

# Chapter 31

## Ethics of Pediatric Bariatric Surgery



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**Abstract** Childhood obesity affects approximately 4.5 million children in the United States, increasing an individual's morbidity and mortality. Several ethical dilemmas arise when considering metabolic and bariatric surgery (MBS) as a treatment option for pediatric patients. The benefit-risk ratio must be determined for each individual patient. Though more research is needed to determine long-term consequences of MBS, obesity without surgical intervention poses a significant risk. A multi-disciplinary approach is needed to determine a patient's candidacy. Assent and consent from a patient and their surrogate decision maker is necessary. In situations where assent is not possible, such as in syndromic obesity, careful consideration is necessary. Psychosocial problems, finances, or insurance status should not be barriers to surgery. MBS centers have a moral imperative for a just allocation of resources.

**Keywords** Metabolic and bariatric surgery · Pediatric surgery · Childhood obesity Ethics · Syndromic obesity

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### Case Presentation

Ms. JY is a 15-year-old female who presents to clinic for evaluation of bariatric surgery. The patient has a BMI of 52 and multiple co-morbidities, including type 2 diabetes, on metformin and insulin, obstructive sleep apnea, and severe depression, managed with sertraline. She has tried multiple structured weight loss programs, including two inpatient stays, without improvement in her weight or co-morbidities. She notes severe anxiety as she has been bullied for years due to her weight. Her mother has undergone Roux-en-Y gastric bypass for morbid obesity and her father has undergone sleeve gastrectomy. Both had uncomplicated courses and have been happy with their results. They both encourage their daughter to proceed with bariatric surgery, though they are worried about the financial burden. The patient is hesitant to proceed because of the necessary lifestyle changes.

## 31.1 Introduction

Childhood obesity rates have reached epidemic proportions and continue to increase, with approximately 4.5 million children meeting criteria for obesity (BMI > 95th percentile for age and sex) or severe obesity (BMI > 120% of 95th percentile or BMI > 35 kg/m<sup>2</sup>) in the United States [1]. Childhood obesity is associated with increased cardiovascular mortality of 3 to 5 times at age 50 compared to those children without obesity, increased risk of type 2 diabetes and its sequelae, obstructive sleep apnea, nonalcoholic fatty liver disease, and gastroesophageal reflux, amongst other co-morbidities [2]. Unfortunately, lifestyle interventions such as diet and exercise have had trouble with short term efficacy and demonstrated minimal long-term benefit [3]. Metabolic and bariatric surgery (MBS) has been shown to be the only efficacious long-term treatment for obesity in adults, not only reducing weight but improving co-morbidities [2]. As MBS becomes a more popular choice for treating pediatric patients, several ethical aspects must be considered. We will attempt to frame the dilemmas presented using the framework presented by Jonsen et al.: medical indications, patient preferences, quality of life, and contextual features (Table 31.1) [4].

## 31.2 Search Strategy

To search the literature, three topics were searched and reviewed. Databases used for all searches were PubMed and Embase. The search was limited to articles from 2008 and newer. The first topic was the ethics of treating childhood obesity. Terms used were “pediatric, child, or adolescent”, “obesity”, and “ethics.” Results were narrowed down by searching for “treatment” or “intervention.” The second topic

**Table 31.1** Ethical framework regarding adolescent bariatric surgery

Ethical components	Questions to ask
Medical indications	<ol style="list-style-type: none"> <li>1. What is this patient's benefit-risk ratio?</li> <li>2. What is the likely outcome with surgery? Without surgery?</li> <li>3. How can ethics research be conducted to improve our knowledge base of medical indications?</li> </ol>
Patient preferences	<ol style="list-style-type: none"> <li>1. What does the parent/guardian want? What does the child want?</li> <li>2. Are there any barriers to assent?</li> <li>3. Are all aspects of informed consent met by the patient, physician and surrogate decision maker?</li> <li>4. Do any special circumstances exist?</li> </ol>
Quality of life	<ol style="list-style-type: none"> <li>1. What does the patient value regarding their lifestyle?</li> <li>2. Are there any psychosocial barriers that must be optimized prior to surgery?</li> <li>3. Do any biases need to be addressed regarding obesity?</li> </ol>
Contextual features	<ol style="list-style-type: none"> <li>1. Is there any provider or health care system issues that might influence treatment decision?</li> <li>2. How can we optimize justice for regarding MBS for all obese adolescent patients?</li> </ol>

Adapted from Jonsen et al. [4]

was pediatric bariatric surgery outcomes. Terms used were “pediatric, child or adolescent”, “bariatric”, “surgery”, and “outcomes.” Articles were narrowed by elevating those relating to complications, long term clinical trials, and fertility/pregnancy. The third topic was ethics regarding management of if disorders or sex development. Keywords were “ethics”, “disorders of sex development” or “gender-affirming”, “treatment” or “intervention.”

## 31.3 Discussion

### 31.3.1 Medical Indications

Ethical practitioners must balance the principles of beneficence and non-maleficence to determine the benefit-risk ratio for the patient (Table 31.2). Practitioners must define the ultimate goals of treating obesity and what interventions lead to those goals, the probability of their successes, and the risks associated with such interventions. The medical problem of childhood obesity is well-defined, and it is well understood that childhood obesity increases an individual's morbidity and mortality [5]. There are many specific goals of treatment, but all must improve quality of life and reduce the risk of death and complications. However, an individual's goals take utmost precedence, and all treatments must be tailored to their specific goals. As bariatric surgery has emerged as a treatment for childhood obesity, several dilemmas have arisen when considering the benefit-risk ratio. Do we have enough data to ensure minimization of risks and long-term complications for MBS, especially

**Table 31.2** Principles of ethics in pediatric bariatric surgery

Autonomy	<ul style="list-style-type: none"> <li>• Both patient assent and parental/surrogate decision-maker consent is required</li> <li>• Surrogate decisions must act in the best interest of the patient</li> <li>• Patient preference must take precedence, and a multi-disciplinary approach is necessary for evaluating a patient's readiness</li> <li>• Goals of treatment should be tailored to a patient's goals</li> </ul>
Beneficence	<ul style="list-style-type: none"> <li>• MBS improves outcomes related to co-morbidities and quality of life</li> <li>• MBS centers must evaluate a patient's preferences and values, medical indications, and likelihood of obtaining desirable medical outcomes</li> </ul>
Non-maleficence	<ul style="list-style-type: none"> <li>• Obesity, without intervention, could impose harm to an individual</li> <li>• More research is needed to further elicit the long-term consequences of MBS</li> </ul>
Justice	<ul style="list-style-type: none"> <li>• MBS centers have a moral imperative to offer bariatric service to all individuals</li> <li>• Distributive justice must be applied to all aspects of MBS care</li> </ul>

given the longevity of most pediatric patients? Given the lack of long-term efficacy of lifestyle changes and the possible mal effects of subjecting a pediatric patient to a therapy unlikely to succeed, is it ethical to offer stand-alone lifestyle changes as a sustainable and efficacious therapy for severe obesity [6]?

### 31.3.2 *Treating Childhood and Adolescent Obesity*

Structured weight loss programs are the current “gold standard” of treatment for obesity [7]. They consist of diet changes, increased activity, behavioral modification, and parental involvement [7]. Parental involvement has been shown to be crucial in addressing environmental factors when dealing with weight loss in pediatric patients. While they are the current mainstay of treatment, they have been shown to have limited sustained improvement in BMI and comorbidities in severely obese populations and older adolescents [6, 8]. The main argument for their use is that they are safe, non-invasive, with limited risk to the patient. The implementation of structured weight loss is varied and there is no consensus on “best” practices [9]. Benefits are minimal with an expected ~1–3 kg/m<sup>2</sup> reduction in BMI and with high rates of non-completion [9]. In a large meta-analysis of all structured weight loss programs, the effectiveness of these interventions was found to be small, with only a 0.25 BMI point reduction [10]. Additionally, these interventions are less likely to be effective in children with severe obesity and in older children [6]. This “gold standard” therapy is considered such because of its minimal direct negative consequences rather than its efficacy.

The American Society for Metabolic and Bariatric Surgery (ASMBS) has recommended that prior weight loss attempts should no longer be a barrier to the surgery [2]. Further, the minimal direct negative consequences are short sighted, as multiple studies have demonstrated the long-term sequelae of pediatric obesity. With the view that this is an “otherwise healthy population,” the practitioner may choose less invasive interventions, which may be to the ultimate detriment of the patient.

### ***31.3.3 Risks and Long-Term Complications of Metabolic Bariatric Surgery***

MBS in pediatric patients has been shown to significantly improve cardiovascular disease (CVD) risk factors, insulin resistance, nonalcoholic fatty liver disease, and quality of life [2]. In studies with long term follow up, patients had a ~27% reduction of weight at 3 years [11]. There is a scarcity of studies analyzing the longer-term outcomes in pediatric patients. There are only 10 studies with follow up longer than five years, and only one at ~13 years [12]. However, there is promising data that adolescents, compared to adults, have similar weight loss with greater improvement of comorbidities [13]. Long term studies in adolescent patients, however, are still pending.

Consideration of the risks of MBS in pediatric patients is important, especially when comparing to lifestyle changes, where physiologic risk is minimal. A multi-center prospective study in this patient population shows that 8% of all pediatric MBS patients experience major perioperative complications, ~15% have minor complications, and ~5% suffer major morbidity in 3 years [14]. The major perioperative complications are reoperation (primarily for bleeding), anastomotic leak, and obstruction. Minor complications include readmission for dehydration, abdominal pain, and UTIs [14]. In the long term, 50% of adolescent bariatric patients experience anemia secondary to low levels of micronutrients (iron, folate, B6, or B12) and vitamin D deficiency [2, 15]. Following surgery, patients must be diligent with their medications, which includes vitamin and mineral supplementation, ursodiol, and acid reducing medications, and protein and fluid intake. Poor compliance to medical therapy in the pediatric population consistently leads to anemia.

Additional considerations must be given to the risk of fertility and pregnancy following MBS. Obesity increases infertility and pregnancy-related morbidity and mortality [2]. Following MBS and weight loss, fertility increase and health outcomes of both mother and child improve [16]. However, pregnancy during the rapid weight loss period following surgery (up to two years post-operatively) in adult patients has been shown to have increased complications including small for gestational age and nutritional deficiency [2, 16]. Most adolescent patients undergo sexual debut during their post-operative period and are thus at increased risk of pregnancy in the aforementioned period [17]. MBS centers must be able to provide ongoing education and counseling regarding these risks and benefits and post-operative contraception.

When evaluating the benefit-risk ratio for a patient, providers and caregivers might be reluctant to offer a drastic, permanent change to an otherwise healthy child. When the benefits are immediate, it is easier to conceptualize the benefit-risk ratio. For example, if a young child is doubled over in pain secondary to appendicitis, a parent will more readily agree to surgery for their unwell child. However, a patient with the disease of obesity may have risks and complications of their disease that are initially less debilitating but are nevertheless considerably harmful.

### ***31.3.4 MBS Candidate Requirements***

The ASMBS offers a comprehensive review of patient eligibility for MBS [2]. One of the requirements is that the potential patients and their support system undergo comprehensive psychological evaluation. This evaluation is intensive and required regardless of pre-existing mental health issues. During this evaluation, a behavioral specialist evaluates the patient's ability to cope with surgery and adapt to the permanent lifestyle changes necessary for success. Not everyone who desires MBS and meets the medical indications for surgery will become a candidate following this evaluation. The impact of a patient's psychosocial support and its ethical implications are discussed in the next section.

The ideal age of surgery has also been debated. The terms "pediatric" and "adolescent" are both used when referring to metabolic and bariatric surgery programs related to children. The recent American Association of Pediatrics (AAP) statement defines "pediatric" as any person less than 18 years old and "adolescent" as any person from age 13 to 18 [18, 19]. The ASMBS has no age guidelines [2]. The minimum age for bariatric surgery is a matter of debate but, according to the AAP policy statement, there is no evidence to support age-based eligibility requirements [18, 19]. Further, evidence in the field shows that metabolic and bariatric surgery does not lead to any stunting of growth [15, 20]. Additional studies have shown continued growth after metabolic and bariatric surgery on patients younger than 14 years old, though long term studies are required [21]. Removing the age requirement increases the number of patients eligible for surgery but raises ethical concerns about the ability of a pediatric patient to express their desire for surgery. These are discussed in the next section.

### ***31.3.5 Patient Preferences***

In the case of pediatric bariatric surgery, one must consider the preferences of the patient and of the parent(s)/guardian(s). This is especially true given the behavioral consequences of these surgeries, such as altered eating habits and the need for lifelong vitamin and mineral supplementation. The majority of pediatric bariatric surgery patients are adolescents, who should provide assent to surgery to maximize outcomes.

### ***31.3.6 Consent and Assent***

Consent is the legal contract that a patient agrees to undergo a medical intervention following an in-depth discussion with the physician regarding details of the treatment options, benefits, risks, and alternatives. Practically it is the agreement that a

physician and a patient enter, respecting a patient's autonomy to choose or express their preferences [4]. As pediatric patients are legally (in most cases) unable to provide consent, the AAP recommends obtaining assent from patients prior to interventions [22]. Assent is an expression of agreement to proceed, rather than a contractual consent [22]. Regarding MBS and pediatric patients, dilemmas arise when parents and patients are not in agreement regarding preferences. This may be magnified by the "elective" nature of MBS procedures. Further, lifestyle habits change dramatically after MBS and the changes are life-long. Though pediatric patients can only assent to the procedure, their preferences should be an essential component of the decision-making process as their motivation often determines success of the operation.

According to ASMBS, when a pediatric patient is capable of assenting, proceeding with surgery requires both positive patient assent and parental consent [2]. Assent requires decision-making capacity and understanding of risks and benefits of the procedure and long-term sequela. Similar frameworks for consent and assent occur in surgery for gender confirmation surgery and Disorders of Sexual Development (DSD).

Transgender and gender nonconforming adolescents often desire gender affirming care, which can include irreversible surgical care. Multiple organizations, including the World Professional Association for Transgender Health (WPATH), have recommended that irreversible procedures be delayed until the patient can legally consent at the age of 18 [23]. However, harm can result in delaying these operations. Guidelines suggest that gender dysphoria itself does not preclude a patient's decision-making capacity. Rather, an understanding of the risks, benefits, and long-term complications matter more than a patient's age alone [24]. Further, minors can legally consent to other treatments in certain conditions including treatment for drug abuse, contraception, and abortion.

Disorders of Sexual Development comprise a spectrum of disorders where external and internal genital are ambiguous or atypical. Surgery can be considered to optimize urogenital function, reduce cancer risk, and alter the appearance of external genitalia. These surgeries were formerly considered in an infant's development. However, as studies have illustrated harm resulting from parental decisions during infancy leading to external genitalia that may not match the patient's gender identity, new ethical guidelines were proposed. While these issues have not been definitively solved, six guiding principles have been proposed: (1) minimizing physical risk to child, (2) minimizing psycho-social risk to child, (3) preserving potential for fertility, (4) preserving or promoting capacity to have satisfying sexual relations, (5) leaving options open for the future, and (6) respecting the parents' wishes and beliefs [25].

Despite the obvious differences between DSD operations and MBS, a number of these basic principles overlap. The utmost importance is reducing risk, both current and future, to a child. Minimizing psycho-social risk continues to be a concern. The decision to intervene early via surgery can have positive and negative consequences and must be properly weighed against non-intervention.

### ***31.3.7 Cognitive Disabilities***

Pediatric obesity is higher in certain subpopulations, including youth with cognitive impairment or developmental disabilities [24]. Additionally, ~25 obesity syndromes exist in conjunction with cognitive impairment/developmental delay (CI/DD), most notably Prader-Willi Syndrome [26]. Children with CI/DD are 2–3 times more likely to suffer from obesity with less treatment options [27]. There is limited data that MBS does offer a hope of reducing their overall mortality and morbidity [27]. With a wide spectrum of cognitive abilities, undergoing psychologic testing during the pre-operative evaluation is challenging. It is likely that these patients will be unable to assent to the procedure. It is imperative that a multidisciplinary team, including psychologist, child life specialist, and social worker have an in-depth knowledge of the patient's cognitive abilities, their guardians' understanding of the procedure, and the patient's psychosocial support system [27]. There is concern that these patients will have limited ability to follow post-operative diet modifications predisposing them to greater complications. There is an imperative to continue to study the long-term effects of MBS on these patients.

The optimal age for MBS in the population of patients with CI/DD is as yet undetermined. As adolescents, these patients typically have a higher level of support system, compared to adult patients with CI/DD. These improved resources, in theory, could lead to improved outcomes.

### ***31.3.8 Quality of Life and Psychosocial Barriers***

The goal of MBS is to improve a patient's quality of life. Multiple studies have noted that physicians are notoriously poor at judging a patient's quality of life [28]. With pediatric patients, a common legal practice evoked is the best interest standard: clinicians and surrogate decision makers must act in the best interest of the child, maximizing benefits and minimizing harms [22]. Competent adults have the ability to express preferences about the future, while drawing on previous experiences to judge future values. Children have a diminished history of preferences and a long future in which to live with the results of these decisions. It is therefore imperative that an MBS committee understand the patient's current preferences, while accounting for the family's values and preferences.

### ***31.3.9 Cultural Norms***

Eating has a strong cultural significance. MBS threatens to alter a support system that is based on those cultural norms. Beyond food, obesity is related with high amount of bias and prejudice in society as well as in the medical field [29]. Patients with obesity can be perceived as lazy, having weak will power, and having poor



adherence to treatments. Obesity can be seen as an individual's failure and lack of personal control with surgery offering a "short cut" that those with better self-control would not necessitate [30]. Although MBS offers an improvement in measurable outcomes, such as reduced cardiovascular incidence and improved glucose control, it can also be seen perpetuating the societal ideals of beauty rather than true health [30]. Ethical physicians must critically evaluate the end points of treatment and their biases. This is best done by evaluating a patient's preferences and values, medical indications, and likelihood of obtaining desirable medical outcomes.

### ***31.3.10 Social Support Structure***

Strong support has positive influence on an adult patient's success following bariatric surgery [31]. Pediatric treatment requires more intimately involved caregivers: encouragement for proper eating, purchasing of appropriate food choices and vitamin supplementation, post-operative visits and appointments. Ultimately, bariatric surgery can be a burden on the patient and the family as their lifestyle is permanently changed. This change is often more expensive and cumbersome, as the pediatric patient is dependent on others for success. This dependence, in addition, provides multiple avenues for potential failure and potential harm. The ASMBS recognizes the importance of social support, but also the increased higher likelihood of dysfunction if denied MBS. Thus, the lack of family support is no longer a barrier to surgery. The ethical question is, is it fair to jeopardize a patient's future wellbeing, due to their current socioeconomic circumstance?

The best interest principal mandates that clinicians proceed in a manner that maximizes benefits and minimizes harm, while keeping the entirety of a patient's interest in mind. In adult patients, lower socioeconomic status can be associated with a lesser weight loss [32]. Adult patients who are married also have better rates of success compared to single patients [33]. With studies like these and more, one could extrapolate that having a strong social and economic support system is imperative for success. However, MBS in an adolescent has the potential to significantly change the patient's trajectory from one of co-morbidities that alter quality of life early in adulthood to one of better health. The potential wellbeing of a child and future adult is in the best interest of the patient. As noted in the October 2019 AAP statement, despite socioeconomic status, race, or other factors, all pediatric patients should have access to MBS [18].

### ***31.3.11 Contextual Features: Justice of Allocation of Resources***

The decision to proceed with bariatric surgery for a patient exists in the context of a larger health care system with limited resources and a growing epidemic of obesity across the world. The principle of justice requires that each participant in a system

receives an equal distribution of the benefits and burdens [4]. Regarding obesity, there exists an inequitable share of the burdens. There are significant health disparities, with higher rates of obesity in African American, Native American, and Hispanic adolescents. Disproportionately, these populations undergo a lower rate of MBS in their adults [2]. Pediatric obesity disproportionately affects the socially disadvantaged as well [34]. Pediatric obesity is more likely to represent a failure of the social structure, rather than the failure of an individual.

MBS surgery centers have a moral imperative to offer bariatric services to all individuals, regardless of their financial resources [18]. Pediatric hospitals and MBS centers must value distributive justice and work tirelessly to ensure distributive justice to all patients [5]. This extends to every aspect of the MBS program: preoperative weight loss programs, post-operative care and access to post-operative nutrition and medicines.

### **Case Conclusion**

Ms. JY undergoes evaluation by a multi-disciplinary team. After thorough discussions with the surgeon, dietician, physiologist, and previous patients, JY feels like she understands what her life will entail should she proceed with surgery. She understands the risks of surgery and well as the risks of her current obesity should she not undergo surgery. The committee decides that she meets criteria for MBS and surgery is offered. She ultimately gives her assent. In preparation for surgery, her parents meet with a financial counselor and discuss options. The hospital has offered her parents help with both the costs of surgery and with prescriptions following.

## **31.4 Conclusion**

There are several ethical issues in pediatric bariatric surgery to consider. The patient's benefit-risk ratio must be optimized. Ultimately more research is needed to further elicit the long-term consequences of MBS on adolescent patients. As it now stands, delaying bariatric surgery could provide more harm to a child compared to the risk of an operation. Patient preferences are of utmost concern and a multi-disciplinary approach is needed. Assent must be obtained from an adolescent, and surrogate decision maker must act in the best interest of the patient. Populations, such as syndromic obesity, exist that warrant careful consideration regarding surgery. Patients, family members, and healthcare providers need to recognize their own biases towards obesity and preferences of quality of life. Difficult psychosocial situations must be optimized prior to surgery but are not barriers that should prevent surgery. Lastly, MBS centers have a moral imperative to provide just allocation of resources to patients, regardless of financial or insurance status.

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