3. Based upon *current medical knowledge* or *best available objective evidence*
4. Determine:
   - The *nature, duration, and severity* of the risk;
   - The *probability* that potentially threatening injury actually will occur; and
   - Whether *reasonable modifications* of policies, practices, or procedures will sufficiently mitigate the risk
Applying Direct Threat Test: STEP 1
Does Eating Disorder pose “Significant Risk” of harm to self or others? *(before)*

High probability of substantial harm and not just a slightly increased, speculative or remote risk.”

- Insufficient risks from OCR Guidance Letters:
  - Dean’s speculative “concern” that student would attempt suicide again after an initial attempt *(Bluffton)*
  - Student’s “veiled threat” to school psychologist that he would commit suicide without anyone knowing and revealing a third unknown suicide attempt *(Marietta)*
  - OCR: threat revealed student’s “difficulty adapting to College life.”
Mortality

- Highest among all psychiatric illness
  - 4% for anorexia nervosa
  - 3.9% for bulimia nervosa
  - 5.2% for ED-NOS (including BED)
- Suicide, malnutrition, mechanical or biochemical injury, complications of obesity
Tenacity of EDs

- Ambivalence towards recovery in AN is a symptom of the illness
- Self-reinforcing behaviors perpetuate BN & BED
Applying Direct Threat Test: STEP 2
Individualized Inquiry & Objective Assessment

Insufficient Inquiry/Assessment from OCR Guidance Letters:

- Did not contact treating MD, counselor or student; did not review any medical or counseling records.

- Consulted student’s medical history and evaluated use of campus resources but did not consult treating MD.

- Decision by Dean, College President, and legal counsel, based on information provided by college psychologist, who had met with student for two one-hour counseling sessions and had contacted treating psychiatrist.

- Jordan Nott sought treatment to avoid self-harm but was withdrawn.

- Time constraints are no excuse, i.e. approaching start of new term.
University Services

• Does University have sufficient resources to conduct “individualized inquiry” & objective assessment?
  • Clinician hours and expertise
  • Medical support
  • Dietetic support
  • Support and monitoring outside the UHC

• Is treatment of serious mental and medical illness within the mission of the University?
Applying Direct Threat Test: STEP 3
Current Medical Knowledge or Best Available Objective Evidence?

- Least guidance here—universities often satisfy this requirement with on-campus medical personnel.

- Insufficient example (sports camp):
  - One MD’s opinion does not suffice.
  - Should consult established medical opinion in the form of reports (CDC, NIH, APA).
Best practices satisfy STEP 3

- APA Practice Guidelines
- UHC Practice Guidelines
- AED Medical Care guide
  - Early intervention
  - Family involvement in treatment
  - Multidisciplinary teamwork
  - Monitor medical risk
Applying Direct Threat Test: STEP 4
Evaluation of the Risk

1. **Nature, duration, and severity** of the risk;
   - School considered use of mental health support resources and disruption but not risk student posed.

2. **Probability** that potentially threatening injury actually will occur;
   - “Concern” for another suicide attempt not proper assessment of likelihood.
   - History of attempts and threat to commit suicide.

3. **Reasonable modifications** of policies, practices, or procedures to sufficiently mitigate risk.
   - Rescind invitation to parents (cause of student’s stress)
   - Remove student from housing [FHA concerns]
   - Reduce course load or create alternative assignments
   - Postpone assignments/exams
   - Work from home
   - Drop courses
   - Change roommates or rooms
   - Withdraw from courses retrospectively
Conclusion...or so we thought?

- Involuntary medical withdrawal policy should be invoked rarely and only after other intervention.

- Sample policy progression:
  1. Procedure Initiation (by any member of community)
  2. Preliminary Determination by Dean of Students
  3. Interim Involuntary Health or Safety Withdrawal
  4. Involuntary Health or Safety Withdrawal (Non-Interim)
  5. Hearing w/ DOS
  6. Decision
  7. Appeal of Involuntary Health or Safety Withdrawal
  8. Readmission
The Next Chapter

• DOJ revised Title II ADA Regulations, effective March, 2011, causing very significant change to “direct threat” test:

1. Student conduct poses “significant risk” of harm to self or others; and
2. Individualized inquiry and objective assessment;
3. Based upon current medical knowledge or best available objective evidence
4. Determine:
   • The nature, duration, and severity of the risk;
   • The probability that potentially threatening injury actually will occur; and
   • Whether reasonable modifications of policies, practices, or procedures will sufficiently mitigate the risk
What does this mean?

• WE DON’T KNOW!

• We do know it raises MANY QUESTIONS:
  • May we take ANY adverse action against students who only pose threat to self?
    • If YES, can they be subject to an alternative form of due process (involuntary medical withdrawal v. disciplinary suspension)?
  • What conditions, if any, may a school place upon a student’s return?
  • Does it matter if the student left voluntarily or involuntarily?

*OCR will issue guidance, hopefully in response to these questions!
Coercion

In absence of a involuntary medical withdrawal policy, we use voluntary methods with some coercion.

Is this ethical?
Ethics

- moral duty

- the science or study of moral values or principles, including ideals of autonomy, beneficence, and justice.

Beneficence

Serving each patient’s best interest.

A moral obligation to act for the benefit of others, incorporating the principle of nonmaleficence (preventing harm).

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Autonomy

Patient’s right to make an informed treatment choice that is free of controlling interferences by others, and precludes personal limitations preventing meaningful choice.

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Competence

ability to understand, reason, and express treatment preference based on personal values, and to appreciate that the illness and decision apply to one’s self.

A competent person demonstrates:
1. appreciation that he or she has a choice
2. understanding of the risks and benefits of each alternative, and likely consequences; and of the medical situation, prognosis, and recommended treatment
3. decisional stability over time

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Illness, cognition & beliefs

- Dementia, Delirium, Depression

- Anorexia nervosa, Bulimia nervosa:
  - Impaired concentration & thought processing, changed beliefs
Choice

- It is not a choice to engage in ED behavior.
- How does one independently choose recovery over the ED?
- How can treatment ethically bring about that choice?
Measuring competence

- There is no valid empirical measure of a person’s ability to understand, reason and express choice based on personal values.

- MacCAT T-test of competence fails to consider that disease can produce pathologic values inconsistent with pre-morbid personal values.

- Tan, 2006; Charland, 2007.
Students’ Pre-morbid values

• Intellectual growth
• Academic achievement, career opportunities
• Athletic or artistic expression
• Social identification & relationships
Illness & decision-making in AN:

- An understanding of risks of extreme thinness may exist and be expressed.

- The Central value of thinness affects thinking about death.

- Does the ill person appreciate that AN affects his or her values? That AN affects him or herself?
Illness & identity

- Value of “lightness,” or thinness: a “pathological value” inconsistent with the same person’s views if they were not affected by ED.
Values also are influenced by

- Families
- Extended social networks
  - friends, faith, culture, athletic team
  - internet communities
Role of family on campus

- Families normally participate in care of ill members.
- Families normally don’t share pathologic (ED) values.
- Most University students are 18+ and live semi-independently, and many seek family involvement in their healthcare decisions.
Coercion on campus

To involve parent(s), bar a student from the gym or athletic team, postpone clinical rotations, or recommend medical leave.

Risks:

Coercion may lead patient to “fight the wrong enemy”, threaten the therapeutic alliance.

In an academic setting, may lead patient to avoid all healthcare
Coercion as nonmaleficence

Possible meaning of non-coercion: “I’m not sick enough.”

Recognizing and not exceeding the limitations of providers and/or clinic setting (nonmaleficence)
Ethics meets EDs

- **Illness affects competence:** “I realized that starvation could make you crazy: there is a thin line between control and madness.” Michael Fassbinder in “Pumped”, NY Times T Magazine, 09/13/09

- **“Compassionate coercion”** is supported by a few small retrospective case studies showing that ED values are not stable over time.

- **Ethics literature supports** routine reassessment of competence, and the idea that coercion can be beneficent when personal limitations exist.

- **Families may represent pre-morbid values & aid in making treatment decisions.**
• We can’t not see these students: in our waiting rooms, classrooms, dining halls, gyms.

• Others on campus are touched or triggered.

• The most severely ill cannot relate to others, yet they seek relief from the burden of their disease.
Ethical care of ill students who refuse standard treatment

Be a clinician

Follow best practices
Monitor & document risk & capacity
Treat symptoms as allowed
Document refusal of recommendations
Consult with other clinicians & University counsel
Coming Soon?

• Best practices guide to ED treatment on campus
• Clarification of relevant law
Not addressed

- Varsity athletes with eating disorders
- Non-clinical faculty’s ethical and legal responsibilities
A+ College student, 20

- may lose full scholarship if she takes medical leave from school
- her divorced parents promote different values, support different treatment & goals
- is unaware of unit protocols (bed rest, timed meals, observed bathroom visits)
- nearest IOP is hours from either parent’s home
Nursing student, 20

- Denies new diagnosis (AN); refuses therapy but agrees to see RD

- Weight drops a bit, intake is restricted

- Parents express concern; student won’t authorize release of information to her parents
College student, 18

- Mandated to SH by University AFC director via Dean of Students; barred from gym (BMI 15). Refuses treatment, gains on own to BMI 18.9.

- Back in gym, drops 4.5 lbs in 15 days; declines reassessment. Parents & student say health center MD is “too direct”.

- Dean learns student is vomiting in classroom building; AFC reports gym overuse.