



The Team, the Team, the Team: Creating a Short Bowel Syndrome Medical Neighborhood

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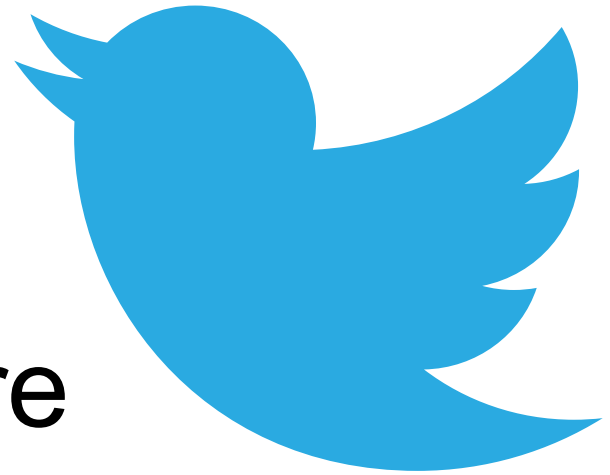
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Learning Objective 1

Integrate an interdisciplinary team to optimize the management of patients with SBS.



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Learning
Objective **2**

Apply efficacy and safety data
to treatment decision-making
for patients with SBS.



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Learning
Objective **3**

Implement best practices from state-of-the-art SBS/IR centers in the community to improve access and care for patients with SBS.



Definitions, Clinical Presentation, and Burden of Disease



Short Bowel Syndrome (SBS)

- Malabsorptive syndrome related to reduced gut length resulting in inability to maintain nutrition, hydration, and micronutrients when consuming normal diet
- Clinical features vary along a continuum, depending on the extent and anatomy of intestine lost and the ability of the patient and the remaining intestine to compensate for the loss
- Patients' treatment needs vary depending on disease severity and resection type
- Note that SBS is distinct from intestinal failure (IF)
 - Need for parenteral support
 - May be due to SBS but also functional causes

SBS in Pediatrics vs. Adults

Pediatrics

- Need for PN for > 42 to 60 days after resection
- Small bowel length < 25% of expected for age
- Etiology: necrotizing enterocolitis, atresia, gastroschisis, volvulus, trauma

Adults

- Remaining small bowel in continuity of < 200 cm
 - Medicare states < 150 cm
- Etiology: post-surgical complications, inflammatory bowel disease, mesenteric ischemia, malignancy

Clinical Presentation of SBS

Pediatrics

- Diarrhea
- Reflux
- Gas and abdominal pain
- Poor growth or weight gain
- Vitamin and mineral deficiencies

Adults

- Diarrhea
- Dehydration
- Gas, bloating, and abdominal pain
- Fatigue
- Malnutrition
- Vitamin and mineral deficiencies

Different Type of SBS According to Anatomical Criteria

SBS Bowel Anatomy Types

End-Jejunostomy



Type 1

- Rapid transit
- Acid hypersecretion
- Poor adaptation
- Large fluid losses
- Malabsorption
- Worst prognosis
- < 100 cm

Jejuno-colonic



Type 2

- Rapid transit
- Poor adaptation
- B12 and bile salt malabsorption
- Variable calorie and fluid absorption
- < 65 cm

Jejunioileo-colonic



Type 3

- Adequate absorption until about 75% resected
- Good adaptation
- Slower transit
- Uncommon; best prognosis
- < 30 cm

Achieving Early and Accurate Diagnosis

- High index of suspicion based on patient history
- Laboratory studies
- Fecal fat test
- Imaging
- Endoscopy
- Colonoscopy

Impact of SBS on QoL and Family

- Adults with SBS on PN¹
 - Most intense concern is being a burden to others
 - Loss of independence
 - Activities require intense planning and are negatively impacted
- Parents of children with SBS²
 - More likely to be physically tired, annoyed, and report problems sleeping
 - Difficulty in spending time with partners, shopping, or taking holidays
- Family QoL outcomes³
 - Those with children age < 5 scored worse on daily family activities, household tasks, and family relationships

QoL = quality of life

1. Carlsson E, et al. *Clin Nutr.* 2003;22(5):445-452. 2. Wong C, et al. *Gut.* 2000;46(2):294-295. 3. Pederiva F, et al. *Eur J Pediatr Surg.* 2019;29(2):196-202.

Treatment of SBS



Nutrition Optimization for SBS-IF

Varies depending on whether the colon is present

- Dietary strategy
 - 5-6 smaller meals or snacks/day
 - Avoid simple carbohydrates
 - Limit lactose and artificial sweeteners
 - Major emphasis on maintaining hyperphagia vs excessive dietary restrictions
- Oral fluid intake
 - Oral rehydration solution or sodium-containing fluids
 - Small, frequent volumes
 - Avoid plain water and sugary beverages
- Vitamin and mineral supplements
- Enteral nutrition
 - Use as a supplement to oral feeding to avoid PN requirement
- Parenteral nutrition should be considered primary treatment

Medications for the Spectrum of SBS

Anti-motility agents

- Loperamide*
- Diphenoxylate*
- Codeine*, tincture of opium*

Gastric acid suppression medications

- Proton pump inhibitors*
- H₂RAs*

Anti-secretory agents

- Octreotide*
- Clonidine*

Small intestinal bacterial overgrowth treatment

- Antibiotics*
- Probiotics*

Bile acid sequestrants

- Cholestyramine*

Trophic agents

- rHGH
 - Somatropin
- GLP-2 analog
 - Teduglutide

*Not approved by the U.S. Food and Drug Administration (FDA) for the treatment of SBS

GLP-2 = glucagon-like peptide-2; H₂RAs = histamine 2 receptor antagonists; rHGH = recombinant human growth hormone

Matarese L, et al. *J Parenter Enteral Nutr.* 2013;37(2):161-170. Cuerda C, et al. *Clin Nutr.* 2021;40(9):5196-5220.

Pharmacotherapy: Gastric Hypersecretion*

- Most common 6-12 months post-op
- Symptoms: heartburn, reflux, abdominal pain
- Proton pump inhibitors* or H₂RAs*
 - Improve digestion and absorption
 - Decrease stool volume
 - Prevent progression to esophagitis or peptic ulcer disease
- Anti-secretory agents
 - Octreotide*
 - Clonidine*

*Not approved by the U.S. Food and Drug Administration (FDA) for the treatment of SBS
Matarese L, et al. *J Parenter Enteral Nutr.* 2013;37(2):161-170. Cuerda C, et al. *Clin Nutr.* 2021;40(9):5196-5220.

Pharmacotherapy: Diarrhea

- Antidiarrheals
 - Loperamide*
 - Diphenoxylate/atropine*
 - Codeine,* tincture of opium*
- Antibiotics*
 - Treatment of small intestine bacterial overgrowth
- Bile acid sequestrants*
 - Most effective in patients with a colon
 - Can reduce fat absorption and fat-soluble vitamin uptake

*Not approved by the U.S. Food and Drug Administration (FDA) for the treatment of SBS
Matarese L, et al. *J Parenter Enteral Nutr.* 2013;37(2):161-170. Cuerda C, et al. *Clin Nutr.* 2021;40(9):5196-5220.

Audience Response

What is a true statement regarding GLP-2s?

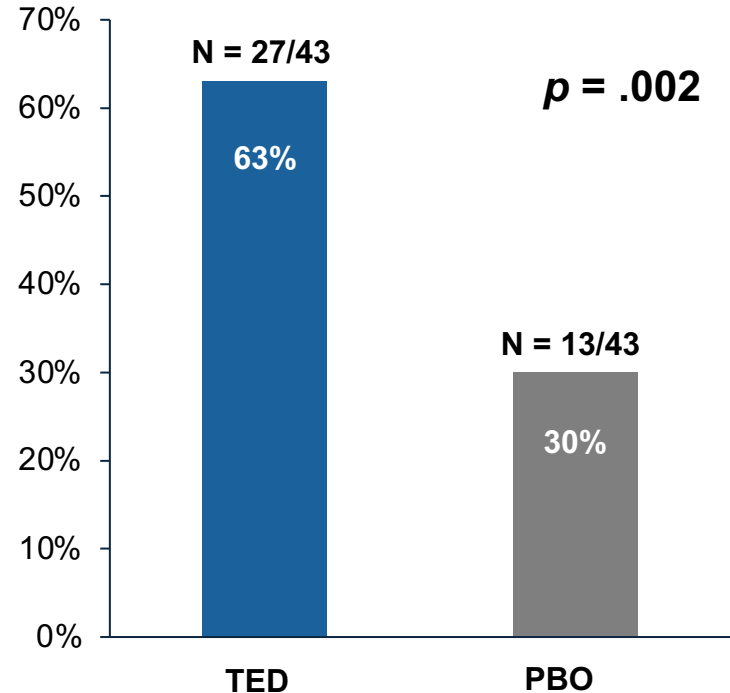
- A. Naturally occurring GLP-2 has a very short half-life of under 10 minutes
- B. They are secreted from intestinal L cells following ingestion of food
- C. Exogenous GLP-2 administration enhances nutrient and fluid absorption
- D. All of the above
- E. I'm not sure

Glucagon-like-peptide 2 (GLP-2) in SBS-IF

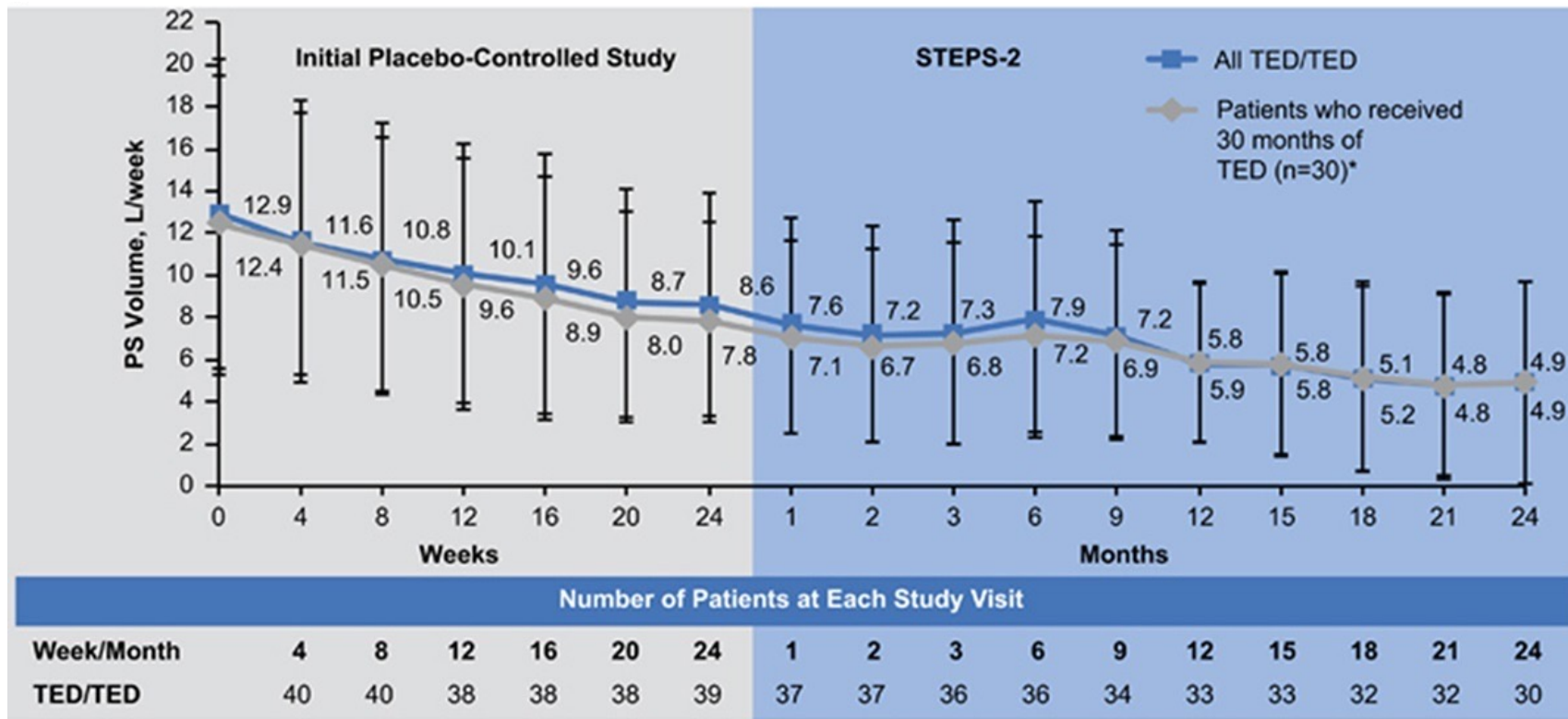
- Promotes intestinal adaptation
- Decreases parenteral nutrition needs
- Teduglutide
 - Approved by FDA for adult and pediatric patients age 1 or older who are dependent on PN
- Future options
 - Weekly GLP-2 injectables
 - Apraglutide: phase III clinical trial ongoing
 - Glepaglutide: phase III clinical ongoing

Teduglutide Efficacy in SBS-IF

- 24-week study of patients with SBS-IF, N = 86
- Administered SQ teduglutide or placebo QD
- Response = % of patients with > 20% reduction in PN volume from baseline at weeks 20 and 24

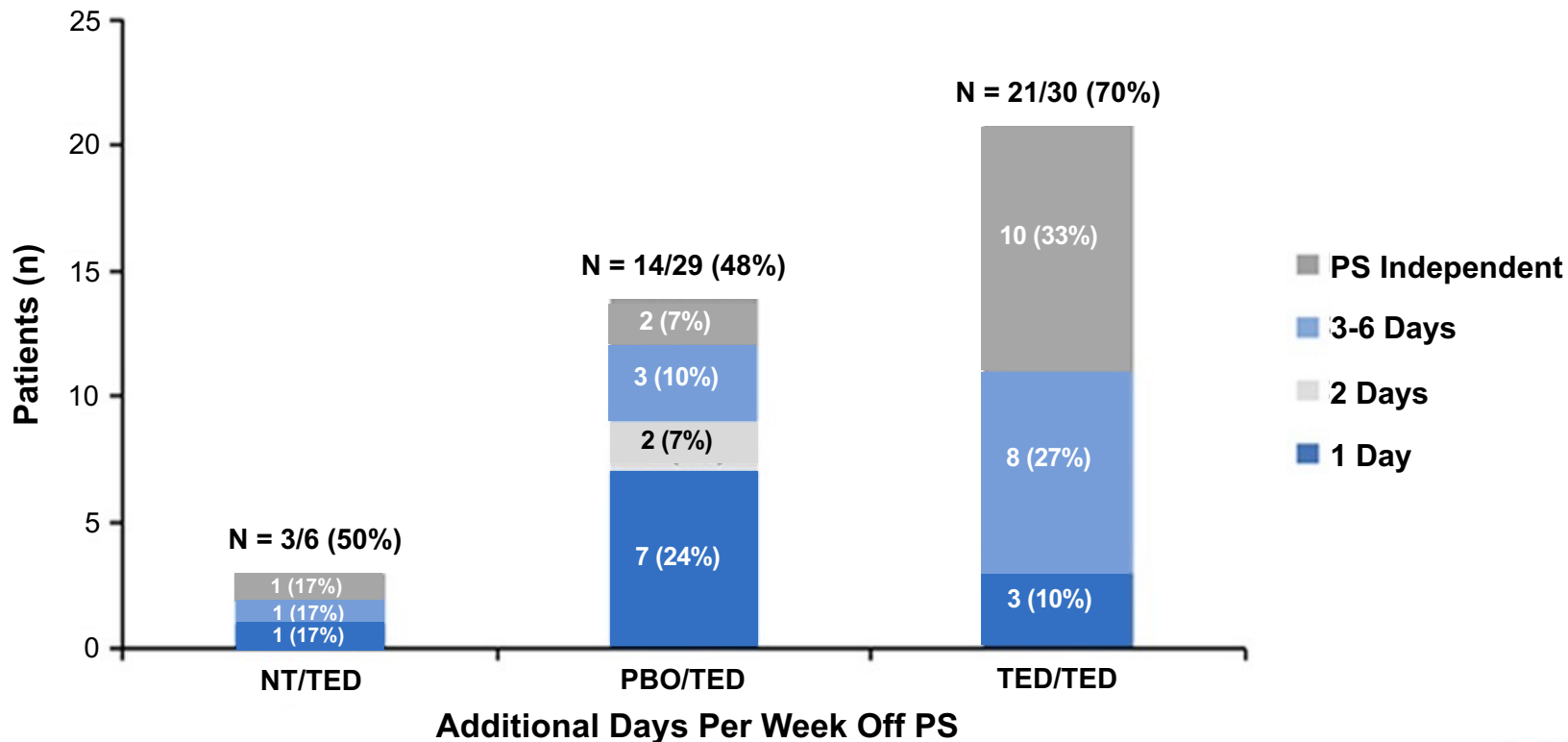


Teduglutide: Long-Term Efficacy in Adults



TED = teduglutide
 Schwartz LK, et al. *Clin Transl Gastroenterol.* 2016;7(2):e142.

Additional Days Off PN from Baseline in STEPS-2



NT = not treated; PBO = placebo
Schwartz LK, et al. *Clin Transl Gastroenterol.* 2016;7(2):e142.

Teduglutide and PS Independence

Pooled analysis of 5 adult clinical trials:
134 patients included

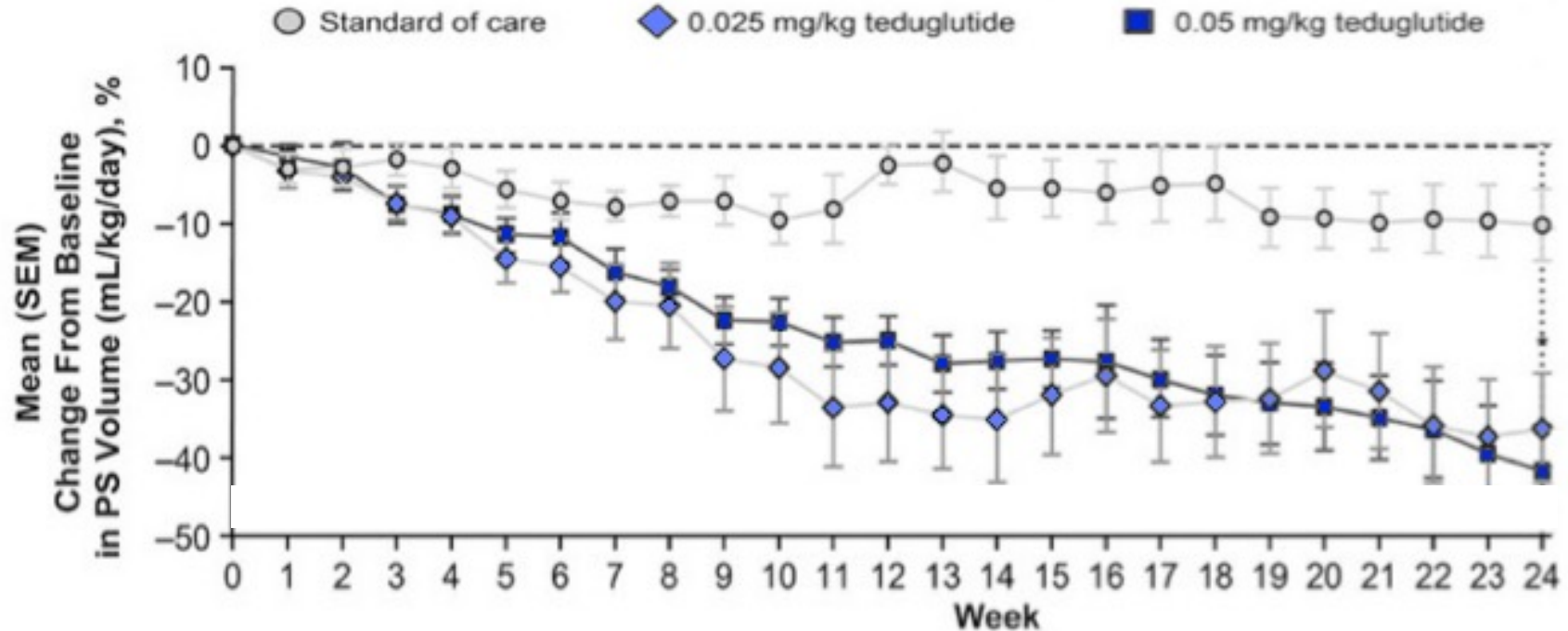
16 patients (12%) achieved
enteral independence

Baseline PS requirements
Duration: range 2-18 years
Days per week: range 3-6 days

75% of patients required ≥ 1 year
of TED treatment before PS
elimination

One patient weaned off PS
after 2.5 years of treatment
with TED

Teduglutide: Efficacy in Reducing Pediatric Parenteral Support (PS)



Teduglutide: Monitoring Recommendations

- Risk for accelerated neoplastic growth
 - Pediatric screening: baseline and annual fecal occult blood screening; 1 year colonoscopy/sigmoidoscopy with a repeat every 5 years or if blood in stool
 - Adult screening: baseline colonoscopy/sigmoidoscopy with repeat at 1 year and then 5 years thereafter
- Intestinal obstruction
- Fluid overload
- Pancreaticobiliary disease
 - Lab monitoring every 6 months
- Monitor for changing drug effects from increased absorption
- Active malignancy (< 5 years) is contraindication to GLP-2

Most Commonly-Reported Teduglutide Adverse Events

	RCT Group (n = 109) n (%)	RCT Extension (n = 173) n (%)	RCT Placebo (n = 59) n (%)
GI stoma complication	17 (37.8)*	31 (45.6)	3 (13.6)
Abdominal pain	42 (38.5)	72 (41.6)	16 (27.1)
Upper respiratory tract infection	30 (27.5)	50 (28.9)	8 (13.6)
Catheter sepsis events	17 (15.6)	47 (27.2)	10 (16.9)
Nausea	29 (26.6)	46 (26.6)	12 (20.3)
Headaches	18 (16.5)	35 (20.2)	9 (15.3)
Asthenic conditions	14 (12.8)	35 (20.2)	7 (11.9)
Injection site reactions	22 (20.2)	33 (19.1)	7 (11.9)

*Of 45 patients with a stoma

RCT = randomized controlled trial

Pape UF, et al. *Therap Adv Gastroenterol.* 2020;13:1756284820905766.

Considerations Before Using GLP-2

- Patient meets criteria for SBS-IF
- PN/IV fluids required $> 3x/week$ for ≥ 1 year
- Patient has been optimized on:
 - Diet therapy
 - Anti-secretory drugs
 - Anti-diarrheal drugs
- Malignancy contraindication
- Partnership exists between treatment team and patient

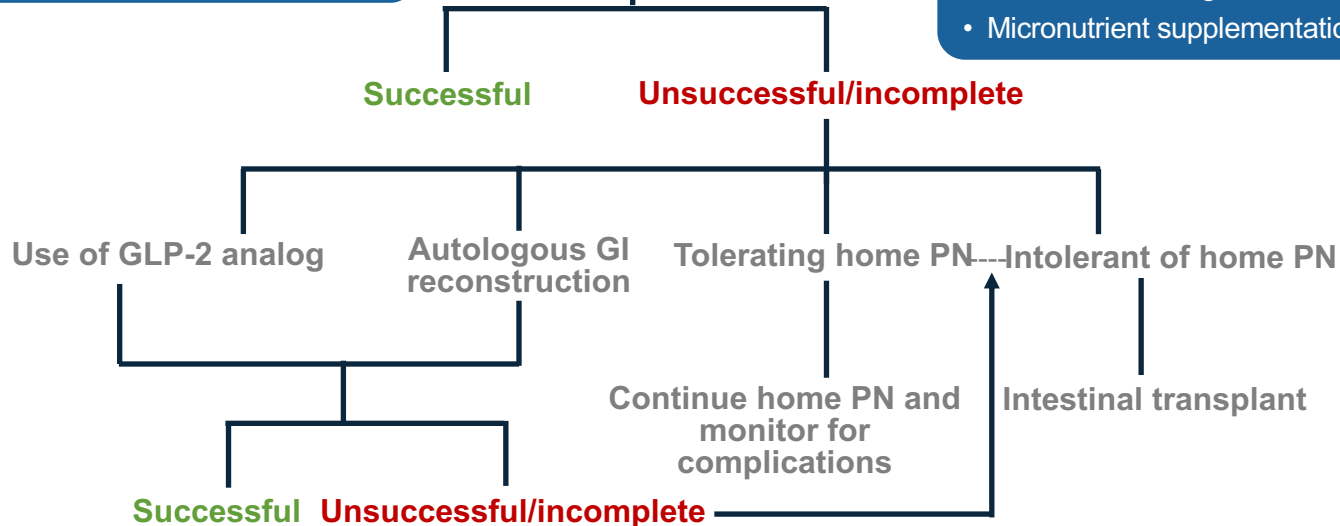
Managing SBS-IF: Overview

PN still frequently necessary

- Does not enhance bowel function
- Costly (> \$100,000/year)
- Reduced quality of life
- 1-2 hospitalizations annually per patient

Attempt to wean PN

- Optimize oral diet and fluids
- Aggressive use of antisecretory and antimotility agents
- Maximize function of remnant bowel surgically if possible
- Careful monitoring of status
- Micronutrient supplementation



The Team Approach to Care and Improving the Quality of Life of Patients



Intestinal Rehabilitation (IR) Team Members

Professional	Role and Services
Gastroenterologist or pediatric gastroenterologist	Inpatient and outpatient medical management
General surgeon or pediatric surgeon	Gastrointestinal surgery, central venous catheter procedures; inpatient and outpatient surgical management
Transplant surgeon	Assessment, surgery, immunosuppression
Adult or pediatric intensivist or neonatologist	Initial inpatient management of and critically ill patients
Interventional radiologist	Central venous line management
Gastroenterology and parenteral nutrition nurses	Line and ostomy care; education
Pharmacist	Preparation of parenteral nutrition; drug-nutrient interactions
Registered dietitian	Nutritional monitoring and counseling
Social worker	Access available resources; support
Psychologist	Individual treatment and family support
Medical educator	Instruction on self care
Physical/occupational/speech therapist	Feeding; mobility and development
Child-life specialist	Child and family support; education

Pediatric IR Benefits

- **NASPGHAN recommends that patients with SBS not making progress towards enteral autonomy and continuing on PN > 3 months be referred to an IR program for consultation or management**
- Decreased number of septic events per 1,000 catheter days
- Decreased time from PN dependence to enteral autonomy
- Decreased mortality rate in patients with long-term PN therapy
- Decreased mortality from IF-associated end-stage liver failure

IR Program Goals

Promote Enteral Autonomy

Promote intestinal adaptation and enteral autonomy
Decrease dependence on parenteral support

Decrease Complications

Decrease morbidity and mortality of SBS as well as associated IF

Improve QoL

Employ best practice strategies to improve QoL
Support patients, families, and caregivers

Research

Conduct research into new treatment options
Collect data on SBS outcomes

Pediatric Transition of Care: SBS Growing Pains

Guideline-Recommended Best Practices

Transition
planning
should
begin at
age 12

Ideal transfer to
adult-oriented
care occurs
between age
18 and 21

Transition
planning
should be part
of standard
clinical care

Transition
planning
should be
individualized

Barriers to Transitions of Care

- Lack of planning or communication surrounding transition
- Lack of training in disease state and PN care
- Lack of social support to replace previous caregiver support
- Inability to locate an adult specialist with knowledge of pediatric SBS
- Patient or caregiver reluctance to transition
- Loss of insurance or financial assistance

Parenteral Nutrition: Patient Burden

Requires significant time

- 10-15 hours of infusion time/day
- Negative psychosocial and mental health impact overall

Resource intensive

- Obtaining, storing, and preparing PN for administration
- Operation of infusion pump
- Catheter maintenance

Risk of complications

- Line-associated infection
- Line-associated thromboembolism
- PN associated liver failure

Significant direct and indirect costs

- Direct costs of PN therapy (copays, insurance premiums)
- Time to manage PN by patient and/or caregivers (uncompensated time)
- Loss of employment

Parenteral Support and QoL

Factors affecting QoL survey scores

Improves with fewer nights per week on PS

Improves with lower volume of PS

Worsens per each additional 1 liter per day of PS

Role of Home Parenteral Nutrition (HPN)

- Main goal is some form of normalcy in lives of patients
- By understanding the perspective of normalization, home infusion nurses and nutrition support clinicians can embrace caregiving strategies and tools consistent with the changing social environment in which the HPN experience is lived

Telehealth to Connect Patients to Specialty Resources

- Telehealth opportunities
 - Screening patients before office visits
 - Visits with patients receiving home PS or infusions
 - Tool for community providers to create team of providers
 - Injection teaching
 - Routine care, including multidisciplinary visits (such as gastroenterologist and nurse coordinator, social worker, dietitian, and additional specialists)
 - Access to urgent evaluations for complications
 - Support for ongoing clinical trials

Support for SBS: Patients and Providers

- Short Bowel Syndrome Foundation website: Lists support groups for patients with SBS as well as their caregivers
<http://shortbowelfoundation.org/>
- The Oley Foundation: Supports patients on home PN
<https://oley.org/>
 - Programs and resources to support
 - Competency
 - Inspiration
 - Normalcy
 - Advocacy



[Welcome | LIFT-ECHO :: Learn Intestinal Failure TeleECHO \(liftecho.org\)](#)

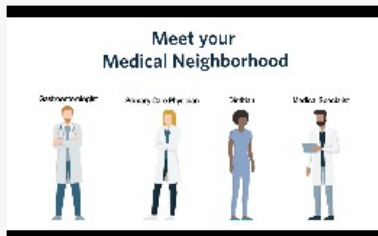


Help LIFT the current standard of intestinal failure care, right from your computer, tablet or smartphone.

Patient Education – CMEO Website

- Share this video with your patients:
<https://www.cmeoutfitters.com/gastro-patient-education-hub/>

Short Bowel Syndrome - What Every Patient Needs to Know



Short bowel syndrome, also known as SBS, occurs when patients cannot absorb nutrients because a significant part of the small intestine has been damaged or surgically removed. This video briefly reviews the causes, symptoms and treatments for short bowel syndrome.

Best Practices for SBS

- Optimize remaining intestinal function
- Decrease symptoms and promote enteral autonomy
- Utilize multidisciplinary team models
- Include psychosocial aspects of disease management in care plan
- Support patient and caregivers
- Develop transitions of care plans for all pediatric patients

SMART Goals

Specific, Measurable, Attainable, Relevant, Timely

- Create a team approach to care
- Optimize nutrition plan
- Recognize potential barriers when transferring pediatric patients to adult care
- QoL improves with fewer nights per week on PS
- Provide regular ongoing education for patients and caregivers

To Ask a Question

To submit a question, please go to the *Questions* panel at the bottom of the screen.

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AFTER
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Questions & Answers





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