

CASE REPORT

Hearing Their Voices: Exploring the Patient Narratives of Adolescent and Young Adults Who Have Undergone Metabolic and Bariatric Surgery: A Case Series

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Abstract:

Background: Severe obesity in adolescence and young adulthood is undertreated which leads to obesity-related chronic diseases that progress into adulthood. Many organizations including the American Academy of Pediatrics (AAP) support early consideration of metabolic and bariatric surgery (MBS) in the pediatric population to reduce morbidity and mortality.

Methods: Five diverse patients who underwent metabolic and bariatric surgery (MBS) in the form of a Roux-en-Y gastric bypass (RYGB) and vertical sleeve gastrectomy (VSG) contributed patient narratives that captured their life, with a focus on health related quality of life, before and after MBS.

Results: MBS leads to significant improvement in health status via decreased mortality and improved health related quality of life.

Conclusion: The perspectives of those patients who have undergone surgery in adolescence and young adulthood are not adequately captured in the medical literature. While the featured voices are not representative of all, their narratives may increase awareness and utilization of MBS in the treatment of severe obesity in the pediatric population.

Keywords: adolescents; young adults; overweight; obesity; bariatric surgery; weight bias

Introduction

Over the last twenty years, the prevalence of severe obesity in children and adolescents has increased significantly¹. Defined as BMI ≥ 35 or $\geq 120\%$ of the 95th percentile or higher (whichever is lower), severe obesity affects more than 4.5 million children and adolescents^{1,2}. Severe obesity is associated with obesity-related conditions including type 2 diabetes, hypertension, and obstructive sleep apnea³. Without treatment of obesity during childhood and adolescence, both obesity and its associated related diseases can progress into adulthood^{2,4}.

The primary goal for obesity treatment in the pediatric population is to improve long-term physical health through permanent healthy lifestyle habits which include efforts to optimize nutrition and

decrease sedentary time⁵. While this may be effective for children and adolescents with overweight or Class I (mild) obesity, those with severe obesity may need to consider metabolic and bariatric surgery (MBS)^{6,7}. The indications for adolescent MBS include⁷:

- BMI ≥ 35 kg/m² or 120% of the 95th percentile with clinical significant obesity associated conditions such as obstructive sleep apnea (Apnea Hypopnea Index (AHI) >5), type 2 diabetes, idiopathic intracranial hypertension, non-alcoholic steatohepatitis, Blount's disease, slipped capital femoral epiphysis, gastroesophageal reflux disease, or hypertension or BMI ≥ 40 kg/m² or 140% of the 95th percentile (whichever is lower).

- A multidisciplinary team must consider whether the patient and family have the ability to adhere to recommended treatments pre- and post-operatively

Metabolic and bariatric surgery (MBS) is a safe and effective treatment to treat severe obesity and reverse obesity associated medical conditions^{4,7,8}.

Since 2012, organized medical organizations, including the American Society of Metabolic and Bariatric Surgery (ASMBS) and recently, the American Academy of Pediatrics (AAP), have published clinical practice guidelines and/or position statements to support MBS as standard of care in children and adolescents with severe obesity^{2,7,9,10}. While the benefits to having metabolic and bariatric surgery in pediatrics are widely publicized^{8,11,12}, the voices of those who have undergone surgery as children and adolescents have been minimally captured in medical literature. This article features the narratives of five racially and ethnically diverse patients who had MBS as an adolescent or young adult to illustrate the impact surgery has on their health and quality of life.

Methods

The patient narratives were collected as part of a larger study which seeks to evaluate the care of adolescents and young adults with severe obesity. Informed consent was obtained, and the Institutional Review Board (IRB) of Mass General Brigham approved this study. Each patient wrote their own narrative. They were instructed to address their life before and after metabolic and bariatric surgery so that the reader might understand their individual experience. Table

1 features some characteristics of the authors whose narratives are featured.

Patient Narratives

Narrative Excerpt 1

“...Looking back at all the different steps that I took to try to lose weight, I knew that it never worked out for me for some reason even though I was constantly exercising and tried different diet plans. [Undergoing weight loss surgery] is what changed everything for me. My quality for life truly changed on that day and I would never trade that in for anything else...”

Before the surgery, I didn't like who I was, but I never realized that it was because my excess weight. My self-esteem was low which made me shy and uncomfortable in my own skin. Today, I am a completely different person. I have this drive, motivation and confidence now that I never knew I would ever have...

The decision to undergo MBS was the best decision I ever made in my life. Surgery is not the easy way out. It is still a constant battle everyday with yourself. Surgery for me was just a little push to help me get to where I am today and continue to be for the rest of my life...”

Narrative Excerpt 2

“...My bariatric surgery was scheduled the summer before my junior year of high school... After 16 years of trying to manage my weight, this was the tool I desperately needed...”

It is now five years since I had weight loss surgery. I work out three to four times a week, eat balanced meals and challenge myself both academically and physically...

Even after surgery, I still sit on the line between having overweight and obesity, but I am finally living a balanced life... Bariatric surgery gave me a sense of control over my weight. I still recognize that there are several steps I must take to manage my obesity, but it feels more manageable now..."

Narrative Excerpt 3

"...I was 20 years old when I had my Roux-en-Y gastric bypass. Since surgery, I have had minimal weight regain because I still carefully monitor and manage my weight ...

My life has improved in ways I could not have even imagined. The stigma and attitudes of everyone around me changed. Jobs are easier to obtain, men began to want to date, and my relationship with my family rapidly improved because we weren't fighting over my weight anymore...

Bariatric surgery isn't without complication. I had kidney and gallstones 6 months following surgery. I still have dumping syndrome. Despite all of this, I would make the same decision. There was such an improvement in my quality of life since surgery and I think it was even better because I got the surgery at a young age..."

Narrative Excerpt 4

"... At 15 years old, with the guidance and support of my parents, I made the bold decision to undergo bariatric surgery. It was a pivotal event in my life and one of the best decisions I have ever made..."

I had surgery in March of my sophomore year in high school and 6 months later, I was 100 pounds lighter. My weight loss led to subtle, profound differences in my

interactions and relationships with my friends, peers, and faculty...After surgery, I was able to focus on socializing with my friends without the weight of my obesity interfering. Gradually, I accrued confidence and increased self-esteem.

The surgery was exactly the jumpstart I needed to get on a path towards a healthy and sustainable lifestyle. It was not an "easy" fix... Despite this, I would do it over again without hesitation."

Narrative Excerpt 5

"I have had issues with my weight for as long as I can remember...Growing up, I never really paid that much attention to my weight problem... However, as I started getting older and was told that I had hypertension, high cholesterol, and prediabetes, I realized that I had to lose weight. I tried going on diets and going to the gym, but none of these measures worked for me..."

I was 25 years old when I underwent MBS. Before the surgery, I rarely went out with my friends. The thought of hanging out with my friends was depressing because I was self-conscious about what I ate and my clothing size. Now, I do not feel insecure eating around my friends because I am able to maintain a healthier diet. I can also go into just about any clothing store I want and find something that will fit my body type. I feel like a normal person who can accomplish anything she sets her mind to without worrying about her weight holding her back..."

Refer to Supplement Data I for full patient narratives.

Discussion

Medical literature continues to illustrate the benefits of MBS but the perspective of those who have undergone surgery is lacking^{13,14}. These patient narratives excerpts illustrate the impact obesity has not only on the health, but on the overall quality of life of the adolescents and young adults featured. This case series is the first to qualitatively depict several themes around adolescent and young adults' struggle with severe obesity including minimal success with previous weight loss attempts, impact of excess weight on interactions with family and friends, feelings of isolation from societal norms, role of obesity on development of other medical conditions, and negative bias associated with MBS as tool for weight loss. Severe obesity in adolescence is associated with a significant impairment in health-related quality of life (HRQOL) as well increased mortality^{15,16}. After surgery, patients face an enhanced quality of life accompanying marked weight loss and treatment of chronic disease^{14,17}.

There has been a slow, but steady increase in the utilization of MBS in youth in the US¹⁸. Unfortunately, access to MBS is elusive for many adolescents and young adults. Primary care providers serve as a source of referral for bariatric surgery, but are less likely to be certified by the American Board of Obesity Medicine (ABOM), which might decrease the likelihood of MBS as a consideration in this population¹⁹. In several leading academic centers, there are significant disparities that exist with regards to youth access to care for MBS. This is even more pronounced for patients from minority racial and ethnic backgrounds^{20,21}. Yet,

several studies have noted favorable metabolic and weight outcomes in adolescents and young adults, regardless of the procedure that has been performed^{13,22-24}.

The young adults featured in this article have no regrets about undergoing MBS at their age, surgery is not appropriate for all patients with severe obesity. Contraindications for MBS include⁷:

- A medically correctable cause of obesity
- An ongoing substance abuse problem within 1 year of surgery
- A medical, psychiatric, psychosocial or cognitive condition that prevents adherence to postoperative dietary and medication regimen
- Current or planned pregnancy within 12 to 18 months of the procedure

Following medical clearance, the pre-operative assessment can be long, lasting several years, as mentioned in selected narratives. Best practice guidelines recommend children and adolescents undergo MBS at a tertiary care center under the management of a multidisciplinary team⁷. This team consists of a pediatric/adolescent obesity medicine specialist, bariatric surgeon, registered dietitian, pediatric psychologist and a patient care coordinator^{7,12}. Each member of the team plays an important role in deciding what procedure is best given the patient's severity of obesity and underlying medical conditions, when a child or adolescent is ready for surgery, and whether the cost of the procedure will be covered by insurance⁶. A recent review of Teen-LABS data demonstrates only 47% of candidates for surgery receive insurance approval following an initial request¹⁰.

After surgery, patients are at risk for postoperative complications including nephrolithiasis, cholelithiasis and dumping syndrome, as one narrative explained. Select patients may need another surgical intervention. A recent review noted 9.6% of patients required an additional procedure within 3 years of initial surgery²⁵. Additionally, patients are at risk for vitamin and mineral deficiencies following MBS and require lifelong supplementation.

All patients following MBS continue their lifelong battle against overweight and obesity. Due to extensive education prior to surgery, young adults and adolescents understand the role of a healthy lifestyle in weight maintenance. Nevertheless, patients may need to utilize anti-obesity medications to mitigate inadequate weight loss or weight regain that can occur following surgery²⁶. While every adolescent and young adult with severe obesity has a different perspective on MBS, the narratives featured in this article provide insight on how surgery can positively impact one's health and overall quality of life—a vantage rarely seen in medical literature.

Conclusion

Prior to metabolic and bariatric surgery, children and adolescents with severe obesity are negatively impacted by excess body weight leading to overall poor physical/mental health and social isolation. The narratives demonstrate how individuals can reclaim their young adulthood through surgery. The decision to undergo metabolic and bariatric surgery requires a collaborative effort between the patient, family and the multidisciplinary team. The associated complications are life-long and need to be discussed with the patient and patient's caregivers prior to operation. There is a need for more subjective studies to assess the patient's perception of MBS, both pre- and post-operatively.

Author Contributions:

VRJ, KAN, JJS, GG, and FAN, co-wrote the paper with input from FCS. FCS designed and directed the paper. All authors reviewed the final manuscript.

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