Obesity Surgery (2019) 29:4114–4126
https://doi.org/10.1007/s11695-019-04219-2

REVIEW

# Bariatric Surgery in Children and Adolescents with Cognitive Impairment and/or Developmental Delay: Current Knowledge and Clinical Recommendations

Brittany E. Matheson, PhD[1] · Danielle Colborn, PhD[1] · Cara Bohon, PhD[1]

Published online: 22 October 2019


## Abstract

Bariatric surgery is an effective treatment for children and adolescents with severe obesity. However, outcomes in youth with cognitive impairments and/or developmental delays are understudied. This paper reviewed the literature on bariatric surgery within this population. Fourteen studies published from 1975 to 2019 were identified. The majority (93%) of studies included patients with genetic disorders. Most studies reported no peri-operative complications (69%) and improved health outcomes (79%), with variable weight-loss results (29.2–86.2% excess weight loss). No significant differences were reported for youth with and without cognitive impairment and/or developmental delay in two studies. Limited available data suggest bariatric surgery may promote weight loss and improve health comorbidities for youth, irrespective of cognitive or developmental functioning. Clinical recommendations for working with patients and families are included.

**Keywords** Bariatric surgery · Adolescents · Developmental disability

Approximately one-third (35%) of children and adolescents in the USA are considered overweight or obese [1]. Moreover, an alarming 5.6% of youth have severe obesity [2], defined as a body mass index (BMI) greater than 120% of the sex-specific BMI-for-age 95th percentile, translating to approximately 4.4 million children and adolescents nationwide [3]. Children and adolescents with obesity are likely to experience weight-related health comorbidities, such as fatty liver disease [4], metabolic risk factors for type 2 diabetes [5], sleep apnea [6–8], dyslipidemia, and elevated low-density lipoprotein cholesterol levels [9, 10], as well as limited mobility and musculoskeletal pain [11, 12]. Moreover, obesity is associated with poorer psychosocial functioning and can negatively impact quality of life [13, 14]. Obesity tracks from childhood to adolescence to adulthood [15], with increased risk of mortality in adulthood [16, 17]. Thus, early intervention efforts designed to promote weight loss and improve health during the child and adolescent years are imperative.

Obesity may not affect all children and adolescents equally. Rather, certain populations may have increased rates of overweight and obesity. Several genetic conditions, such as Prader-Willi syndrome (PWS) and Bardet-Biedl syndrome (BBS), have known associations with obesity [18–20]. Both PWS and BBS also include cognitive impairments and/or developmental delays in addition to central obesity [18, 20]. Children with trisomy 21, or Down syndrome, and autism spectrum disorder (ASD) also often have greater than expected rates of overweight and obesity [21–23]. Beyond specific syndromes and disorders, children with intellectual and developmental disabilities have been found to be 2–3 times more likely to be obese compared to children without cognitive or developmental delays [24]. In adolescents, a systematic review and subsequent meta-analysis determined that adolescents with intellectual disabilities were 1.54 times more likely to be overweight and 1.8 times more likely to have obesity than typically developing adolescents [25]. It is possible that these youth experience additional challenges related to eating behaviors and exercise/mobility that lead to excess weight gain over time.

✉ Brittany E. Matheson, PhD
bmatheson@stanford.edu

[1] Department of Psychiatry and Behavioral Sciences, Division of Child and Adolescent Psychiatry, Stanford University School of Medicine, 401 Quarry Road, Stanford, CA 94305, USA

Behavioral weight-loss treatments have limited efficacy [26–28], with only one-third of children maintaining weight loss over time [29]. Importantly, randomized clinical trials of behavioral weight-loss interventions for children and adolescents with cognitive and/or developmental delays or impairments are lacking [23]. Thus, treatment options remain limited, if not experimental, for these children. However, the negative physical and psychosocial health sequelae associated with overweight and obesity still necessitate treatment options to limit excess weight gain.

Bariatric surgery is one treatment that may promote weight loss and limit excess weight gain in individuals with severe obesity. More than 1,600 adolescent weight-loss surgeries are performed annually [30] with updated guidelines from the American Society for Metabolic and Bariatric Surgery recommending increased access to surgical treatments for severely obese adolescents [31]. Not only can bariatric surgery result in significant weight loss, it may also improve weight-related health comorbidities such as diabetes and cardiovascular risks [32, 33] with the potential to reduce premature death by upwards of 30–40% with successful surgery [34, 35]. Compared to adults, adolescents undergoing bariatric surgery experience similar weight-loss outcomes though are more likely to have resolution of weight-related health comorbidities, such as type 2 diabetes and hypertension [36]. Successful outcomes following bariatric surgery often require careful consideration of lifestyle changes in order to promote health and continued weight loss following surgery.

Despite limited data on outcomes in children and adolescents with cognitive and/or developmental delays, the improvements of obesity-related health comorbidities following bariatric surgery in youth [31, 36, 37] suggest this treatment option can enhance health and quality of life. However, recommending weight-loss surgery in children and adolescents with cognitive impairment and/or developmental delays presents unique challenges. Is it medically or ethically justifiable to exclude individuals who cannot assent from receiving weight-loss surgery, particularly if these individuals have higher rates of obesity and are suffering from weight-related health conditions? How can readiness for surgery be ascertained if a child's cognitive functioning prohibits him or her from understanding the implications of weight-loss surgery? Do these youth understand the peri- and post-operative risks associated with surgery? Will they be able to follow through with behavioral recommendations to promote continued weight-loss success? Given recent, as well as anticipated, increases in adolescent bariatric surgery [31, 38, 39], these questions are crucial to answer to better inform patient care and possibly improve post-bariatric surgery outcomes.

Due to the medical and ethical complexity of performing bariatric surgery in children and adolescents with developmental and/or cognitive delays, this paper reviews the current literature regarding bariatric surgery in these populations as well as provides guidelines for providers. We included reports of clinical outcomes, including weight and weight-related health comorbidities, in addition to adverse events and additional surgeries. A prior review on bariatric surgery in individuals with intellectual disability by Gibbons and colleagues [40] found wide variability in weight-loss outcomes across 16 studies with 49 total patients (12% to 86% excess weight loss; %EWL), with almost two-thirds of studies reporting no complications post-surgery. Only five studies included in the prior review included children and adolescents [40]. As such, we will highlight all studies pertaining to children and adolescents, including those listed in the Gibbons review, to comprehensively examine the literature within this population. We also include recommendations for evaluation, pre-operative procedures, and working with patients and families that are interested in weight-loss surgery, extending and expanding upon recommendations from the pediatric health psychology literature. Lastly, we end with a discussion on these important clinical issues and hope to inspire further investigation into this underdeveloped area of research.

## Description of Search Results/Methods

We conducted a comprehensive literature review searching PubMed (which encompasses MEDLINE) and PsycINFO databases for published articles on bariatric surgery in children and adolescents with cognitive impairments and/or developmental delays. Databases were searched with the following terms: "bariatric surgery," "weight loss surgery," "sleeve gastrectomy," "Roux-en-Y," "gastric bypass," with "cognitive impairment," "developmental delay," "autism spectrum disorder," "Down syndrome," "Prader-Willi," and "Bardet-Biedl" in combination with "children," "youth," and "adolescent."

Studies were included in this review if they were published in a peer-review journal between 1975 and 2019. Studies examining both child and adolescent populations were included. Single case reports were also included. Exclusionary criteria included non-peer-reviewed reports or articles for which no English translation was available. Reviews and commentaries of previously published findings were also excluded. A total of 96 unique searches were run through both databases based on utilizing every combination of the search terms defined above. Initial search results returned 1,453 articles for consideration. After removing duplicates, 329 unique articles remained. The authors then screened the remaining titles and abstracts, which resulted in 36 articles for consideration. A total of 14 articles met inclusion criteria by the authors for this review.

We recognize that the various disorders and syndromes included as search terms are not equivalent and have varying presentations, etiologies, and correlates, often within the same diagnostic classification. In our review, we are not seeking to homogenize patients across groups or disorders nor are we

suggesting that is an acceptable approach. Rather, our intent is to highlight the common factor that assent in some cases may be impaired, though not necessarily so, and evaluation of preparedness for surgery may be challenging. Whenever appropriate, youth should always be involved in every step of the pre-bariatric surgery teaching and evaluation process. Moreover, we recommend an individualized, patient-centered approach to care for every individual seeking bariatric surgery, with appropriate consultation with experts in cognitive and developmental delay as needed.

## Review of Literature—Children and Adolescents

A total of 14 articles met the inclusion criteria defined above and included children and adolescents (see Table 1). The results are presented as follows and organized by case study/case series report and clinical studies with comparison groups. One retrospective chart review of eight patients included one youth with BBS [52]. This study was included in Table 1 for completeness. However, since outcomes were collectively reported and it is unknown how the patient with BBS fared, this study will not be discussed onwards.

### Comparison of Outcomes

It is difficult to compare surgery outcomes included in this review to expected outcomes in typically developing adolescents, as successful surgery outcomes in youth are not well-defined. In the largest longitudinal multi-site study of bariatric surgery outcomes in adolescents to date (Teen-Longitudinal Assessment of Bariatric Surgery, Teen-LABS trial), a total of 242 youth underwent weight-loss surgery, with long-term outcomes suggesting lasting weight and health effects [37, 55]. A variety of surgery techniques were included in the study, with the most frequent procedure being the Roux-en-Y gastric bypass (66% of surgeries), followed by the vertical sleeve gastrectomy (28%), and the adjustable gastric banding (6%) [56]. No deaths and only minimal peri-operative complications were reported following surgery [56]. Minor complications were reported in 36 patients (15% of the sample) whereas major complications such as reoperations were reported in 19 patients (8% of sample) [56]. Average percent weight loss was 27% at 3-year follow-up and 26% at 5-year follow-up [36, 37]. Importantly, the Teen-LABS trial excluded participants if they could not provide informed consent or communicate with study staff [56], which limits the generalizability of these outcomes to children and adolescents with cognitive impairment and/or developmental delays. Moreover, the studies presented in this review reported on weight loss using a variety of methods, including change in weight or BMI, percent ideal body weight (%IBW as determined by using 50th percentile for age and height, or more often referred to as median body weight), percent excess weight loss (%EWL), and percent excess body mass index lost (%EBMIL). As such, we decided to present the results for each of the studies in the attached table, as well as the following text, without making direct comparisons to data from typically developing youth, unless a comparison group was included in the study design.

### Case Study/Case Series Reports

We found eleven unique case studies and case series reports on bariatric surgery in children and adolescents with cognitive impairment and/or developmental delay.

#### Weight Outcomes

Across single case studies and case series reports, reported %EWL ranged from 29.2 to 86.2% at last reported follow-up. The lowest %EWL was observed for a patient with the shortest reported follow-up (29.2% EWL at 6 months post-surgery [44]), with greater weight loss reported in studies with longer follow-ups [42, 45, 47, 49, 50]. However, these statistics are challenging to interpret, given differences in sample populations and surgical procedures. The wide variability in weight outcomes could be due to any number of factors, including heterogeneity in age ranges and follow-up time periods (6 months to 14 years post-surgery). This illustrates the challenge in extrapolating findings from a handful of case studies to larger populations and highlights the need for more systematic studies.

Several studies reported on case series of children and adolescents undergoing weight-loss surgery. Three patients with PWS ages 14, 15, and 18 years old were followed for 2 years after laparoscopic mini gastric bypass and found to have an average 79% EWL at that time, with no complications, weight regain, or need for additional surgeries reported [50]. A case study following three patients with PWS ages 15, 18, and 23 years old also found decreased weight and improved health outcomes 2 years after bariatric surgery [47]. Moreover, the authors reported an average of 63.2% EWL at the 2-year time point [47], which was largely driven by one individual who underwent laparoscopic mini gastric bypass (86.2% EWL compared to 50–53% EWL). As noted, one of the three patients studied was 23 years old, and thus, findings may not generalize across the age-spectrum to younger patients.

A case series reported on the long-term outcomes for 15 patients with PWS (ages 12–31 years old) who underwent biliopancreatic diversion procedure [49]. Six of the patients were 18 years or younger [49]. Patients in the study were observed to lose on average 59% EWL at 2 years, which declined at proceeding follow-up time points such that by 10 years, it was only 40% EWL. Of note, age at time of surgery and %EWL at 5-year follow-up were not correlated [49]. Two

**Table 1** Bariatric surgery in children and adolescents with cognitive impairment and/or developmental delays

| Authors | Patients (*N*) | Age (year) | Clinical diagnosis | Procedure | Follow-up time | Weight outcomes | Health outcomes (improvements) | Adverse events (peri-operatively) | Adverse events (post-operatively) | Need for additional surgeries |
|---|---|---|---|---|---|---|---|---|---|---|
| Case studies | | | | | | | | | | |
| Antal & Levin, 1996 [41] | 1 | 13 | PWS | BPD | 2 years | Lost 40 kg (80% of pre-operative overweight) | Mobility, glucose, cholesterol, triglycerides | Severe respiratory problems; discharged home 14 days after surgery with intermittent oxygen needed | None (respiratory problems resolved) | No |
| Daskalakis, Till, Kiess, & Weiner, 2010 [42] | 1 | 16 | BBS | Roux-en-Y | 3.5 years | 63.89% EWL; 52.28 kg/m$^2$ to 34.85 kg/m$^2$ | Mobility, hypertension, hyperuricemia | None | None | No |
| Till, Blüher, Hirsch, & Kiess, 2008 [43] | 1 | 8 | PWS | LSG | 9 months | 56.3 kg/m$^2$ to 40 kg/m$^2$ | Sleep apnea, psoriasis, glucose intolerance | None | None | No |
| Martinelli et al., 2019 [44] | 1 | 16 | PWS | LSG | 2 and 6 months | 2 months: 16% EWL; 6 months: 29.2% EWL | Blood pressure control, glucose levels, glycated hemoglobin levels | None | None | No |
| Yu, Di, & Jia, 2013 [45] | 1 | 17 | PWS | LSG | 15 months | 45.8% EWL; 46.7 kg/m$^2$ to 33.7 kg/m$^2$ | Remission of type 2 diabetes mellitus | None | None | No |
| Case series | | | | | | | | | | |
| Anderson, Soper, & Scott, 1980 [46] | 11 | 13 | PWS | Gastric bypass ($n$ = 10); gastroplasty ($n$ = 1) | 5 years | 231% IBW to 176% IBW (average) | Not reported | Wound infection ($n$ = 1); longer average hospital stay for patients with PWS (15 days compared to 11 days) | Diarrhea from dumping ($n$ = 1); death ($n$ = 1) not related to surgery (patient refused revision of operation and died from congestive heart failure 50 months after surgery) | Yes ($n$ = 4) |
| Fong, Wong, Lam, & Ng, 2012 [47] | 3 | 15, 18, 23 | PWS | LSG ($n$ = 2); LMGBP ($n$ = 1) | 2 years | 63.2% EWL (average); 50.5% and 52.8% (LSG) and 86.2% (LMGBP) | Decreased fasting active ghrelin | None | Iron deficiency anemia in LMGBP patient | No |

**Table 1** (continued)

| Authors | Patients (*N*) | Age (year) | Clinical diagnosis | Procedure | Follow-up time | Weight outcomes | Health outcomes (improvements) | Adverse events (peri-operatively) | Adverse events (post-operatively) | Need for additional surgeries |
|---|---|---|---|---|---|---|---|---|---|---|
| Marceau et al., 2010 [48] | 3 | 15–16 | PWS | BPD/DS | 1–14 years | Patient 1: 78.5 kg/m$^2$ to 61.8 kg/m$^2$ (2 years) to 82.4 kg/m$^2$ (4 years); patient 2: 57 kg/m$^2$ to 36 kg/m$^2$ (6 months) to 48.4 kg/m$^2$ (14 years); patient 3: 48 kg/m$^2$ to 32.4 kg/m$^2$ (1 year) to 41 kg/m$^2$ (6 years) to 33 kg/m$^2$ (13 years after first surgery and 7 years after second procedure) | Patient 1, unknown; patient 2, asthma improved and insulin discontinued; health problems returned with weight regain; patient 3, sleep apnea resolved; health problems returned with weight regain | Respiratory and infectious complications; hospitalizations 13–22 days (5.1 days for patients without PWS) | One patient died from complications after reoperation following weight regain 4 years post initial surgery | Yes ($n$ = 2) |
| Marinari et al., 2001 [49] | 15 | 12–31 (21 ± 5) | PWS | BPD | 10 years | 59% EWL (2 years); 56% EWL (3 years); 46% EWL (5 years); 40% EWL (10 years) | Resolution of type II diabetes mellitus; hypercholes--terolemia; hypertension | None | Incisional hernias ($n$ = 2); bone demineraliza-tion ($n$ = 1); deaths ($n$ = 2): 1 death due to respiratory failure 9 years after surgery; 1 death unrelated causes to obesity or surgery at 6 years post-surgery | Yes ($n$ = 1) |
| Musella et al., 2014 [50] | 3 | 14, 15, 18 | PWS | LMGBP | 2 years | 79% EWL | Hypertension, sleep apnea, ghrelin | None | Mild iron-deficiency anemia ($n$ = 1) | No |
| Soper, Mason, Printen, & Zellwege-r, 1975 [51] | 7 | 15 (med--ian) | PWS | Gastric bypass, gastropla-sty | 3 years | Less weight loss than patients without PWS, median weight loss not presented for patients with PWS | Not reported | Not reported | Not reported | Yes ($n$ = 3) |
| Chart reviews | | | | | | | | | | |
| | 8 (1 with BBS) | 11–18 | BBS | LSG | 1 year | | | None | | No |

**Table 1** (continued)

| Authors | Patients (*N*) | Age (year) | Clinical diagnosis | Procedure | Follow-up time | Weight outcomes | Health outcomes (improvements) | Adverse events (peri-operatively) | Adverse events (post-operatively) | Need for additional surgeries |
|---|---|---|---|---|---|---|---|---|---|---|
| Ates et al., 2018 [52] | | | | | | 40 kg mean weight loss (6 months); continued weight loss in subset patients at 12 months; not separated out by patient with BBS | Resolution comorbidities in subset (not separated out for patient with BBS) | | Death ($n$ = 1) at 5 days post-surgery due to pneumococcal pneumonia | |
| Clinical studies | | | | | | | | | | |
| Alqahtani et al., 2016 [53] | 24 patients with PWS (1:3 PWS to control group matched for age, sex, and BMI) | 4–18 (10.7) | PWS | LSG | 5 years | 59.7% EWL at 1 year for PWS (compared to 61.7% EWL in controls); 38.4% EWL at 5 years for PWS (compared to 75.4% EWL in controls); no group differences in BMI change though significant difference in %EWL | Obstructive sleep apnea, hypertension, type II diabetes mellitus, dyslipidemia | None | Hospitalization ($n$ = 1; obstructive sleep apnea and heart failure 5 years post-surgery) | No |
| Hornack, Nadler, Wang, Hansen, & Mackey, 2019 [54] | 17 patients with CI/DD (46 controls) | 13–24; (17.7 ± 2.7) | IQ < 80 ($n$ = 9) or parent report of intellectual impairment or developmental disability ($n$ = 8); Down syndrome (3) | LSG | 2 years | %EBMIL for CI/DD group: 3 months, 39%; 6 months, 48%; 12 months, 58%; 24 months, 39%; no group differences | Not reported | Not reported | Not reported | Not reported |

*BBS*, Bardet-Biedl syndrome; *BPD*, biliopancreatic diversion; *BPD/DS*, biliopancreatic diversion with duodenal switch; *BMI*, body mass index; *CD/DI*, cognitive impairment/developmental disability; *IBW*, ideal body weight; *LMGBP*, laparoscopic mini gastric bypass; *LSG*, laparoscopic sleeve gastrectomy; *OSA*, obstructive sleep apnea; *PWS*, Prader-Willi syndrome; *%EBMIL*, percent excess body mass index lost; *%EWL*, percent excess weight loss

studies reported good weight loss outcomes in youth with PWS following gastric bypass [46, 51]; one study reported weight loss averages of 176% IBW (median body weight) at 5-year follow-up [46] whereas the other did not report median weight loss [51].

In contrast, a case series of three children with PWS who underwent biliopancreatic diversion with duodenal switch reported initially positive results in terms of weight-loss post-surgery; however, all patients experienced weight regain 4–5 years post-surgery [48]. Further, two of the patients underwent a second operation and the third patient was also considering re-operation at time of publication [48].

### Health Outcomes

In addition to weight-loss outcomes, 9 of the 11 studies also reported improvements or resolution of weight-related health comorbidities following weight-loss surgery. Specifically, studies highlighted improvements in hypertension and hyperuricemia [42, 44, 49, 50, 53], dyslipidemia [41, 53], glucose intolerance [43, 48], and remission of type 2 diabetes [45, 49, 53]. Several studies reported improvements in fasting ghrelin levels [47, 50]. Sleep apnea resolved for many patients across several studies [43, 48, 50, 53]. Improvements in mobility were also reported [41, 42]. The remaining two studies did not report on health outcomes [46, 51], and thus, it is unknown how surgery impacted these patients beyond weight-loss results. Despite initially positive results, one report noted a return of health problems following weight regain for all three patients [48].

### Presence/Absence of Adverse Events

Three of the 11 studies reported peri-operative adverse events/complications, which included severe respiratory problems and infections [41, 46, 48]. Two studies reported longer hospitalizations following surgery for patients with PWS compared to patients without PWS due to respiratory complications and infections [46, 48]. The remaining studies reviewed reported no complications following surgery.

Four studies reported post-operative complications for patients within the follow-up period, ranging from iron deficiency anemia [47, 50] to incisional hernias and bone demineralization [49]. Additional surgical procedures were reported in four studies. In one case series report, two of the three patients underwent secondary weight-loss operations approximately 4–6 years after surgery, with the third patient considering an additional surgery given weight regain at 10 years after initial operation [48]. Unfortunately, one patient died from complications sustained following additional surgery [48]. Another study reported two deaths in patients with PWS during the study, with one patient death related to respiratory failure 9 years post-surgery and another death 6 years post-surgery unrelated to obesity [49]. One patient died 4 years post-operatively due to congestive heart failure; the authors report that patient declined revision of operation prior to death [46].

## Clinical Studies

Only two clinical studies have directly compared bariatric surgery outcomes in these groups. A matched control study reported outcomes after laparoscopic sleeve gastrectomy in 24 children and adolescents (ages 4–18 years old) with PWS and 72 patients without PWS [53]. Another study reported on weight outcomes following laparoscopic sleeve gastrectomy in a sample of 17 patients (ages 13–24 years old) with cognitive and/or developmental delays compared to 46 patients without impairments [54].

### Weight Outcomes

No significant differences were reported in post-operative weight-loss outcomes between children and youth with and without cognitive and/or developmental delays. Comparing outcomes among youth with and without PWS, the authors found no significant group differences regarding post-operative BMI change at various time points over a 5-year follow-up period [53]. However, groups appeared to separate on %EWL by 5 years post-surgery (38.4 % EWL for patients with PWS compared to 75.4% EWL for patients without PWS [53]). Similarly, a separate study found no differences in post-operative weight-loss outcomes at any follow-up time point up to 2 years post-surgery (at 3, 6, 12, and 24 months) between youth with and without cognitive and/or developmental delays [54].

### Health Outcomes

There were no reported differences in health-related comorbidities following surgery between the two groups, with 95% of comorbidities improved or resolved across the sample [53]. There were no reports of mortality in the 5-year study, though one patient with PWS was readmitted due to health-related complications (obstructive sleep apnea and heart failure) [53]. Health outcomes were not reported in the study by Hornack and colleagues (2019).

### Presence/Absence of Adverse Events

No adverse events or complications were reported for patients in either study [53, 54]. Whereas the authors specifically mentioned the lack of complications post-surgery in one study [53], information regarding complications was not reported in the other study [54]. No reoperations were reported in either study [53, 54].

### Summary of Research in Children and Adolescents with Cognitive Impairment and/or Developmental Delay

A total of 14 studies were identified and reported on outcomes in 89 youth. Outcome data from studies included in this review suggest that bariatric surgery is a relatively safe procedure with limited adverse events or post-surgical complications for children with cognitive and/or developmental delays. Similar outcomes in terms of weight loss, as well as adverse events and need for additional surgeries, were observed in the two studies directly comparing children with and without cognitive impairment and/or developmental delay. Across studies, patients lost weight following bariatric surgery, though some studies reported that weight loss was not sustained as expected at long-term follow-up and/or additional surgeries were recommended [46, 48, 49]. Importantly, weight-related health comorbidities often improved or resolved (79% of studies), which highlights the utility of weight-loss surgery in severely obese children and adolescents, particularly in the short-term. However, the three reported deaths related to surgical complications ($n = 1$) and obesity-related health comorbidities ($n = 2$) within the small number of total cases identified are concerning, as this rate is higher than typically reported in adolescent bariatric studies [36, 55, 56]. It should be noted that these deaths occurred across studies with varying surgical procedures and follow-up time points, and thus, conclusions regarding mortality risk following weight-loss surgery in this population remain unknown. Long-term follow-up with larger samples is needed to better understand outcomes of bariatric surgery in children and adolescents with cognitive impairment and/or developmental disabilities over time.

Although the literature search was conducted to include all studies of bariatric surgery in youth with cognitive impairment and/or developmental delay, the majority of the studies identified were for patients with PWS. Two of the studies included patients with BBS and one study included patients with Down syndrome. None of the studies identified patients with ASD. Wherever possible, research should seek to study and report on outcomes across syndromes and diagnoses in order to best inform treatment options for larger groups of heterogeneous patients with cognitive and/or developmental delays.

The emerging outcomes data from weight-loss surgery in children and adolescents with cognitive and/or developmental delays is promising. Adult studies have also supported weight-loss surgery as one treatment option for this population, though also highlight significant variability in outcomes across studies and patients [40]. Studies published since the Gibbons review suggest significant weight-loss outcomes, improved health comorbidities, and limited post-operative complications for adults with cognitive impairment and/or developmental delays [57–59]. One recent study with two young adults (a 25-year-old patient with PWS; a 28-year-old patient with Down syndrome) reported significant weight-loss at 1-year post-surgery (55% EWL and 90% EWL, respectively), with noticeable improvements in health-related comorbidities for both patients (i.e., glucose intolerance, hypertension) [58]. However, a retrospective chart review of 6 adult patients (two patients with Down syndrome; four patients with cognitive impairment of unknown cause) found a mean of 31.1% EWL at 33.7 months (mean average time since surgery), which is less than typically expected for populations without cognitive impairment [59]. Although these studies were conducted in adults, it is important to consider how generalizable the available findings from these case reports and small case series may be to youth undergoing bariatric surgery. Additionally, it is possible that children and adolescents may have improved outcomes due to the resources and support of families and caregivers, which may be less readily accessible for adults living independently or in assisted living facilities. More research is needed to clarify expectations in terms of weight loss following surgery as well as to provide additional information regarding interventions that may be able to enhance weight-loss success for this population over time, particularly if long-term follow-up data suggest a greater likelihood of weight regain and resurgence of health problems.

## Limitations

There are several limitations of the current literature that are worth highlighting, including the reliance on small sample sizes and case reports. It is important to study bariatric surgery outcomes in non-typically developing populations with systematic, rigorous methods whenever ethically possible. Further, the variability in weight-loss surgical procedures (e.g., laparoscopic sleeve gastrectomy, Roux-en-Y, biliopancreatic diversion) makes it difficult to compare outcomes, though weight-loss differences between the Roux-en-Y and gastric sleeve procedures may be less pronounced in children and adolescents [31]. Additionally, two of the included studies were published over 35 years ago [46, 51] and may not be as directly comparable to newer studies given advances in surgical procedures. Longitudinal studies are needed to better understand long-term outcomes in adolescent bariatric surgery in general as well for youth with cognitive and/or developmental delay. Additionally, it is important to assess and report quality of life post weight-loss surgery. More research is needed to fully elucidate the short- and long-term impacts of bariatric surgery in children and adolescents with cognitive and/or developmental delays.

## Discussion and Clinical Recommendations

Overall, the limited literature exploring bariatric surgery in children and adolescents with cognitive impairments and/or

developmental delays suggests a need for additional research. It is still unknown if the same risks and benefits associated with weight-loss surgery apply to this population. Importantly, the question of assent in children who do not have the capacity to cognitively understand the risks of surgery should be addressed. It is imperative that support structures are identified and in place for patients who cannot assent to weight-loss surgery in order to help maximize likelihood of post-operative success. For youth, as well as adults, with cognitive impairment and/or developmental disability, the pre-evaluation process should be utilized to carefully identify not only medical but also psychosocial support systems. In addition to attending all teaching and psychoeducation sessions, identified support individuals should be included in the pre-surgical evaluations by psychology and social work teams. Recent guidelines recommend that patients with limited capacity to assent have an identified secondary caregiver in the event that the primary caregiver becomes unavailable or incapacitated [31].

Social support systems and caregivers will likely play a significant role in ensuring adherence to medical and nutritional recommendations, both pre and post weight-loss surgery, for individuals across the age-spectrum with cognitive impairments and/or developmental delays. Thus, it is important to assess for caregiver understanding of medical team recommendations and ensure adequate supports are in place to follow recommendations. Whenever possible, the patient should be involved in complying with treatment recommendations. The use of visual schedules and reminders, repeated prompts, and reinforcement systems may help patients with limited cognitive understanding follow instructions for successful hospital stays as well as post-surgical outcomes [60–62]. As with all patients, it is important to assess and screen for access to appropriate medical and psychological care for follow-up and help patients and families problem-solve barriers that might interfere with obtaining adequate continued care.

While the following recommendations focus on children and adolescents with cognitive impairment and/or development delay, these recommendations may also be useful for providers working with diverse populations of patients seeking bariatric surgery. The following clinical recommendations could also be applicable to adults with limited cognitive functioning as well as individuals with impaired receptive or expressive language skills, deafness or hard of hearing, or non-native speakers. Providers are reminded that significant individual differences occur in terms of cognitive functioning and adaptive skills. Thus, the following recommendations are suggested as guidelines for bariatric surgery teams to consider and should be thoughtfully integrated and implemented based on individual patient-specific needs.

**Preparation for Surgery** Preparing children and adolescents with cognitive impairment and/or developmental delays for weight-loss surgery may require adaptations to the standard evaluation procedures. Providers and families may want to begin preparing the patient for surgery well in advance to help adjust to changes in routine. It may be useful to do a "walk through" or practice hospital visit prior to surgery to help familiarize the patient with the hospital environment, nursing staff, and clinic procedures [63–65]. Bariatric surgery teams should consider consulting with and working alongside social work, psychology, and child life specialists to help the patient transition to and from the hospital, decrease anxiety, and increase comfort with the unfamiliar hospital environment. Social stories, a technique used in ASD interventions, can be useful in helping patients prepare by reviewing what is socially expected in medical clinics and hospital settings [63, 66, 67]. Social stories and scripts have been used to reduce anxiety and increase compliance with medical procedures, such as blood draws [68] and imaging tests [69], in children and adolescents with cognitive impairments and/or developmental delays. Social stories could also be useful in teaching and reinforcing post-operative nutrition and lifestyle changes for patients undergoing bariatric surgery. Social stories can be developed in advance of upcoming procedures, clinical visits, or hospital stays and be routinely reviewed in advance with patients at home. Visual materials and activity schedules are effective intervention strategies to ease transitions and promote positive behavioral changes in children with intellectual and developmental disabilities [70–72]. The use of visual schedules in bariatric surgery could help patients anticipate upcoming changes to routines and make modifications to dietary intake and exercise post-surgery. Visual schedules may also be helpful for patients to know what to expect during surgery or hospital stays [64, 73], which may help reduce anxiety.

**Interactions with Providers** Physicians and providers also play an important role in helping patients with cognitive and/or developmental impairments prepare for weight-loss surgery. Physicians and providers should strive to explain procedures not only to parents/caregivers but also to patients, which may require multiple repetitions. Collaboration in communication between parents and providers is predictive of overall satisfaction with services [74] for children with developmental disabilities receiving medical care. Providers should also keep in mind that receptive and expressive language skills may vary from patient to patient. Therefore, it is possible that a child understands more than he or she can effectively communicate to the treatment team. Whenever possible, providers should speak directly to the patient and use developmentally appropriate language based on the child's receptive language abilities, which may serve not only to enhance understanding but also to promote compliance, reduce anxiety, and minimize resistance from the patient [75].

Providers may also consider using visual materials or supports to supplement instructions or recommendations communicated verbally. Some children may benefit from having routine procedures, such as temperature or blood pressure

readings, explained in advanced using pictures or words that the patient can easily understand. Patients may also benefit from watching or performing practice procedures enacted on a doll or stuffed animal [65, 68]. For instance, patients may better understand what is expected of them if they first watch a stuffed bear prepare for a hospital stay, perform a sleep study, eat smaller meals, take vitamins, undergo surgery, etc. Video modeling has also been helpful in reducing agitation and increasing compliance in children with ASD and/or cognitive impairments during medical procedures, ranging from physical exams [76] to dental procedures [77] to magnetic resonance imaging scans [78].

Medical fears are common for children with cognitive impairments and/or developmental delays [79, 80]. Interactions with providers and hospital staff may be improved with simple interventions to help patients feel more comfortable. For example, children and adolescents may pair a physician's "white coat" or a nurse's "scrubs" with previous negative experiences, such as when they received a shot or underwent a painful medical procedure. It may be helpful to remove the white coat or stethoscope for interactions in which they are not needed to increase patient's comfort and decrease agitation associated with these salient external cues. Interventions that utilize in vivo exposures, desensitization, modeling, and distraction techniques have also been found to increase compliance and decrease anxiety and avoidance-related behaviors in medical settings for children with cognitive impairments and/or developmental delays [80, 81].

**Collaboration with Ethics Committees** In cases in which a child or adolescent cannot provide informed assent due to cognitive or developmental limitations, surgical teams should consider involving their hospital or academic institution's ethics committee [31]. Published guidelines by the American Academy of Pediatrics provide recommendations regarding the role and structure of institutional ethics committees in pediatric settings [82]. Effective partnerships can not only reduce risk but also enhance patient care by ensuring appropriate informed consent processes were conducted and inviting individuals outside of the surgical team to review cases. Adolescent bariatric surgery programs may consider initiating a systematic protocol for bringing forth cases to ethics committees anytime that a child cannot provide assent so as to not preclude surgery just because a child has limited cognitive abilities [31].

**Medical Adherence/Compliance with Treatment Recommendations** As with any child undergoing bariatric surgery, the role that caregivers and guardians play in promoting successful short- and long-term outcomes cannot be understated. For children and adolescents with cognitive and/or developmental delays, the caregiver may be largely if not solely responsible for post-operative care as well as introducing and helping patients maintain post-operative dietary changes and lifestyle recommendations. As such, preparation for surgery should closely involve parents, caregivers, and guardians with additional focus on skills that they will need to help their loved one be successful post-surgery. In particular, the psychological evaluation and nutrition education pre-surgery should highlight the need for caregivers to take an active role in providing and overseeing the day-to-day care required post-surgery. Whenever possible, information should still be presented to the patient.

Reinforcement systems may be particularly useful in shaping health behaviors with children and adolescents [83–85], regardless of cognitive or developmental status. Reward systems may be implemented to increase compliance with medical recommendations, vitamin intake, regularly attending appointments, making healthy food choices, and engaging in physical activity and exercise behaviors. Health-related goals may be incorporated into new or already existing reinforcement structures or token economies [86, 87]. Parents and caregivers should identify rewards that are not food related, which could be challenging given the saliency and utility of food-based rewards.

## Summary and Conclusions

Overall, the limited research evidence suggests that bariatric surgery can be safely performed and does not result in worse weight-loss and/or health outcomes post-surgery for children and youth with cognitive impairments and/or developmental delays. However, few studies have systematically researched this question with rigorous scientific methods and with follow-up beyond 2 years. Thus, the generalizability of results is severely limited. Until additional research is completed, it is important that surgical teams clearly inform patients and families about the limited outcome data in this population to allow caregivers and guardians to make informed decisions regarding the health of their child. Treatment teams should make every effort to inform families of both the risks of surgery as well as the risks of not performing surgery, including the known health consequences of severe obesity if left untreated.

For bariatric surgery teams working with youth with cognitive impairments and/or developmental delays, we suggest close collaboration with experts in child development and behavior as well as consultation with ethics committees whenever possible. Providers may be able to employ simple adaptations and strategies to help children feel more comfortable with the surgical process and better prepare families for success with post-surgical diet and lifestyle changes. It may also be useful to review caregivers' support systems and offer psychosocial and psychological treatment recommendations in order to support their care of the patient, prevent caregiver burnout, and provide emotional support for the caretaking role. It is likely that adequate caregiver and/or psychosocial support will be essential to successful surgical outcomes, perhaps even more

so than in typically developing populations, yet this hypothesis should be tested through research and clinical outcomes data. As weight-loss surgery becomes a more viable and accessible option to a greater number of youth, more research is needed to better understand the risks and benefits of weight-loss surgery in severely obese children and adolescents with cognitive impairments and/or developmental delays.

**Funding** This study was funded by 5K23 MH10679404 (PI: Bohon).

## Compliance with Ethical Standards

**Conflict of Interest** The authors declare that they have no conflict of interest.

**Ethical Approval** This study does not contain any studies with human participants or animals performed by any of the authors.

**Informed consent** Informed consent was obtained from all individual participants included in this study.

## References

1. Fryar C, Carroll M, Ogden C. Prevalence of overweight, obesity, and severe obesity among children and adolescents aged 2–19 years: United States, 1963–1965 through 2015–2016. CDC Stacks. 2018 [cited 2019 Jul 8]. Available from: https://stacks.cdc.gov/view/cdc/58669.
2. Ogden CL, Carroll MD, Lawman HG, et al. Trends in obesity prevalence among children and adolescents in the United States, 1988-1994 through 2013-2014. J Am Med Assoc. 2016;315:2292–9.
3. Skinner AC, Skelton JA. Prevalence and trends in obesity and severe obesity among children in the United States, 1999-2012. JAMA Pediatr. 2014;168(6):561–6.
4. Vajro P, Lenta S, Socha P, et al. Diagnosis of nonalcoholic fatty liver disease in children and adolescents: position paper of the ESPGHAN Hepatology Committee. J Pediatr Gastroenterol Nutr. 2012 May;54(5):700.
5. Goran MI, Ball GDC, Cruz ML. Cardiovascular endocrinology 2: obesity and risk of type 2 diabetes and cardiovascular disease in children and adolescents. J Clin Endocrinol Metab. 2003;88:1417–27.
6. Kohler MJ, Lushington K. Differences in the association between obesity and obstructive sleep apnea among children and adolescents. J Clin Sleep Med. 2009;6:6.
7. Marcus CL, Brooks LJ, Ward SD, et al. Diagnosis and management of childhood obstructive sleep apnea syndrome. Pediatrics. 2012;130(3):e714–55.
8. Tauman R, Gozal D. Obesity and obstructive sleep apnea in children. Paediatr Respir Rev. 2006;7(4):247–59.
9. Cook S, Kavey REW. Dyslipidemia and pediatric obesity. Pediatr Clin N Am. 2011;58(6):1363–73.
10. Deckelbaum RJ, Williams CL. Childhood obesity: the health issue. Obes Res. 2001;9(S11):239S–43S.
11. Smith SM, Sumar B, Dixon KA. Musculoskeletal pain in overweight and obese children. Int J Obes. 2014;38(1):11–5.
12. Taylor ED, Theim KR, Mirch MC, et al. Orthopedic complications of overweight in children and adolescents. Pediatrics. 2006;117(6):2167–74.
13. Griffiths LJ, Parsons TJ, Hill AJ. Self-esteem and quality of life in obese children and adolescents: a systematic review. Int J Pediatr Obes. 2010;5(4):282–304.
14. Schwimmer JB, Burwinkle TM, Varni JW. Health-related quality of life of severely obese children and adolescents. J Am Med Assoc. 2003;289(14):1813–9.
15. Singh AS, Mulder C, Twisk JWR, et al. Tracking of childhood overweight into adulthood: a systematic review of the literature. Obes Rev. 2008;9(5):474–88.
16. Bjørge T, Engeland A, Tverdal A, et al. Body mass index in adolescence in relation to cause-specific mortality: a follow-up of 230,000 Norwegian adolescents. Am J Epidemiol. 2008;168(1):30–7.
17. Reilly JJ, Kelly J. Long-term impact of overweight and obesity in childhood and adolescence on morbidity and premature mortality in adulthood: systematic review. Int J Obes. 2011;35(7):891–8.
18. Cassidy SB, Schwartz S, Miller JL, et al. Prader-Willi syndrome. Genet Med. 2012;14(1):10–26.
19. Goldstone AP, Beales PL. Genetic obesity syndromes. Obes Metab. 2008;36:37–60.
20. Forsythe E, Beales PL. Bardet–Biedl syndrome. Eur J Hum Genet. 2013;21(1):8–13.
21. Bertapelli F, Pitetti K, Agiovlasitis S, et al. Overweight and obesity in children and adolescents with Down syndrome—prevalence, determinants, consequences, and interventions: a literature review. Res Dev Disabil. 2016;57:181–92.
22. Krause S, Ware R, McPherson L, et al. Obesity in adolescents with intellectual disability: prevalence and associated characteristics. Obes Res Clin Pract. 2016;10(5):520–30.
23. Matheson BE, Douglas JM. Overweight and obesity in children with autism spectrum disorder (ASD): a critical review investigating the etiology, development, and maintenance of this relationship. Rev J Autism Dev Disord. 2017;4(2):142–56.
24. Rimmer JH, Yamaki K, Lowry BMD, et al. Obesity and obesity-related secondary conditions in adolescents with intellectual/developmental disabilities. J Intellect Disabil Res. 2010;54(9):787–94.
25. Maïano C, Hue O, Morin AJS, et al. Prevalence of overweight and obesity among children and adolescents with intellectual disabilities: a systematic review and meta-analysis. Obes Rev. 2016;17(7):599–611.
26. Danielsson P, Kowalski J, Ekblom Ö, et al. Response of severely obese children and adolescents to behavioral treatment. Arch Pediatr Adolesc Med. 2012;166(12):1103–8.
27. Nemet D, Ben-Haim I, Pantanowits M, et al. Effects of a combined intervention for treating severely obese prepubertal children. J Pediatr Endocrinol Metab. 2012;26(1–2):91–6.
28. Solmi M, Köhler CA, Stubbs B, et al. Environmental risk factors and nonpharmacological and nonsurgical interventions for obesity: an umbrella review of meta-analyses of cohort studies and randomized controlled trials. Eur J Clin Investig. 2018;48(12):e12982.
29. Epstein LH, Paluch RA, Roemmich JN, et al. Family-based obesity treatment, then and now: twenty-five years of pediatric obesity treatment. Health Psychol. 2007;26(4):381–91.
30. Griggs CL, Perez NP, Goldstone RN, et al. National trends in the use of metabolic and bariatric surgery among pediatric patients with severe obesity. JAMA Pediatr. 2018;172(12):1191–2.
31. Pratt JSA, Browne A, Browne NT, et al. ASMBS pediatric metabolic and bariatric surgery guidelines, 2018. Surg Obes Relat Dis. 2018;14(7):882–901.
32. Chikunguwo S, Dodson PW, Meador JG, et al. PL-101: durable resolution of diabetes after Roux-en-Y gastric bypass is associated with maintenance of weight loss. Surg Obes Relat Dis. 2009;5(3):S1.
33. Kokkinos A, Alexiadou K, Liaskos C, et al. Improvement in cardiovascular indices after Roux-en-Y gastric bypass or sleeve gastrectomy for morbid obesity. Obes Surg. 2013;23(1):31–8.

34. Adams TD, Gress RE, Smith SC, et al. Long-term mortality after gastric bypass surgery. N Engl J Med. 2007;357(8):753–61.
35. Sjöström L, Narbro K, Sjöström CD, et al. Effects of bariatric surgery on mortality in swedish obese subjects. N Engl J Med. 2007;357(8):741–52.
36. Inge TH, Courcoulas AP, Jenkins TM, et al. Five-year outcomes of gastric bypass in adolescents as compared with adults. N Engl J Med. 2019;380(22):2136–45.
37. Inge TH, Courcoulas AP, Jenkins TM, et al. Weight loss and health status 3 years after bariatric surgery in adolescents. N Engl J Med. 2016;374(2):113–23.
38. Tsai WS, Inge TH, Burd RS. Bariatric surgery in adolescents: Recent national trends in use and in-hospital outcome. Arch Pediatr Adolesc Med. 2007;161(3):217–21.
39. Zwintscher NP, Azarow KS, Horton JD, et al. The increasing incidence of adolescent bariatric surgery. J Pediatr Surg. 2013;48(12):2401–7.
40. Gibbons E, Casey AF, Brewster KZ. Bariatric surgery and intellectual disability: furthering evidence-based practice. Disabil Health J. 2017;10(1):3–10.
41. Antal SC, Levin H. Biliopancreatic diversion in Prader-Willi syndrome associated with obesity. Obes Surg. 1996;6(1):58–62.
42. Daskalakis M, Till H, Kiess W, et al. Roux-en-Y gastric bypass in an adolescent patient with Bardet–Biedl syndrome, a monogenic obesity disorder. Obes Surg. 2010;20(1):121–5.
43. Till H, Blüher S, Hirsch W, et al. Efficacy of laparoscopic sleeve gastrectomy (LSG) as a stand-alone technique for children with morbid obesity. Obes Surg. 2008;18(8):1047.
44. Martinelli V, Chiappedi M, Pellegrino E, et al. Laparoscopic sleeve gastrectomy in an adolescent with Prader-Willi syndrome: psychosocial implications. Nutrition. 2019;61:67–9.
45. Yu H, Di J, Jia W. Laparoscopic sleeve gastrectomy in Chinese female patient with Prader–Willi syndrome and diabetes. Surg Obes Relat Dis. 2013;9(2):e25–7.
46. Anderson AE, Soper RT, Scott DH. Gastric bypass for morbid obesity in children and adolescents. J Pediatr Surg. 1980;15(6):876–81.
47. Fong AKW, Wong SKH, Lam CCH, et al. Ghrelin level and weight loss after laparoscopic sleeve gastrectomy and gastric mini-bypass for Prader–Willi syndrome in Chinese. Obes Surg. 2012;22(11):1742–5.
48. Marceau P, Marceau S, Biron S, et al. Long-term experience with duodenal switch in adolescents. Obes Surg. 2010;20(12):1609–16.
49. Marinari GM, Camerini G, Novelli GB, et al. Outcome of biliopancreatic diversion in subjects with Prader-Willi syndrome. Obes Surg. 2001;11(4):491–5.
50. Musella M, Milone M, Leongito M, et al. The mini-gastric bypass in the management of morbid obesity in Prader–Willi syndrome: a viable option? J Investig Surg. 2014;27(2):102–5.
51. Soper RT, Mason EE, Printen KJ, et al. Gastric bypass for morbid obesity in children and adolescents. J Pediatr Surg. 1975;10(1):51–8.
52. Ates U, Ergun E, Gollu G, et al. Pediatric laparoscopic sleeve gastrectomy in Turkey: short-term results. Pediatr Int. 2018;60(5):461–6.
53. Alqahtani AR, Elahmedi MO, Al Qahtani AR, et al. Laparoscopic sleeve gastrectomy in children and adolescents with Prader-Willi syndrome: a matched-control study. Surg Obes Relat Dis. 2016;12(1):100–10.
54. Hornack SE, Nadler EP, Wang J, et al. Sleeve gastrectomy for youth with cognitive impairment or developmental disability. Pediatrics. 2019;143(5):e20182908.
55. Inge TH, Jenkins TM, Xanthakos SA, et al. Long-term outcomes of bariatric surgery in adolescents with severe obesity (FABS-5+): a prospective follow-up analysis. Lancet Diabetes Endocrinol. 2017;5(3):165–73.
56. Inge TH, Zeller MH, Jenkins TM, et al. Perioperative outcomes of adolescents undergoing bariatric surgery: the Teen–Longitudinal Assessment of Bariatric Surgery (Teen-LABS) Study. JAMA Pediatr. 2014;168(1):47–53.
57. Bhardwaj N, San Martin V, Heinberg L, Burguera B. SAT-101 The combination of anti-obesity medications and bariatric surgery can be effective in resetting the cerebral adipostat in individuals with autism suffering from severe obesity. J Endocr Soc. 2019 [cited 2019 Jul 8];3(Supplement_1). Available from: https://academic.oup.com/jes/article/3/Supplement_1/SAT-101/5482861.
58. Cazzo E, Gestic MA, Utrini MP, et al. Bariatric surgery in individuals with severe cognitive impairment: report of two cases. Sao Paulo Med J. 2018;136(1):84–8.
59. Daigle CR, Schauer PR, Heinberg LJ. Bariatric surgery in the cognitively impaired. Surg Obes Relat Dis. 2015;11(3):711–4.
60. Johnson N, Rodriquez D. Children with autism spectrum disorder at a pediatric hospital: a systematic review of the literature. Pediatr Nurs. 2013;39(3):131–141.
61. Scarpinato N, Bradley J, Kurbjun K, et al. Caring for the child with an autism spectrum disorder in the acute care setting. J Spec Pediatr Nurs. 2010;15(3):244–54.
62. Thunberg G, Johansson M, Wikholm J. Meeting the communicative rights of people with autism—using pictorial supports during assessment, intervention and hospital care. Autism Spectr Disord - Recent Adv. 2015 [cited 2019 Jul 7]; Available from: https://www.intechopen.com/books/autism-spectrum-disorder-recent-advances/meeting-the-communicative-rights-of-people-with-autism-using-pictorial-supports-during-assessment-in.
63. Koski S, Gabriels RL, Beresford C. Interventions for paediatric surgery patients with comorbid autism spectrum disorder: a systematic literature review. Arch Dis Child. 2016;101(12):1090–4.
64. Thompson DG, Tielsch-Goddard A. Improving management of patients with autism spectrum disorder having scheduled surgery: Optimizing practice. J Pediatr Health Care. 2014;28(5):394–403.
65. Vaezzadeh N, Douki ZE, Hadipour A, et al. The effect of performing preoperative preparation program on school age children's anxiety. Iran J Pediatr. 2011;21(4):461–6.
66. Smith C. Using social stories to enhance behaviour in children with autistic spectrum difficulties. Educ Psychol Pract. 2001;17(4):337–45.
67. Taghizadeh N, Davidson A, Williams K, et al. Autism spectrum disorder (ASD) and its perioperative management. Pediatr Anesth. 2015;25(11):1076–84.
68. Davit CJ, Hundley RJ, Bacic JD, et al. A pilot study to improve venipuncture compliance in children and adolescents with autism spectrum disorders. J Dev Behav Pediatr. 2011;32(7):521–5.
69. Johnson N, Bree O, Lalley EE, et al. Effect of a social script iPad application for children with autism going to imaging. J Pediatr Nurs. 2014;29(6):651–9.
70. Knight V, Sartini E, Spriggs AD. Evaluating visual activity schedules as evidence-based practice for individuals with autism spectrum disorders. J Autism Dev Disord. 2015;45(1):157–78.
71. Koyama T, Wang H-T. Use of activity schedule to promote independent performance of individuals with autism and other intellectual disabilities: a review. Res Dev Disabil. 2011;32(6):2235–42.
72. Lequia J, Machalicek W, Rispoli MJ. Effects of activity schedules on challenging behavior exhibited in children with autism spectrum disorders: a systematic review. Res Autism Spectr Disord. 2012;6(1):480–92.
73. Chebuhar A, McCarthy AM, Bosch J, et al. Using picture schedules in medical settings for patients with an autism spectrum disorder. J Pediatr Nurs. 2013;28(2):125–34.
74. Galil A, Bachner YG, Merrick J, et al. Physician–parent communication as predictor of parent satisfaction with child development services. Res Dev Disabil. 2006;27(3):233–42.
75. Thorne A. Are you ready to give care to a child with autism? Nursing. 2007;37(5):59.

76. Cuvo AJ, Reagan AL, Ackerlund J, et al. Training children with autism spectrum disorders to be compliant with a physical exam. Res Autism Spectr Disord. 2010;4(2):168–85.
77. Nelson TM, Sheller B, Friedman CS, et al. Educational and therapeutic behavioral approaches to providing dental care for patients with autism spectrum disorder. Spec Care Dentist. 2015;35(3):105–13.
78. Nordahl CW, Mello M, Shen AM, et al. Methods for acquiring MRI data in children with autism spectrum disorder and intellectual impairment without the use of sedation. J Neurodev Disord. 2016;8(1):20.
79. Evans DW, Canavera K, Kleinpeter FL, et al. The fears, phobias and anxieties of children with autism spectrum disorders and Down syndrome: comparisons with developmentally and chronologically age matched children. Child Psychiatry Hum Dev. 2005;36(1):3–26.
80. Gillis JM, Hammond Natof T, Lockshin SB, et al. Fear of routine physical exams in children with autism spectrum disorders: prevalence and intervention effectiveness. Focus Autism Dev Disabil. 2009;24(3):156–68.
81. Slifer KJ, Avis KT, Frutchey RA. Behavioral intervention to increase compliance with electroencephalographic procedures in children with developmental disabilities. Epilepsy Behav. 2008;13(1):189–95.
82. Bioethics C. on. Institutional Ethics Committees. Pediatrics. 2001;107(1):205–9.
83. Bernard RS, Cohen LL. Increasing adherence to cystic fibrosis treatment: a systematic review of behavioral techniques. Pediatr Pulmonol. 2004;37(1):8–16.
84. Gilliam MB, Ross K, Futch L, et al. A pilot study evaluation of a web-based token economy to increase adherence with a community-based exercise intervention in child and adolescent cancer survivors. Rehabil Oncol. 2011;29(2):16.
85. Luersen K, Davis SA, Kaplan SG, et al. Sticker charts: a method for improving adherence to treatment of chronic diseases in children. Pediatr Dermatol. 2012;29(4):403–8.
86. Doll C, McLaughlin TF, Barretto A. The token economy: a recent review and evaluation. Int J Basic Appl Sci. 2013;02(01):19.
87. Alstot AE. The effects of peer-administered token reinforcement on jump rope behaviors of elementary physical education students. J Teach Phys Educ. 2012;31(3):261–78.