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Ethics and psychosocial aspects in child and adolescent candidates for bariatric surgery

Luiza Amélia Cabus Moreira

Abstract

The treatment and prevention of obesity in childhood and adolescence are often discussed by both physicians and the lay public. Even with little information in relation to the long-term consequences of bariatric surgery in this age group, there is evidence to suggest that this procedure is being offered more and more frequently. Extremely relevant ethical issues exist relating to concepts such as beneficence, autonomy, capacity and equality. The aim of this paper was to discuss the ethical and biopsychosocial aspects involved in decisions about performing this surgery to treat obesity in children and adolescents, through a literature review of Pubmed from May 1994 to May 2015 using the terms "ethics" and "bariatric surgery" × "adolescents" × "children". The surgical treatment of obesity in children and adolescents is controversial. Physicians should be aware of this and make currently existing information available to parents and patients.

Keywords: Ethics-Bioethics. Adolescent. Obesity. Bariatric surgery.

Resumo

Ética e aspectos psicossociais em crianças e adolescentes candidatos a cirurgia bariátrica

Tratamento e prevenção da obesidade na infância e adolescência são discutidos entre médicos e público leigo. Há poucas informações disponíveis sobre cirurgia bariátrica nessa faixa etária quanto a consequências em longo prazo, mas dados sugerem que esse procedimento é oferecido cada vez mais frequentemente. Surgem questões éticas de extrema relevância relacionadas a conceitos como beneficência, autonomia, capacidade e igualdade. O objetivo deste trabalho é discutir aspectos éticos e biopsicossociais envolvidos na decisão sobre a intervenção cirúrgica para casos de obesidade em crianças e adolescentes. Trata-se de revisão de literatura mediante pesquisa no banco de dados PubMed entre maio de 1994 e maio de 2015, utilizando os termos "ethics" e "bariatric surgery" × "adolescents" × "children". Verificou-se que o tratamento cirúrgico da obesidade em crianças e adolescentes é controverso. Médicos devem estar atentos ao disponibilizar para pais e pacientes todas as informações atualmente existentes.

Palavras-chave: Ética-Bioética. Adolescentes. Obesidade. Cirurgia bariátrica.

Resumen

Ética y aspectos psicosociales en relación a niños y adolescentes candidatos a cirugía bariátrica

El tratamiento y la prevención de la obesidad en la infancia y en la adolescencia suelen ser discutidos entre los médicos y el público en general. Incluso con escasa información sobre la cirugía bariátrica en este grupo etario en relación con sus consecuencias a largo plazo, existen datos que sugieren que este procedimiento se ofrece cada vez con más frecuencia. Surgen cuestiones éticas de extrema relevancia vinculadas a conceptos como beneficencia, autonomía, capacidad e igualdad. El objetivo de este trabajo es discutir los aspectos éticos y biopsicosociales que intervienen en la decisión sobre la realización de cirugías para casos de obesidad en niños y adolescentes. El estudio se trató de revisión de literatura, mediante investigación en la base de datos PubMed para el período comprendido entre Mayo de 1994 y Mayo de 2015, utilizando los términos "ética" y "cirugía bariátrica" × "adolescentes" × "niños". Se verificó que el tratamiento quirúrgico de la obesidad en niños y adolescentes es controvertido. Los médicos deben estar atentos a poner a disposición de los padres y pacientes todas las informaciones actualmente existentes.

Palabras clave: Ética-Bioética. Adolescentes. Obesidad. Cirugía bariátrica.

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Declara não haver conflito de interesse.

Recent years have seen a growing interest in the treatment of obesity, especially among the pediatric population, as this condition tends to continue into adulthood and result in clinical and psychological problems such as depression and low self-esteem 1. According to Barlow, the American Academy of Pediatrics (AAP)² makes clear the need to identify and treat obesity at various ages. It recommends that children aged between two and 18 years old with a body mass index (BMI) between the 85th and 95th percentiles for age and gender (evaluated by growth curves) are at risk of obesity and should be treated. Those with a BMI>95th percentile for age and gender are obese and weight gain should be stopped and reversed. According to the 2007 AAP criteria², an increase of between 10% and 20% in the frequency of obesity in children has been identified over the last 30 years, with an even greater incidence in populations at risk (50 to 60%) 3,4.

Although the prevention of obesity in children and adolescents receives substantial attention, the effectiveness of preventive measures is little known ^{5,6}. There are several options for treating young patients with obesity, including lifestyle changes, diet and pharmacological treatment, but their efficacy is limited ⁷⁻⁹. Programs targeting dietary changes and increased physical activity together produce an average loss of 5% of body weight and, in general, studies have descried its effectiveness as low ¹⁰⁻¹².

The success of bariatric surgery (BS) among adults has generated the possibility of it being used with children and adolescents. However, surgical intervention in this age group presents specific issues. The question is: should BS become a standard treatment for children and adolescents with severe obesity? The aim is to minimize health problems, but there is no data on the safety, evolution and cost-effectiveness of the procedure among this age group. In addition, the lack of maturity of young people generates problems in relation to autonomy ^{13,14}.

It should also be understood that surgery does not cure obesity and that children and adolescents may not fully understand that such treatment does not represent a solution, but an intervention that will limit their social activities related to food. They may not understand that they should adhere to a diet, perform physical activity and replenish vitamins and other elements that may not be absorbed because of the procedure ¹³.

The objective of the present study is to discuss the ethical and biopsychosocial factors involved

in decisions on surgical intervention for cases of obesity in children and adolescents. It is a literature review carried out by means of a search of the PubMed database, comprising the period between May 1994 and May 2015, using the terms "ethics" and "bariatric surgery" × "adolescents" × "children".

Aspects involved in the discourse on obesity

The treatment of childhood obesity raises numerous ethical, moral, and legal issues. The significance of obesity in Western society is a crucial factor and one which goes beyond medical questions, as the body is an important part of the self-representation of individuals. A thin or slim body is considered beautiful and interpreted as normal and healthy ¹⁵. The control of eating habits becomes a way of disciplining the body. There seems to be widespread thought that the obese individual is someone who cannot "control" themselves ¹⁶, making them primarily responsible for complications due to weight ¹⁷.

There are at least two discourses on obesity, that differ in their interpretation ¹⁷: 1) obesity is not a disease but an individual characteristic. It is a consequence of individual choices and, therefore, the individual should take full responsibility; 2) obesity is a disease or at least a risk factor for other diseases (hypertension, diabetes etc.) and should be treated.

Despite expressions such as "the obesity epidemic" and the identification of a gene for obesity, which link to environmental and genetic factors and imply that being obese is not simply a choice ^{18,19}, there is a widespread belief that obesity is a behavioral issue linked to a lack of control on the part of both children and their legal guardians. This belief infers that people are obese because they eat too much and do not exercise, which generates stereotypes and discrimination ²⁰ such as the idea that overweight and obese people are lazy, unmotivated, less competent and lack self-discipline ²¹.

Stereotypes and prejudices result in discrimination about appearance and affect the integrity and dignity of young people who are obese and are going through a vulnerable and susceptible phase of development. They also raise the question of whether pharmacological or medical interventions are an appropriate solution to a social problem ²². In the United States, the most discriminated group is obese people, and

this prejudice is legal, with restrictions in public places and discrimination in the workplace ²³. Obese children are at greater risk of not continuing their studies ²⁴ due to several factors: the physical characteristics of the school, which has seats and tables that are inadequate for obese people; bullying; a lack of social opportunities, such as participating in sports and games; and discrimination on the part of teachers.

According to Christopher Mayes ²⁵, the argument used by some scholars of the subject, namely that obesity is a choice, as it stems from an unsuitable diet and little exercise, is highly simplistic. Those who argue that there is a choice mean that the individual "has to pay for their decisions" and that the state must intervene to reduce the costs to society. However, Mayes proposes a counterargument by questioning the benefits to the industry that proposes to fight obesity. Obviously, individual behavior contributes to weight gain, but focusing solely on the individual and ignoring genetic, social, cultural, economic, and environmental factors that precede individual behavior leads to even greater stigmatization of obesity.

According to Venkatapuram, Bell and Marmot ²⁶, a considerable body of evidence suggests that health in general and obesity in particular are a result of the way in which society organizes itself through economic and social policies and practices. In this context, the issue that obesity is more prevalent in less privileged socioeconomic groups and among those of non-Caucasian ethnicity, which may hinder the access to treatment of persons belonging to minorities, must also be considered ^{3,27,28}.

Obesity is better understood as a disease whose pathophysiology of response to environmental factors is genetically determined and which, simply put, is a result of the imbalance between consumption and energy expenditure. At present, the regulation of hunger, satiety and energy use are scientifically little known²⁹, and therefore bariatric surgery emerges as a symptomatic solution that may be seen as part of the medicalization of the private sphere and of the life of each individual²⁷.

Medical consequences

In addition to the previously mentioned psychosocial aspects, obesity is associated with several comorbidities: type II diabetes and hyperinsulinemia ³⁰, sleep apnea and hypertension ³¹,

hepatic steatosis ³², myocardiopathy ³³ and gastroesophageal reflux disease ³⁴. In the long term, obese people have a lower life expectancy, an increased risk of cardiovascular disease, and an increased risk of cancer (colon, prostate, and breast) ³⁵. While some of the established complications can be reversed with effective weight loss, others cannot ^{25-27,36}.

Ethical aspects of bariatric surgery in children and adolescents

In addition to the ethical issues of beneficence, non-maleficence, autonomy and justice, it should also be considered that bariatric surgery is a relatively innovative treatment and its long-term consequences are unknown ^{37,38}. It should therefore be carefully evaluated, especially when considering procedures in the pediatric population ³⁹.

General information regarding the procedure

Some extremely relevant information to the understanding of the issue has already been established. This includes which surgeries are available, what are the recommendations of the guidelines regarding the indication and contraindications of BS, its controversial elements and risks to the pediatric age group. There are three bariatric surgery procedures currently available:

- 1) Roux-en-Y gastric bypass: a procedure that can be performed laparoscopically, resulting in restrictive functioning and malabsorption ⁴⁰, which can lead to malabsorption of nutrients such as vitamin B12, calcium, vitamin D, iron and thiamine. Several guidelines agree that it is appropriate for adolescents ⁴⁰⁻⁴². It appears to be comparatively effective when evaluated in studies with adults ⁴²;
- Adjustable gastric band: not yet approved for adolescents due to a lack of studies and the presence of complications, such as displacement of the balloon⁴². However, it can be considered in individualized cases;
- Vertical gastrectomy: not yet approved for adolescents due to a lack of studies ⁴².

Brei and Mudd ⁴³ evaluated the US and Canadian guidelines for bariatric surgery in adolescents in the period between 2007 and April 2013. Seven guidelines were evaluated, and the authors observed variations in the criteria for the definition of adolescence. Yermilov et al. ⁴⁴ defined ages ranging from 12 to 18 years, while

August et al. ⁴⁵ defined this group based on the pubertal stage. Barlow ⁴⁶ used physical maturity as a minimum criterion but defined age limits of 15 for boys and 13 for girls, as are generally used. Pratt et al. ⁴² classified 95% of expected height in adulthood from radiographs and concluded that this cut-off point limits the use of BS for those under 12 years of age.

As such, the authors generally agree that skeletal maturity is recommended as a criterion for adolescent candidacy for surgery, since the microdeficiencies resulting from the surgical procedure may compromise growth. Another relevant finding in the study by Brei and Mudd 43 is the lack of consistency about which comorbidities and at what level of severity surgery should be recommended and what BMI should be the cutoff point. BMI>40 kg/m², regardless of comorbidities, would be indicative of BS 40,47, while other guidelines 44,45 consider surgery for BMI>40 kg/m² only if there are severe comorbidities. Michalsky et al. 41, Pratt et al. 42 and Barlow 46 also use BMI > 40 kg/m² with comorbidities, but do not specify their degree of severity.

There are those who consider BMI > 35 with serious comorbidities a recommendation for BS in adolescents 41,44,47, but the Society of American Gastrointestinal and Endoscopic Surgeons 40 does not specify how severe these comorbidities should be. In general, comorbidities include type II diabetes, obstructive sleep apnea, pseudotumor cerebri. Nonalcoholic steatohepatitis, dyslipidemia and impaired quality of life 41,42,44. Depression is the most commonly considered contraindication, but if it is controlled then BS can be performed, as is the case with other psychopathological profiles 40-42,45. Pregnancy and Prader-Willi syndrome are exclusion criteria 45, as is untreated endocrinopathy 47.

Inge et al. 48 performed the largest study of BS-related complications. They evaluated 242 adolescents in five centers in the USA and adverse effects were classified as major (risk of death) and minor. During the first 30 postoperative days, 8% of the patients had major complications, including intestinal obstruction, bleeding, and anastomotic leaks. Minor complications (urinary tract infection, solid organ damage, atelectasis, pneumonia, bleeding without the need for transfusion) occurred in approximately 15% of patients. Data from The Bariatric Outcomes Longitudinal Database indicate a mortality rate of 0.13% and

level of 10.27% for other complications, which are generally considered minor ⁴⁹.

The question of beneficence

Beneficence is the ethical principle that determines that physicians must act for the benefit of the patient, seeking ways to restore health and promote well-being 39. In order to adequately comply with this principle, when the decision to perform surgery is made, some questions to verify the additional steps that must be taken to mitigate the possible undesirable effects of the procedure should be answered. 1) Is there support from the pediatric/ surgery societies to carry out the intervention on children and/or adolescents?, 2) Does the hospital or service that carries out the procedure have a monitoring program, which is recommended both before and after the procedure?; 3) Does the surgeon or clinician recommend the surgery, and the family and the patient consent?

For Hofmann 13, there are three basic questions to be answered to ensure beneficence in case of bariatric surgery for children and adolescents: 1) does bariatric surgery benefit the adolescents and children?; 2) what are the long-term effects?; 3) what is its efficacy, effectiveness and efficiency? In order to preserve the principle of beneficence in the case of BS, the results of the surgical procedure should be better than those of clinical treatment (restrictive diets, exercise programs, behavioral therapy) regarding the reversal of medical and psychological problems caused by obesity. Violation of beneficence will occur when children and adolescents with morbid obesity do not undergo proper preoperative assessment of comorbidities. It will also be violated if medical/behavioral treatment is not attempted and if the surgical team or hospital is unable to perform the procedure and provide the necessary follow-up after surgery 39.

The association between obesity and increased morbidity and mortality shows the need for effective treatment for obesity. However, current medical and behavioral interventions for morbid obesity (BMI≥40 kg/m²) rarely result in effective weight loss and, even when this occurs, maintaining said weight loss is not common in the long term. Therefore, surgery is more effective not only in relation to weight reduction when compared to clinical treatments, but also in terms of maintaining its possible long-term beneficial effects ^{13,39}.

BS performed in adolescents results in a reduction of 33-37% of initial BMI during in the first

year after being carried out, and studies suggest that the earlier the procedure is performed, the greater are the chances of results approaching "normal" goals. That is, those who undergo the procedure with a BMI of 55 kg/m² should reach, if the operation is successful, 35 kg/m². Likewise, if BS is performed on adolescents with a BMI of 45 kg/m², the expected result will be 30 kg/m². As the cut-off point for the recommendation of BMI surgery is high, in most cases grade I obesity has already been reached, which necessitates the maintenance of diet, physical activity and follow-up by a specialized team, and the continual repetition of this information 50-52.

Olbers et al. ⁵¹, in a prospective, two-year study in adolescents who underwent BS, found that weight loss was maintained throughout that period. Sugerman et al. ³⁸ reported that 20 adolescents with a mean BMI of 52 kg/m² lost on average 36% of BMI, achieving 34 kg/m² in five years, which was maintained for around ten years after surgery, a result similar to that observed in adults. This study provides no information about whether there was weight gain after this follow-up period. In addition, the sample number was small.

A systematic review by Treadwell, Sun and Schoelles ⁵³ found that there was a significant reduction in BMI, either with laparoscopic adjustable gastric banding (LAGB) or Roux-en-Y gastric bypass (RYGB). The surgery resolved some medical conditions, such as hypertension and diabetes, but the detailed description of these results was not satisfactory. More frequent complications for LAGB were band slippage and micronutrient deficiency, but band erosion, hiatal hernia and wound infections also occurred. More serious complications occurred with RYGB, such as pulmonary embolism, shock, intestinal obstruction, postoperative bleeding and severe malnutrition ⁵³.

Few studies have evaluated the psychosocial effects of bariatric surgery, and results are based on small samples and short-term follow-up ⁵⁴. Some studies indicate significant rates of depression and low self-acceptance in adolescents following the installation of an adjustable gastric band ⁵⁵. When post-bariatric surgery results are not as expected, people may feel ashamed and guilty. ⁵⁶ This indicates that there is a need for psychological counseling before and after BS, as well as psychosocial support for the most vulnerable subgroups of adolescents ⁵⁴.

There is little high quality knowledge about the benefits in this age group. If the non-controlled series of selected centers are evaluated,

there appears to be benefits to bariatric surgery, but there is a lack of evidence of the long-term outcomes 13,14,39,42 . For Han, Wu, Lean, the risks of bariatric surgery are considerable and its safety and efficacy in children remains unknown. Therefore, surgery should be reserved for the more severely obese (BMI > 50 kg/m²) or BMI > 40 kg/m² with significant comorbidities and even in such cases with extreme caution 57 .

Autonomy

Respect for patient autonomy is important from a legal and medical ethical point of view. In order for the autonomy principle to be preserved, it is necessary for the individual to have competence and receive adequate information ⁵⁸. The decision on performing BS in children and adolescents is challenging, given the reduced autonomy and greater vulnerability of this group ⁵⁹. Surgery always requires great trust between patient and physician, as inevitably the patient loses autonomy at the time of surgery.

In pediatric patients, the decision lies with those responsible, who are required to give consent for surgery as they are supposed to be in a better position to know what is best for their children. For parents, the decision for surgery to be carried out may occur after months of seeing their children attempt to lose weight ineffectively or after the diagnosis of a severe comorbidity, such as type II diabetes 38. In all cases where BS is recommended it is important to evaluate the genuine knowledge of the parents and the patient about the procedure. Such careful evaluation is of paramount importance as there can be much optimism about the procedure, based on information from the media, lay publications or the internet. The desire to have a socially accepted body free of comorbidities may interfere with the deeper understanding of surgical risks.

Patients and their caregivers should be fully aware of the irreversible nature of some techniques in the case of Roux-en-Y gastric bypass surgery for which psychological assessment and monitoring are indispensable ³⁸. Parents may have different conceptions about the severity of obesity, as well as divergent interests as to what should be done. There are those who do not even know that their child is obese, and others who, due to their own issues, imagine that the situation is more serious than it really is ⁶⁰. It is generally assumed that parents are in the best position to know what it is best for their

children, but this may be questioned in the case of some obese children ⁶¹.

Faced with the social pressures on people with obesity and the desire to overcome this condition, a fundamental question to be considered is: do families and adolescents really understand and retain the information written and explained in the informed consent document? A study that evaluated adults undergoing RYGB in a number of stages after surgery showed that only one-third responded correctly to questions regarding the procedure and its complications one year after its completion 62.

Health professionals tend to be pessimistic about the abilities of obese people to cope with their situation ⁶³ and are often reluctant to recommend bariatric surgery for children ⁶⁴. The reason for this may be the lack of evidence of the effectiveness of the procedure and its outcomes in children, as well as fears regarding its complications ⁶³. Some studies indicate that beliefs and values about the causes of obesity influence the views of doctors and patients about appropriate treatment for this condition, as well as the issue of free and informed consent ^{13,65}.

The process leading to the obtaining of such consent must be gradual. This may take months, and during this period patients and parents should engage in weight reduction and behavioral modification programs. The progressive engagement of the patient and their family also includes simultaneous consultations with the surgeon so that surgical options, risks, complications and the chance that weight loss goals and control of comorbidities will not be achieved by BS can be discussed. It is necessary to understand the degree of development and understanding of adolescents, their values, goals and their capacity to realize the importance of committing to other practices that should be associated with the surgical procedure.

The work of the social worker is indispensable for assessing the family context and its ability to provide postoperative vitamin supplements, willingness to accompany the patient in visits to the medical group, and capacity to supervise the child. The adolescent must be able to understand that changing their diet is part of the process that follows BS, so that the results obtained are maintained, and to realize that possible side effects can be permanent ³⁹. The hierarchy of intervention often demands a change in lifestyle and drug treatment before surgery ⁶⁶.

For Raper and Sarwer ⁶⁷, there are minimum elements that should be included in the informed consent and be shown to and discussed with parents and adolescents:

- Presentation of diagnosis, including degree of obesity and extent of comorbidities in clear language, as well as the pathophysiology of obesity and its complications;
- Nature of bariatric surgery videos can help;
- Risks and benefits of the intervention, including discussion of each complication and what this may mean from a practical point of view (e.g., if anastomosis dehiscence occurs there is a risk of death and urgent reoperation);
- The behavior of the patient should continue after the procedure to achieve the objectives of weight loss and the maintenance of the same, as well as the reversal of comorbidities;
- Medical and surgical care and other issues in the postoperative period;
- Alternatives to surgical intervention, with their risks and benefits;
- Risks/benefits of not receiving surgical/medical treatment;
- Financial cost of both surgery and possible complications;
- Know the performance results of the team that will carry out the procedure and compare them with other services;
- Whether the patient will be included in a clinical research study.

The patient should be able to understand the risks of the procedure and its long-term consequences. It must be understood that BS will not save the individual's life immediately and that it is irreversible (except for the adjustable gastric band), and that success depends on the change and maintenance of eating habits and lifestyle ⁶⁸. Free and informed consent should also contain information on the irreversibility of Roux-en-Y gastric bypass surgery and explain that the consequences of the procedure after several years are unknown.

Justice

This principle requires that all those who need BS must have access to the procedure. However, bariatric surgery is a costly procedure and can drain resources from other areas of health. On the other hand, it can avoid future hospitalization, treatment

and medication costs of patients whose condition of obesity could have been treated surgically. Health interventions linked to obesity may be prescribed in the best interest of the common good as it is predictive of significant health problems in children and adolescents. However, such interventions can become paternalistic and infringe on the autonomy of the individual. There are many other values besides health, and limits to invasion or intrusion should be based on the common good, even in the area of health ⁵⁸.

Obesity is socially segmented. Studies in the USA show that children and adolescents with lower socioeconomic status and who belong to minorities are more affected by both overweight and obesity ^{3,69}. These surveys indicate that surgery is performed to a lesser extent in African-American, Hispanic, or low socioeconomic status patients with morbid obesity. In the pediatric population in the USA, obesity occurs in one in three children belonging to less favored social groups, with particularly high rates among African-Americans, girls, Hispanics and indigenous people of both genders ⁷⁰. Therefore, as it affects disadvantaged groups, it is likely that access to surgery for children and adolescents is unequal, as is the case with adults ⁷⁰.

Can the Brazilian Sistema Único de Saúde (the Unified Health System) afford the costs of the surgical procedure for all those who need it? Is it possible for everyone in the country to have access to the procedure? And will we be able to proceed in an equal manner with regard to everything that must precede surgical intervention: counseling, psychiatric and psychological support, and a physical education program for weight loss? These are broad questions that require considerable reflection.

Final considerations

There is no doubt among experts in the treatment of obesity and surgeons that adolescents with comorbidities who cannot achieve a healthy weight using conventional strategies should be considered candidates for BS. This decision must be made on an individual basis, through extensive discussion with the family and with the agreement of the patient's physician. As Godoy et al. described ⁷¹,

The awareness of the patient and their family of all stages of the process and its short- and long-term implications is of great significance to the success of the procedure. Establishing a relationship of co-responsibility between the team, the patient and their families emphasizes a commitment to changing attitudes about food choices and living habits, promoting the changes necessary to achieve the desired results.

The dignity of the individual is one of the major foundations of society and consists, above all, of seeing the human being as an individual able to respond adequately to their own needs. Respect is the greatest cornerstone for achieving this goal, and in clinical practice allows the patient to submit to the recommendations, know their risks and benefits and direct their choice to the option that best suits them, consciously considering the scientifically proven and ethically acceptable principles.

The contraindications to BS also need to be known and considered. Documented attempts at weight loss and adequate family support are essential prerequisites. Children and adolescents referred for BS should be attended at a specialized center with a multidisciplinary team with experience in evaluating and managing medical comorbidities associated with obesity and the ability to provide long-term follow up. Children, teens, and parents need to understand the nature of the surgical treatment and the role they play in its success or failure and demonstrate that they will adhere to the lifestyle changes that must be maintained. Above all, the family and the patient must understand that BS is not an effective procedure in all cases and is not a cure for obesity, but an instrument available in selected cases. Lifestyle control and change, however, remain key elements for the maintenance of weight throughout life.

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