When They Can’t ‘Just Eat’: Palliative Approaches and End-of-Life Considerations in Adults with Eating Disorders

Presenter:
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Medical Grand Rounds

April 4, 2017 ~ 8-9 am ~ Q&A 9-9:30 am
Providence St. Vincent Medical Center

April 5, 2017 ~ 8-9 am ~ Q&A 9-9:30 am
Providence Portland Medical Center

Donor contributions to Providence St. Vincent Medical Foundation make this lectureship possible.
Established in 2006, the Goldman-Berland Lectureship in Palliative Medicine honors two Providence St. Vincent Medical Center physicians, Robert Goldman, MD, and John Berland, MD. These physicians have been recognized for their outstanding whole-person patient care and for being advocates and innovators in palliative care. Dr. Goldman was a medical oncologist who helped initiate the Providence Home Hospice Program in the 1970s. Dr. Berland, a retired general internist, has a passionate interest in palliative care, and wants to make sure that Providence clinicians know how to provide excellent care for patients with advanced chronic, life-limiting or terminal illnesses.

The Lectureship is a funded program of the Providence Center for Health Care Ethics. The Center was established in 2000 and contributes to excellence in health care by providing ethics education, consultation, research and scholarship. The Center also supports palliative care by coordinating palliative care efforts throughout the Oregon region of Providence Health & Services, and by sponsoring educational opportunities in palliative care, such as a palliative care elective for Providence internal medicine and family medicine residents.

The Goldman-Berland Lecturer is a clinician recognized nationally for excellence in palliative and end of life care. Previous Goldman-Berland scholars and their Medical Grand Rounds topics include the following:

2007 - Steven Pantilat, MD, FACP, Founding director of the Palliative Care Service at University of California San Francisco Medical Center, and professor of clinical medicine in the Department of Medicine at UCSF School of Medicine. Palliative Care: What It Offers Patients and Clinicians.

2008 - Ira Byock, MD, Director of Palliative Medicine at Dartmouth-Hitchcock Medical Center, Chair of Palliative Medicine at Dartmouth Medical School in Lebanon, New Hampshire. What Are Doctors For? The Physician-Patient Relationship through the End of Life.

2009 - Judith Nelson, MD, J.D., Associate director of the ICU at Mt. Sinai Medical Center and professor of medicine, Mt. Sinai Medical School of Medicine, New York City. Palliative Care in the ICU: Closing the Gap Between What We Know and What We Do.

2010 – Kathleen Puntillo, RN, DNS, FAAN, Professor emeritus of nursing and research scientist at University of California, San Francisco with ongoing clinical practice in critical care nursing. The Epidemic of Procedural Pain in Acute and Critical Care.

2011 – Mary Hicks, MSN, APN-BC, Palliative Care nurse practitioner and Elizabeth DiStefano, RN, BSN, Palliative Care administrator, St. John Health System, Detroit, MI. How Palliative Care Transformed Our Hospital: Lessons from Detroit.

2013 – Angelo Volandes, MD, MPH, Faculty at Massachusetts General Hospital and Harvard Medical School, Boston, MA. Patient Decision-Making in 2013: How Video Tools Break Down Barriers in the ICU/Clinic.

2014 – Erik Fromme, MD, MCR, FAAHPM, Medical director of Oregon Health & Science University Palliative Care Service, assistant director of OHSU Center for Ethics in Health Care and associate professor of medicine, nursing and radiation medicine, Portland. Communication Tools for All Inpatient Admissions.

2015 – Michael Rabow, MD, FAAHPM, Professor of Clinical Medicine and Urology at the University of California, San Francisco, director of Symptom Management Service at the Helen Diller Family Comprehensive Cancer Center, director of Symptom Management & Palliative Care Consultation Service at UCSF/Mount Zion Hospital. The Evolution of Palliative Care: What All Providers Need to Know.
Dr. Gaudiani is the Founder and Medical Director of the Gaudiani Clinic. Board Certified in Internal Medicine, she completed her undergraduate degree at Harvard, medical school at Boston University School of Medicine, and her internal medicine residency and chief residency at Yale, where she won numerous clinical awards. Dr. Gaudiani moved to Denver in 2007, choosing Colorado with her husband because its emphasis on the outdoors, incorporating nature into daily life, and the importance of family activity time seemed like a great way to foster work-life balance.

In 2008, she helped start the [ACUTE Center for Eating Disorders at Denver Health](http://www.acutecenter.org) in its current form, as the nation’s top medical stabilization center for adults with eating disorders too medically compromised to receive care in a mental health setting. After seven great years there, she left as its Medical Director to pursue her vision of outpatient care, founding the Gaudiani Clinic. During her years at ACUTE, Dr. Gaudiani became a nationally recognized internist for her work on the medical complications of eating disorders.

Dr. Gaudiani has lectured nationally and internationally, is widely published in the scientific literature as well as on blogs, is on the editorial board of the International Journal of Eating Disorders, and sits on the board of [IAEDP (International Association of Eating Disorder Professionals)](http://www.iaedp.com) as the only internist. She is one of the only outpatient internists in the United States who carries the Certified Eating Disorder Specialist designation. In founding the Gaudiani Clinic, she has established a nationally unique outpatient medical setting, not dictated by restraints on visit time or insurance rules, where strong, supportive, and healing relationships with patients help them achieve wellness while remaining in their communities. Through lectures and consulting work, Dr. Gaudiani continues to improve the quality of medical care for patients with eating disorders in treatment programs around the country.
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Goldman-Berland Speaker 2017
Jennifer L. Gaudiani, MD, CEDS
Founder & Medical Director
Gaudiani Clinic

Objectives:
• Understand eating disorders better, including morbidity and mortality
• Understand the variety of end of life considerations through a case-based discussion.
• Gain familiarity with eating disorders and palliative/end of life care

No financial disclosures
What are eating disorders?
- Anorexia nervosa (restrictive or purging subtype)
- Bulimia nervosa
- Binge eating disorder
- Avoidant restrictive food intake disorder

**Anorexia Nervosa (AN)**
- **Genetic** predisposition in personality & temperament “loads the gun”
- **Environment**, with hyper-focus on dieting, weight loss, and thinness, “pulls the trigger”

**Epidemiology**
- 0.5-1% of American women have AN
- Highest mortality rate of any mental illness
- Fewer than 50% recover, 30% improve, and about 20% develop a severe and enduring form of the illness.
- 5-20% of patients with AN will die from it
  - Half from medical causes, half from suicide
- 90% of patients with AN are female
- Those with AN have a 6x mortality rate compared with age-matched peers, up to 45x for those with lowest BMI (<10 kg/m2)
Epidemiology

- Even with treatment, many with AN do not recover (20-25% long term)
- “Severe and enduring anorexia nervosa,” or SE-AN, also called SEED (“severe and enduring eating disorder”)
- However, full recovery is possible, even for those who have been ill for years

Recovered

Then…

Now

Reconnecting body & soul
Case 1

Christy

• 36 year old woman with eating disorder since age 14 since teen years, AN-BP for 2 years (predominantly laxative abuse)
• In and out of treatment countless times
• Each relapse is worse, and happens faster, than the one before
• Fully weight restored several times (ie not a patient who serially flees treatment early)

Christy

• Comes to ACUTE for the first time in Nov 2010 at 68 lbs, 5’2”, stays 2 weeks, discharges at 73 lbs to residential center
• Bonds with staff, engages, has a normal hospital course
• Stays in res for 2 months, discharged at 104 lbs
Christy

- Right after leaving res, relapses.
- Re-presents to ACUTE 9/2011 at 63 lbs: very weak, falling, difficulty swallowing, severely ill, severely dehydrated
- On the night of admission, says she made a mistake, not ready for treatment, wants to leave AMA
- Agrees to stay 1 week
- Leaves 6 days later AMA
  - Psychiatry consult/decision making evaluation undertaken
  - Has capacity
  - Palliative care option raised
  - Long talk with parents

Christy

- Patient signs a DNR/I order with parents present, with PCP
- No hospice service in Virginia, her home state, will accept anorexia nervosa as a terminal diagnosis. Her PCP rejects calls to support her comfort and fires her.
- In 3/2012: “I know this is my decision and I could choose to continue to suffer, but I am in so much pain physically I am not sure how much more I can take. I still walk with a cane and my legs work some of the time. I am unable to really bend over without being in pain, and I can’t bend my knees all the way. Basically if I fall or end up on the ground, I have to call someone to get up. My current weight as a few days ago is 50 lbs and I am on about 35-50 laxatives a day. I don’t throw my food up. Do you have room at the hospital for me?”

Christy

- 3/2012 admits to ACUTE at 52.7 lbs, 48% IBW, profoundly dehydrated. Critically ill, multi-organ failure, cognitive slowing, dysgeusia, asks for a nasogastric tube at admission because of bad taste in mouth.
- Within one week begins to talk of leaving ACUTE AMA again. Not suicidal.
- Deeply ambivalent about getting recovered, being recovered, and staying recovered.
Christy

- 3 weeks later, body weight is 70 lbs with some persistent edema
- She says she has to leave AMA and cannot do more treatment
- She has parents, a sister, and nephews near her VA home and安排s GI follow-up
- Extensive conversations ensue to try and convince her to stay. She understands the risks of leaving and doesn’t want to die but doesn’t feel she can tolerate the process of recovery again.
- Family closely updated

Christy

- 9/2012 lets ACUTE know that hospice still not totally comfortable with anorexia nervosa as a terminal diagnosis.
- Has a hospital bed and oxygen at home. Living with parents now.
- Lets us know she’s 39 lbs, can’t move, has bedsores. Wants to come to ACUTE “to take the edge off” but doesn’t plan on a full recovery.
- Clearly can’t fly commercially, so we urge local hospital and from there, air ambulance
  - Wondering though whether this is futile
- She chooses to remain at home
- Passes away in November

Literature & Concepts Review
Key concepts in refractory cases

- Keep working to motivate voluntary acceptance of treatment, including discussion of harm reduction goals
  or
- Take autonomy and treat against the patient's will
  or
- Permit food/treatment refusal and support medically/emotionally

Start with motivation

- Clinicians with real eating disorder expertise
- Give it all you've got
- Consider a “time limited trial of treatment”

Harm reduction

- Always appropriate to allow patient to establish unique goals and values, but…
- For adolescents and those early on in disease, full weight restoration and multi-disciplinary care that embraces the family of origin are most appropriate, not harm-reduction
Harm reduction

- Set treatment goals well below those for full recovery, that both allow a quality of life described/imagined by the patient and are more palatable to the patient (e.g., weight goals)
- For older patients, with more chronic course

Guardianship/civil commitments

- In brief...
- Capacity evaluations and guardianships most typically around medical instability/medical causes
- Grave disability/civil commitments center around mental health diagnoses
- Options vary by state. Colorado has strong mental health laws more likely to take autonomy in favor of saving lives

When is commitment not right?

- Patients with:
  - Repeated elopements
  - Prolonged need for involuntary tube feedings (persistent inability to take in food)
  - Multiple previous treatment programs
  - Older age
  - Patient who meets criteria for a harm reduction model, palliative care, or hospice care (Westmoreland, 2016)
### Framework for palliative care in AN

- Is the patient 30 or above? OR, if in their 20s, have they been sick without meaningful remittance of disease since childhood?
- Have they completed the gold standard of care for AN (full weight restoration) recently, and not experienced relief of the AN thoughts/distortions?
- Have they received high quality eating disorder specific mental health care in the recent past?
- Do they have capacity to make medical decisions?

### Capacity in AN

- Individual’s ability to:
  - Understand information regarding their condition
  - Appreciate the consequences of the decision they makes
  - Reason through the information needed to make this decision
  - Communicate their choice

### Capacity in AN

- “Tell me about the benefits and burdens of going through residential treatment again”
- “What are your goals for your quality of life?”
- “Why have you hit a wall at this particular point?”
- Provider:
  - Be non-assumptive (moving away from “just eat,” “just try one more time,” “just go to treatment again”)
  - Recognize that suffering of the mind might be as real and painful as that of the physical body
Ability to decline care

- A scientist recovered from an eating disorder suggests patients may decline care when they:
  - Are competent (does not preclude mental illness/distortions of AN)
  - Have a realistic expectation regarding outcome (ie, the patient must know that refusing nutrition will lead to death)
  - Express that their decision is based on a realistic assessment of their current quality of life, and the low probability that treatment will succeed.
  - Is consistent in communicating their desires

  (McKinney 2015)

Severe Persistent Mental Illness

- SPMI: multiple comorbidities and higher-than-average mortality rates

- “The Swiss Academy of Medical Sciences guidelines on palliative care specify several groups of psychiatric patients who can potentially benefit from such approaches: ‘Many psychiatric disorders can have a chronic course or are characterized by frequent relapses. In such cases a palliative approach is all the more important that does not primarily aim at fighting the disease but at optimal management of the symptoms and disability. Quality of life can often be improved and suicide risk can be reduced when palliative support and attention take place in addition to curative or disorder-specific treatments. Difficult situations arise in particular from therapy-refractory depressions with repeated suicide attempts with intent to die, severe cases of schizophrenia with, from the patient’s perspective, insufficient quality of life, and severe anorexia.”’ (Trachsel et al, 2016, emphasis mine)

Palliative psychiatry

- Features of palliative psychiatry
  - Provides support in coping with and accepting of distressing mental symptoms
  - Affirms life but acknowledges that SPMI can be incurable
  - Integrates the physical, psychological, social, and spiritual aspects of patient care
  - Offers a support system to help patients to live as actively as possible until death
  - Offers a support system to help family members to cope during patient’s SPMI
  - Uses a team approach to address the needs of patients and their families
  - Will enhance quality of life and may also positively influence the course of the SPMI
  - Is applicable in conjunction with other therapies oriented towards prevention, curation, rehabilitation, or recovery
Palliative care

- Candidates for palliative care typically have had:
  - Multiple previous treatments and no remission in symptoms or ability to sustain weight gain despite a return to goal weight
  - Not able to sustain a harm reduction model

Criteria

- There is no magic number (e.g., number of times hospitalized, years with disorder, medications tried, or expected days until death)
- It’s the whole story of each patient that helps guide clinicians

What this isn’t

“So you want to die?”

(Maybe the most common and unkindest reaction of a consulting team)
Futility: What can make AN terminal?

- It’s not that there is no known or available cure
- It’s patients’ inability to accept that their critically low weight is life threatening
- They want to live, but cannot do what is needed to stay alive (eat, restore weight)
- This apparent tension, especially in a highly articulate, intelligent person, can raise questions of decision making capacity (resist)

What does palliative/hospice care look like in AN?

Options and offerings

- You may have to do a lot of convincing/educating
- Supportive therapy
- Medications for anxiety and depression
- Commitment not to force treatment against one’s will
- Spiritual support, art therapy, massage (touch remains a vital human need)
- Intensive support of the family, who may not feel comfortable with the terminal diagnosis
- Open-ended offering of a higher level of care if desired (but in highly sensitive patients, avoid reopening grief/guilt around a death viewed by many as a “choice”)
And then, hospice…

- As ever, supportive enumeration of what to expect
  - It can take a long time to die of malnutrition
- Medical equipment in the home, if desired, when self-care cannot be performed
  - Bed, skin care, ADLs, treatment of anxiety, physical pain, nausea
- Ongoing family support

Preaching to the converted

- Every person with a potentially fatal illness deserves to have a compassionate, educated talk about the possibility of death
- My patients feel deeply relieved when this is brought up and discussed openly, not just as a threat.
- Because it's not as if they haven't thought about it. A lot.

A reminder…
References


Any questions?

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