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Ethical Issues in Treating the Morbidly Obese Adolescent

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Case Study

Chief Complaint & History of Present Illness

Amy ("Amy" is a fictitious name), a fourteen year old girl weighing 559 pounds, came into the emergency center. Her chief complaint was redness, warmth, and tenderness of the skin over her abdomen and suprapubic area. The girl had been in a "normal" state of health until 72 hours prior when she became aware of the redness. This redness spread toward the umbilicus before she was able to seek medical attention. She had no previous history of trauma or infection (Appendix A).

Past Medical History

The girl's parents reported she had always been "tall and heavy for her age". They further reported that her weight gain really accelerated after age ten years. In the past year she had gained more than 100 pounds. She had not seen a primary care physician in more than five years. The girl had difficulty with ambulation and even getting to standing position from her bed. She did not attend school and had not for two years. She stated she believed she must eat hourly for fear of dying without this excessive food intake. She denied headache, vomiting, visual disturbances, polyuria, polydipsia, joint pain, neck swelling, abnormal hair or skin, hirsutism, easy bruising, or symptoms

relieved by eating. Her parents provided all of her meals. She had never tried weight loss programs of any sort nor had she asked for physician involvement in her problem with obesity. She had regular menses. She was an only child. She lived with her parents, neither of whom was overweight or obese.

Physical Exam

Significant findings on exam include morbid obesity (559 pounds) and 66.5 inches tall. Her body mass index (BMI) of 88.9 placed her clearly above the 95th percentile. Blood pressure ranged from 135 to 150 over 80 to 85mmHg with a large cuff. Acanthosis nigricans was present. Her abdomen had striae and a large pannus. Erythema, warmth and tenderness were present from the suprapubic area to the umbilicus. Skin under the pannus and over the medial thighs was macerated. She was able to stand when assisted (Appendix A).

Assessment and Plan of Care

A diagnosis of cellulitis with a confounding factor of morbid obesity was made. Antibiotics were started and the cellulitis soon resolved. A psychiatry consult was obtained. Amy was diagnosed with anxiety and depression. She began fluoxetine hydrochloride at 20mg per day. The family was also referred for family therapy. It was determined that the abnormal weight gain was related to excessive food intake and decreased physical

activity. Since the weight gain could not be attributed to endocrine or genetic disorders, obesity-related morbidities (infection, hypertension and psychological dysfunction) required therapy. Options for care included modification of calorie intake, physiotherapy with incremental increases in physical activity, appetite suppressants, and bariatric surgery.

Consultants within the case were not in agreement related to the more intensive therapies (pharmacotherapy and bariatric surgery). The disagreement was more related to the patient's age and the potential harm of gastric bypass. Additional disagreement focused toward the lack of previous attempts at weight loss, role of the parents and patient in the decision, and the degree of obesity (Cuttler, Whittaker, & Kodish, 2005).

Ethical Dilemma

This case raises concern not only from the healthcare providers' perspectives but also from the family and patient's perspectives. The first concern is related to the role of intensive therapy for obesity management in the adolescent. Secondly, there is some concern over the role the parents played in contributing to the current problem. In other words, did the parents act negligently or abusively by continuing to perpetuate the girl's poor dietary management, decreased physical activity, and total lack of medical care?

Ethics

The obesity epidemic has been well discussed in current literature (Cuttler, et al., 2005; Saguy & Riley, 2005; Powers, Rehrig & Jones, 2007; Hinds, 2005). And, while the authors agree about the increasing prevalence of childhood obesity, there remains some disagreement related to definitions of obesity versus overweight. It is estimated that in the United States, 15 to 30% of children ages six to seventeen years are overweight or obese (Cuttler, et al., 2005). Obesity, left untreated, has known deleterious effects on one's overall health. Thus, treating an obese adolescent may prevent the harmful, comorbid conditions known to accompany obesity such as Type II diabetes, hypercholesterolemia, hypertension, orthopedic and neuralgic conditions (Hinds, 2005). Conversely, longevity studies of adolescents undergoing gastric bypass are not available. So, long-term effects of such intense therapy are not known. Overarching ethical themes in Amy's case are centered on beneficence; acting in the best interest of the child. According to Lo (2005), however, acting in the best interest of the patient may not come without controversy. Discussions related to quality of life are central to plans of care for obese adolescents. Quality of life is subjective for each party involved and should consider Amy's functional abilities,

personal happiness, pain, and dignity. Additionally, a tendency toward medical paternalism in a case such as this could lead to conflicts between parents and providers while each entity attempts to act in the best interest of the patient.

Therapeutic Options

The main theme or question raised in Amy's case is not whether or not to treat her morbid obesity, but which approach is more appropriate. Modification of Amy's caloric intake is one option proposed by the caregivers. Other, more intensive options proposed were pharmacotherapeutics and surgical; neither of which are without controversy in the literature.

Caloric Modification

Sedentary lifestyle and poor nutrition are known to be factors in the development of obesity (Saguy & Riley, 2005; Powers, et al, 2007). In the absence of genetic factors, one could assume that given the chance, Amy may have some success in weight reduction if she were able to modify her diet to include low-fat, high-fiber choices and participate in some aerobic exercise. Proponents of this option would likely argue that this is the safest and most reasonable approach given Amy's age of 14 years. Since Amy had not made previous weight loss attempts one could expect some benefit from making these modifications.

Opponents of caloric modifications in such morbid cases of obesity argue that patients like Amy did not arrive at such states by accident. Powers, et al., (2007) reported results of a systematic review of various weight loss programs. The authors summarized that high cost and attrition rates increased the probability of regaining as much as 50% of the lost weight within the first two years following the program. This suggests that sustainability of such lifestyle changes will be difficult. Similarly Vazzana (2008) states that non-surgical approaches to weight loss result in negligible weight loss that likely will be regained.

Amy's case is complicated further by her youth. Amy's parents purchased, prepared, and "delivered" every morsel of food that entered her body for the previous two years. One is likely to be skeptical that caloric modification and increased exercise would be carried out by the same two average-weight individuals who allowed their 14-year old daughter to balloon to 559 pounds. It is easy to see how medical paternalism could easily be injected into the case on this reason alone.

Pharmacologic Intervention

Amy's plan of care included the addition of 20mg of fluoxetine hydrochloride (Prozac) per day. This was given to treat anxiety and depression. One could argue that treating an

underlying cause of overeating may well improve her condition. Any weight loss from this, however, will likely be minimal unless coupled with caloric modification and increased activity (Cuttler, et al., 2005). The Food and Drug Administration (FDA) has approved orlistat (Alli) for treatment of obesity for children ages 12 to 16 years. Cuttler, et al., (2005) report a recent study that showed a 4% weight loss in adolescents who took orlistat for 3 months. Other studies are now being conducted related to drugs such as sibutramine and metformin. Without specific guidelines, it is likely that the use of medication to facilitate weight loss will continue to come under close scrutiny. An additional study revealed that results were improved when the drug (sibutramine) was combined with behavior therapy.

Opponents to utilization of medications to facilitate weight loss use the Hippocratic Oath against physicians who advocate their use in obese patients. Saguy & Riley (2005) report that fat acceptance advocates frequently use the phrase, "first do no harm" in postings within their listserv. The fat acceptance advocates frequently discuss having taken amphetamines as adolescents and the mental and physical they anguish endured. Researchers in the field of fat acceptance highlight studies

such as Phen-fen's connection to heart valve problems and the adverse effects of weight-cycling as rationale for non-use.

Surgical Intervention

Bariatric surgery has been offered to adolescents for the past 50 years (Wittgrove, 2003). Its popularity has risen over the past 20 years. Magee Women's Hospital of University of Pittsburgh Medical Center reported increased numbers (12 between 1999 and 2002; >100 between 2002 and 2004) of applications from adolescents for bariatric surgery (Warman, 2005). This increase has driven leading pediatric surgeons to collaborate on guidelines for patient selection, surgical treatment, and long-term follow up. Inge, et al (2004) published guidelines for evaluation of adolescents considered to be candidates for bariatric surgery. Surgical intervention is not intended as first line therapy and is not to be offered hastily. In fact, the consensus of Inge, et al (2004) is that bariatric surgery should be considered only after demonstration of the following: failure of organized attempts at weight loss (\geq six months), nearly attained physiologic maturity, severe obesity (BMI \geq 40), ability to commit to comprehensive medical and psychological evaluations before and after surgery, supportive family environment, capacity of the patient to make decisions, ability and willingness to adhere to nutritional guidelines following

the procedure, and ability to provide informed assent to surgery. Even with the development of comprehensive guidelines for patient selection, appropriateness of bariatric surgery must still be determined on a case by case basis. Although bariatric surgery has been sanctioned as the most effective strategy for long-term weight loss and maintenance for adults, no endorsement is available for its role in adolescent weight management (Vazzana, 2008).

Aside from the obvious benefit of weight loss and reduction of comorbidities, Vazzana (2008), reports data from recent studies observing psychological and quality of life outcomes. Psychiatric symptoms are one of the most common comorbidities in adolescents being evaluated for bariatric surgery. Amy's case was not unique in that she suffered from anxiety and depression. According to Vazzana (2008), quality of life scores and body image ratings improved significantly following bariatric surgery.

As with other interventions, bariatric surgery in adolescents does not come without controversy. In Amy's case, no previous attempt at weight loss had been attempted. She would not qualify for bariatric surgery until such attempts were made. Vazzana (2008) reported indicators of poor adjustment following bariatric surgery in the adolescent population. Engaging in high

risk behaviors such as drug use, gang involvement and unsafe sexual practice are found to have occurred in a small percentage of patients reported in the literature. The author further states the concern of researchers that some of the patients may turn to drugs similar to how they previously turned to food to suppress their emotions. Bariatric surgery itself is known to carry risk of post-operative complications including undiagnosed or untreated obstructive sleep apnea, previous airway difficulties and hypoventilation syndrome (Warman, 2005).

Legal Issues

A second issue raised in Amy's case is that of confidentiality. This ethical issue carries legal implications as well. All states require healthcare workers to "report suspected child abuse or neglect to child protective services" (Lo, p. 42, 2005). In this case, Amy's parents continued to feed their morbidly obese teenager hourly and did not seek medical attention for her condition for five years. At best, their behavior is neglectful; at worst, abusive. Are caregivers in this case required to report this type of behavior?

The Florida Department of Children and Families (FDCF) defines abuse as "non-accidental infliction of physical or psychological injury...by a parent, adult household member or other person responsible for care of the child" (Ladenson,

2002). In a case similar to Amy's, the FDCF attempted on four different occasions to get approval of the juvenile courts to grant oversight of the child's health. Taylor, a 156 pound seven year old, lived with his father and grandmother who each failed to acknowledge Taylor's weight stating he was big like his father was as a child. A county judge failed to rule in favor of the FDCF stating there was insufficient justification for the department to intervene.

Several articles expand on the concept of obesity as a disease entity (Cuttler, et al, 2005; Hinds, 2005; de Vries, 2006). If accepted as a disease versus a symptom, then failure to seek medical attention on behalf of the dependent minor could be considered negligent. Thus, failure of the healthcare worker to report such neglect is also unlawful.

As one could expect, however, proof of neglectful actions is difficult, costly, and distracting from the more prominent issue of delivery of appropriate care. In Amy's case, little information was given related to the parents' neglectful behavior. In fact, there were no negative comments made toward them at all. The burden of proof rests solely on the healthcare provider. If the healthcare team employs the ethical guideline of beneficence and is acting in the best interest of the patient, removal of the "only child" of the parents will likely

only perpetuate Amy's depression and anxiety and would be counterproductive to weight loss intervention.

Personal Decision

As a pediatric nurse practitioner, I am faced with the issues surrounding pediatric and adolescent obesity. This case is not unlike cases I currently manage. In the case of Amy, I am in favor of a comprehensive program that includes nutritional education for Amy and her parents, structured physical therapy program, psychological counseling and behavior modification. These efforts will not be as effective if Amy's parents are not involved. It is hoped that successful steps in a comprehensive program will facilitate Amy's success in more intensive therapy if it should be required at some point in the future.

Before leaving Texas Children's Hospital in Houston, Texas, the pediatric surgery department had begun steps toward provision of bariatric surgery for adolescents. At the time (2004), few centers were available in the United States that were devoted to adolescent surgical intervention. Many conversations between the skin care team and the surgical team focused on long-term success of a program in a population that remained dependent on the very caregivers that were active contributors to the obese state that put them in the program. It was determined that doing nothing would be just as incorrect as

refusal to offer chemotherapy to a cancer patient would be unthinkable.

Summary

Obesity is a disease of childhood. It requires that healthcare providers, insurers, patients, and families treat it as such. Amy's case is not unique. In fact, with the increasing rate of childhood obesity, one could expect such cases to become more reported. The provision of ethical care requires that healthcare providers utilize the guideline of beneficence as they approach cases such as Amy's.

Amy's state of morbid obesity and young age directed the steps of the healthcare team in its provision of care for the patient and her family. Acting in the best interest of the patient, the healthcare team did recommend that the family begin care by participating in a comprehensive program that provided psychological and familial counseling, behavior modification, physical therapy, weight reduction through decreased food intake and intensive education regarding nutrition and exercise. Further need for more intense therapy will be assessed and regular intervals as determined by Amy's progress in the comprehensive program.

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Appendix A

Patient Visit Note

Name: Amy A. Age: 14 years Accompanied by: Parents

Pulse: 80bpm Respiration: 20/minute Temperature: 37.5C.

Blood Pressure (large cuff): 135/80; 150/85mmHg

Weight: 559 pounds (>97th%) BMI: 88.9

Height: 66.5 inches (75-90th%)

Chief Complaint: redness, warmth, and tenderness of skin over abdomen. Usual state of health until 3 days prior to admit. S/s began as redness over suprapubic area, extended toward umbilicus.

Past Medical History: Negative for trauma, previous infections. No medical care for past 5 years. Difficulty getting out of bed or walking without assistance. Does not attend school. Home schooled for 2 years. Eats hourly and believes will die unless takes in frequent food. Prior to immobility, was able to obtain own food. Parents now serve all meals. No medical care related to obesity. No attempt at weight loss.

Physical Exam:

General appearance: alert, cooperative, anxious

ROS: denies HA, vomiting, visual disturbances, polyuria, polydipsia, joint pain, neck swelling, abnormal hair or skin, hirsutism, easy bruising, or symptoms relieved by eating. Menses

regular. Only child living with parents. Both parents average weight.

Focused Physical Exam: Acanthosis nigricans present. Abdomen with striae and pannus. Redness, warmth and superficial tenderness from suprapubic skin fold to umbilicus. Erythematous macerated skin beneath pannus and on medial thighs. No lymphadenopathy. No abdominal guarding, rigidity, no tenderness. Breasts and pubic hair Tanner Stage V.

Assessment: Cellulitis superimposed on morbid obesity.

Plan: Antibiotic therapy for cellulitis

Psychiatry Consult: Anxiety and Depression identified.

Treated with 20mg Prozac daily.

Labs and Tests: Oral glucose tolerance test (peak glucose, 141 mg/dL); thyroid function (negative); overnight dexamethasone suppression test (negative); lipid profile (WNL); liver enzymes (WNL); leptin (WNL); chromosome studies (negative)

Case study adapted from (Cuttler, et al., 2005)

Appendix B

Case Consultation

Worksheet A

Step1: Personal Responses

Patient: agreed to be seen in medical facility. Agreed to take medication to resolve cellulitis. Agreed to take medication for identified depression and anxiety disorder.

Parents: Ignored child's overall health status for 2-5 years. Agreed to seek care for child. Agreed to allow child to undergo psychiatric evaluation.

Caregiver Response: Initial: anger toward parents related to child's condition. Subsequent: focused on best interest of the child.

Step 2: Facts of the Case

Morbidly obese 14 year old female with several comorbid factors including hypertension, cellulitis, depression, anxiety, Acanthosis nigricans, immobility, and social isolation. See Appendix A for further details.

Step 3a: Clinical/Psychosocial Issues Influencing Decision:

Child is in immediate need for antibiotic therapy for cellulitis. Child's morbid disease state required intervention to reduce weight thus reducing comorbid factors. Child's parents have neglected to seek medical attention for 2-5 years according to reports. Due to child's documented anxiety and depression, psychiatric involvement is necessary in order to regulate mood. Patient's decreased mobility status is concerning as subsequent comorbidities are likely such as venous insufficiency, pulmonary embolism, etc.

Step 3b: Initial Plan

Antibiotics for cellulitis; psych consult; Prozac for anxiety and depression; referral to adolescent weight loss clinic. Short term and long term follow up to determine necessary intensive treatment.

Step 4: Policies & Ethical Code Directive

Hard paternalism versus soft paternalism

Beneficence

Confidentiality (? Report to child protective services?)

Step 5: Ethical Principles Analysis

Beneficence: Act in the best interest of the patient

Paternalism: Can paternalism be justified in this case? Since the family failed to make appropriate decisions prior to ER visit, does one expect them to make appropriate decisions now? Should the healthcare team inject its own ideas without consideration of the family's wish?

Confidentiality: Was lack of education of appropriate nutrition and parenting skills an issue in the family's lack of medical assistance? Are healthcare providers obligated to report this case to child protective services.

Step 6: Possible Legal Issues

Potential need for legal assistance related to child protective services involvement. If healthcare providers choose not to report the family to child protective services, then further deterioration in Amy's health could result in legal action against the healthcare providers.

Case Consultation

Worksheet B

Plan & Implementation Strategy

1. Begin antimicrobial therapy for cellulitis
2. Psych consult (eval and treat)
 - a. Prozac 20mg day for anxiety and depression
 - b. family counseling
 - c. behavioral modification
3. Enrollment in comprehensive weight loss program to include structured weight loss, increased physical activity, counseling and nutrition education.
4. Reintegrate into public school system.

Strategy: Include parents at all levels of therapy. Involve Amy in decision making related to therapy.

Write down how your plan:

Advances Clinical/Psychosocial Interests:

The patient obtains the immediate care necessary. Appropriate intermediate goals are established and long-term goals are established. Intensive education reinforces the time and level of commitment necessary from the parents and family.

Adheres to agency policies and professional ethics codes: Caregivers work within the ethical framework of beneficence.

Minimizes harm and maximizes other ethical principles to the extent possible for the client and relevant others:

Acting under the ethical guideline of beneficence, the healthcare providers are able to provide for the well being of Amy. Efforts are maximized as the goal of the team as well as the patient and family is to provide care that benefits Amy.

Caregivers initial concerns were centered around the negligence of the family in obtaining appropriate medical care as Amy continued to gain weight at such a rapid pace. It is understandable that paternalism could have played a direct role in dictating Amy's plan of care. Using soft paternalism, the caregiver can give strong recommendations yet allow the family to make pertinent choices for care.

Allows you to operate within the law:

The only true legal concern within this case was related to confidentiality and the need for reporting negligent behavior to Child Protective Services.