




Management of short-bowel syndrome: A survey of unmet educational needs among healthcare providers

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Abstract

Background: Management of short-bowel syndrome with intestinal failure (SBS-IF) is complex and requires a multidisciplinary approach. Because of the rarity of SBS-IF, healthcare professionals (HCPs) often lack clinical experience with the disease and may benefit from education regarding SBS-IF and its management. This study identified unmet educational needs related to the management of patients with SBS-IF.

Methods: This was a prospective, web-based survey (December 2019–January 2020) in which a series of clinical questions were posed to US HCPs after presenting three standardized SBS-IF cases to assess current practice patterns. HCPs were then asked a series of questions to identify potential knowledge gaps and unmet educational needs relating to SBS-IF management.

Results: Overall, 558 HCPs completed the survey, with 12%–38% having a formal SBS-IF multidisciplinary team currently available to make treatment decisions within their institution. Clinicians involved in care included gastroenterologists (93%), registered dietitians (79%), gastroenterology nurse practitioners and physician assistants (37%), registered nurses (43%), social workers (45%), and psychologists/psychiatrists (27%). There was underuse of published guidelines and limited understanding of the course of intestinal adaptation. Responses to the clinical scenarios highlighted disparities in SBS-IF care delivery, including diagnosis, management goals, medications prescribed, and nutrition practices.

Conclusions: Future SBS-IF educational interventions for HCPs should aim to improve awareness and understanding of the disease, facilitate timely diagnosis, and standardize management practices to ensure patients receive optimal interdisciplinary care as widely as possible.

KEYWORDS

diagnosis, education, knowledge gaps, management, research and diseases, short-bowel syndrome, survey

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CLINICAL RELEVANCY STATEMENT

This study highlights knowledge gaps and inconsistent management practices among US healthcare professionals involved in treating patients who have short-bowel syndrome with intestinal failure. The study also proposes areas for further education to facilitate improved clinical practice.

INTRODUCTION

Short-bowel syndrome (SBS) is a chronic and severe disease resulting from physical loss and functional deficiency of portions of the intestine, primarily due to surgical resection.^{1,2} SBS is characterized by a collection of clinical features, such as malnutrition, dehydration, electrolyte disturbances, and malabsorption.^{3,4} SBS is the leading cause of chronic intestinal failure (IF): the reduction of gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that parenteral nutrition (PN)/intravenous (IV) supplementation is required to maintain vital functions.⁵ SBS-IF is rare, with an estimated prevalence in adults of 0.4–25.0 per million in the United States and in Europe, with prevalence increasing.^{6–9} Recent improvements in management (notably owing to improved understanding of physiological changes and how to augment them to gain enteral autonomy) have improved the historically high morbidity and mortality of SBS-IF.^{10,11}

The complex individualized management of SBS-IF requires the expertise of several different specialist healthcare professionals (HCPs), including registered dietitians, gastroenterologists, surgeons, registered nurses, and social workers, working as a multidisciplinary team for the best outcomes.^{5,12–16} However, there remain disparities of care in terms of access to a multidisciplinary approach.¹³ As a further complication, to date, despite the availability of multiple published guidelines for the diagnosis and management of SBS-IF,^{14,17–24} treatment algorithms and care pathways are usually not well established, even within specialist SBS-IF centers.²⁵

The rarity of SBS-IF can limit HCPs' experience of patients with this disease. As a result, the journey for patients with SBS-IF is often characterized by a lack of psychosocial, medical, and financial support.^{26,27} It has been previously reported that HCPs may benefit from improved education about SBS-IF and nutrition.^{28–30} Many patients with SBS-IF continue to experience a lowered quality of life characterized by ongoing and lifestyle-altering diarrhea, malnutrition, abdominal pain, weight loss, and dehydration.⁹

Our study aimed to identify HCPs' unmet educational needs related to the management of SBS-IF.

METHODS

Survey development

An electronic survey to assess current practice patterns was created and distributed using Qualtrics survey software between December 2019 and January 2020 to gastroenterologists, surgeons, pediatricians, registered dietitians, nurses, and gastroenterology physician assistants and nurse practitioners in the United States. Experience in treating patients with SBS-IF was not an inclusion requirement for HCPs participating in the survey.

Clinician contact information was obtained from a proprietary database of clinicians who opted in after participation in previous studies and internet searches of available contact information in specialties of interest. Email invitations were sent to 750 gastroenterologists, 1470 surgeons, 1382 pediatricians, 162 gastroenterology nurse practitioners and physician assistants, 280 registered nurses, and 1175 registered dietitians. Because of our use of paid honoraria and need to have certain specialties included in our study, a quota system was used to gather the sample. Once estimates for the appropriate power were reached, the online platform closed to new respondents. Based on this approach, a traditional response rate was not calculated.

This novel case-vignette survey was developed with an expert gastroenterologist and focus groups of HCPs experienced in the management of SBS-IF ($N = 40$). The focus groups used a nominal group technique process and were conducted by CE Outcomes (Birmingham, AL) using a two-part, asynchronous, modified Delphi technique platform.^{31,32}

This case-based study protocol was determined to be exempt from institutional review board review by Western Institutional Review Board (WIRB; Puyallup, WA) under 45 CFR §46.104(d)(2) because the research only includes interactions involving educational tests, survey procedures, interview procedures, or observations of public behavior.

Survey distribution

For responses to questions on treatments, HCPs ranked their choices (1 being the most important and 5 being the least important). The ranked choices were subsequently given points based on preference (choice 1 [most important] = 5 points; 2 = 4 points; 3 = 3 points; 4 = 2 points; 5 = 1 point); unchosen treatments were given no points. Mean scores were then calculated for each choice. Other questions used a multiple-choice format. HCPs were then asked a series of questions to rank SBS areas for potential knowledge gaps and unmet educational needs relating to the management of SBS-IF (the survey questions are provided in the supporting information).

Statistical analysis

Continuous variables were reported as means, and categorical variables were summarized as frequency and percentage. Descriptive data analysis and chi-square tests, t tests, and z tests were performed to assess factors associated with HCP practice patterns, knowledge, and goals. Statistical analysis was performed with SPSS Statistics 27 (IBM).

RESULTS

A total of 558 US HCPs completed the survey (demographics are shown in Table 1). A formal SBS multidisciplinary team is available to make treatment decisions according to 12%–38% of respondents. The survey revealed that the following specialists are typically involved in the management of SBS patients: gastroenterologists (93%), gastroenterology nurse practitioners and physician assistants (37%), registered nurses (43%), registered dietitians (79%), surgeons (53%), pharmacists (53%), social workers (45%), and psychiatrists/psychologists (27%). The clinical practice guidelines typically used

when managing SBS-IF include those from the American Society for Parenteral and Enteral Nutrition (ASPEN) (20%–77%), the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) (11%–45%), and center- or institution-specific guidelines (16%–28%), or no use of clinical guidelines for SBS management was noted (15%–39%). Respondents approximated the length of time for intestinal adaptation to occur in patients with SBS not previously treated with medical therapy as 4–6 weeks (0%–6%), 4–6 months (16%–30%), 1 year (20%–47%), 2 years (8%–25%), and unsure (5%–56%).

Case 1: Management of a patient newly diagnosed with SBS

Part A

An 18-year-old man presents with weight loss and fatigue 4 weeks after total colectomy followed by proximal end jejunostomy (proximal bowel length of 50 cm) for refractory ulcerative colitis. Oral intake has been

TABLE 1 Demographics of healthcare professional respondents to survey.

	Gastroenterologists (n = 133)	Pediatricians (n = 152)	Surgeons (n = 100)	Gastroenterology nurse practitioners and physician assistants (n = 45)	Registered nurses (n = 25)	Dietitians (n = 103)
Years in practice, mean (SD; range)	28 (11.8; 60)	28 (10.9; 51)	29 (10.6; 45)	14 (7.9; 38)	23 (10.1; 32)	22 (10.5; 40)
Number of patients seen per week, mean (SD; range)	79 (42.4; 235)	90 (45.9; 273)	55 (45.8; 199)	56 (35.0; 190)	45 (33.3; 96)	29 (29.0; 157)
Number of pediatric patients seen per week, mean (SD; range)	15 (21.5; 90)	81 (39.0; 275)	5 (12.5; 100)	5 (12.6; 50)	14 (25; 100)	5 (7.9; 45)
Managing patients with SBS-IF						
Currently manage	52%	14%	21%	42%	16%	19%
Managed in past	42%	54%	55%	42%	28%	52%
Never managed	6%	32%	24%	16%	56%	28%
Academic setting	42%	36%	47%	49%	60%	20%
Presence of MDT						
Yes (formal)	38%	26%	14%	27%	36%	12%
Yes (informal)	30%	22%	9%	47%	24%	36%
No	28%	32%	38%	22%	12%	34%
Practice location						
Urban	53%	43%	50%	60%	52%	34%
Suburban	40%	49%	36%	36%	44%	47%
Rural	7%	9%	14%	4%	4%	19%

Abbreviations: MDT, multidisciplinary team; SBS-IF, short-bowel syndrome with intestinal failure; SD, standard deviation.

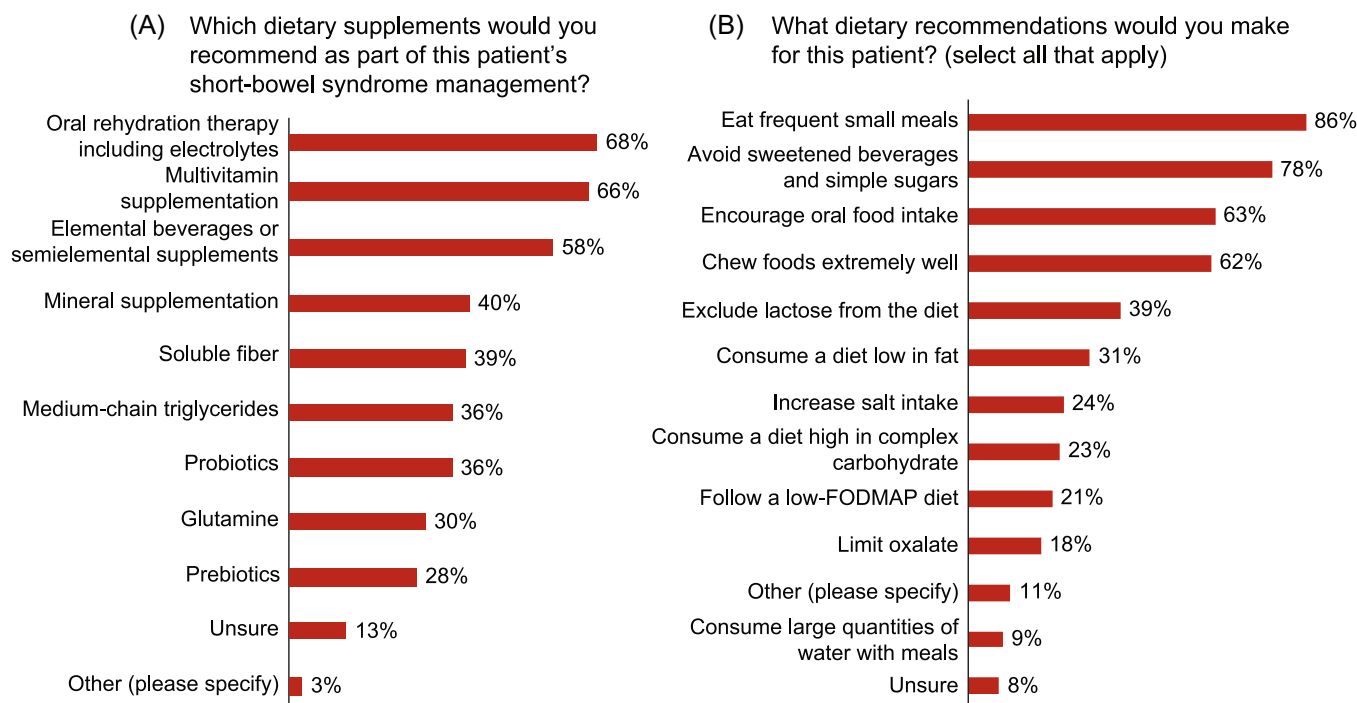


FIGURE 1 Nutrition recommendations from registered dietitians ($n = 103$) for short-bowel syndrome case 1. FODMAP, fermentable oligosaccharides, disaccharides, monosaccharides, and polyols.

1–2 L of Gatorade daily, plus water and soda, and 1500 kcal of food per day. His ostomy bag requires emptying at least 10 times per day and a few times overnight. He reports dark urine and decreased urinary frequency. His weight is 67 kg, compared with 76 kg at the time of hospital discharge. Clinical signs of dehydration are present.

Among all HCPs, the most common diagnoses to explain this patient's weight loss were "dehydration" (67%–91%) and "protein-calorie malnutrition" (77%–84%). Dehydration is a common symptom of SBS owing to fluid and electrolyte malabsorption.⁹ In this standardized case, oliguria with dark urine is a symptom of dehydration, which often occurs when intake exceeds intestinal absorptive capacity. Identification of the diagnosis is needed to prescribe the appropriate management (PN support). Notably, a subset of specialists highly ranked vitamin B₁₂ deficiency, iron deficiency, and occult small-bowel Crohn's disease, even though the natural history and clinical symptoms were inconsistent with those diagnoses. For example, the onset of vitamin B₁₂ deficiency in SBS may occur from several months to years, owing to large body reserves, and the symptoms of vitamin B₁₂ deficiency, in addition to fatigue, include mental status changes, paresthesia, and glossitis.

Part B

The patient continues to improve and is discharged from the hospital while receiving parenteral support. Two weeks after discharge, the patient returns to the office for a follow-up appointment. He had been receiving PN (including IV lipids) cycled over 12 h, which provides

hydration of 3 L per day and 2000 kcal and 110 g of protein per day (1.5 g/kg/day). His weight has increased 2 lbs (0.9 kg) from the time of hospital discharge. He is taking loperamide 4 mg three times daily, plus ranitidine in his PN. He has decreased his intake of high-sugar beverages. His daily energy intake from food is around 1200 kcal. Stoma output is now approximately 2.5 L per day (1.5 ml/kg/h).

Respondents in general prioritized the goals of this patient's SBS as follows (mean score, measured from 1 to 5): optimizing quality of life (2.76), avoiding hospitalization (2.14), increasing oral dietary intake (1.74), weaning PN (1.74), and limiting diarrhea (1.73). Differences across specialties were noted according to deviations from the mean. Gastroenterologists, nurse practitioners, and physician assistants prioritized minimizing the risk of central-line infection (2.64 and 2.89, respectively). Increasing oral dietary intake was prioritized among registered dietitians and registered nurses (2.48 and 2.32, respectively). For full results, see the supporting information.

Among prescribers (all HCPs, except for registered dietitians), recommendations for pharmacotherapy for this patient's SBS were as follows: an antimotility agent (2.86), an antisecretory agent (2.0), oral rehydration solution (1.72), a glucagon-like peptide-2 (GLP-2) analog (1.16), and antacid medicine (1.15). Again, differences across specialties were noted according to deviations from the mean. Gastroenterologists and surgeons prioritized antisecretory agents (2.45 and 2.45, respectively).

Recommendations by registered dietitians for this patient's SBS management are listed in Figure 1 and include the following dietary supplements: oral rehydration therapy including electrolytes (68%),

multivitamin supplementation (66%), and elemental/semielemental beverages (40%). Dietary recommendations included eating frequent small meals (86%), avoiding sweetened beverages and simple sugars (78%), encouraging oral food intake (63%), and chewing food extremely well (62%).

Case 2: Management of patient with improving SBS-IF, discontinuing PN

A 56-year-old woman with history of Roux-en-Y gastric bypass undergoes intestinal resection as a complication of small-bowel obstruction adhesions that led to ischemia and was found to have 30 cm of jejunum and 15 cm of terminal ileum. Postoperatively, she is kept "nothing per mouth" and PN support is started. Now, on postoperative day 5, she begins having bowel movements and is feeling hungry.

In all types of surgery leading to SBS, including bariatric surgery, intestinal rehabilitation may begin as soon as there is return of bowel function. Respondents recommended the following: the initiation of oral intake (48%–71%), initiation of oral intake with tube feeds (8%–26%), "nothing by mouth" with initiation of tube feeding (0%–16%), deference to registered dietitian recommendations (1%–8%), PN support only (13%), and unsure (0%–9%). When approaching PN weaning, 53%–100% respondents would individualize PN reductions on the basis of a patient's symptoms, hydration, laboratory results, and body weight, and 0%–33% respondents could follow the recommendations of a registered dietitian for weaning. In contrast to other specialties, registered dietitians preferred explicit nutrition intake criteria for PN infusion weaning. Diagnostic and therapeutic management recommendations among prescribers are shown in Figure 2.

DISCUSSION

We present the findings of an educational needs survey among US HCPs involved in the management of SBS-IF. Using standardized clinical scenarios with various HCP specialties (ie, gastroenterologists, pediatric gastroenterologists, surgeons, registered dietitians, physician assistants, and nurse practitioners), we identified opportunities to strengthen SBS knowledge and build provider confidence in delivering state-of-the-art care.

Less than half of HCPs reported that their patients with SBS-IF were treated by formal multidisciplinary teams. Gastroenterologists and registered dietitians are most consistently at the core of the SBS-IF multidisciplinary management team. Registered nurses, social workers, and psychologists/psychiatrists are underused in supporting patients with SBS-IF, according to this survey. Access to high-quality SBS-IF care can be limited. In a previous study (a multinational, online survey assessing treatment-related complications and healthcare utilization of patients with SBS-IF receiving parenteral support),

a quarter of patients reported that it was hard to find HCPs specializing in SBS-IF locally.³³

Some disparities in SBS-IF care delivery can be explained by the variation in responses to the standardized clinical scenarios. For example, there was little consensus on prescribing medications, including GLP-2 agonists, for patients with SBS-IF. Among respondents who were registered dietitians, multiple simultaneous nutrition recommendations were offered during an initial consultation with a patient with SBS-IF. Typically, clinicians may advise patients to decrease hypotonic fluids (eg, water, soda, and Gatorade) and encourage patients to consume isotonic fluids such as World Health Organization (WHO) oral rehydration solution, as tolerated.³⁴ Many HCPs were uncertain about how and when to wean patients with SBS-IF from PN appropriately. Similarly, there was little consensus on a variety of other nutrition practices, such as prescribing nutrition supplements and administering tube feeds. Educational programming needs to help HCPs develop core competencies in evidence-based SBS-IF management practices to provide the best specialty care.

Opportunities were identified to address education gaps, as these related to SBS-IF care. For example, we found a limited understanding of the natural history of intestinal adaptation, which is the compensatory process after extensive intestinal resection in SBS.³⁵ The duration for intestinal adaptation is up to 2 years, which was correctly identified by only approximately a quarter of HCPs responsible for managing patients with SBS-IF.³⁶ Up to half of HCPs in some specialties were unsure of the duration of intestinal adaptation. Understanding, or misunderstanding, of intestinal adaptation in SBS-IF may have implications for when patients and families receive counseling regarding their diagnosis and potential treatment options.

There are challenges in finding an appropriate strategy to best educate providers. With the relative infrequency of patients with SBS in most clinical practices, HCPs may not prioritize time for more extensive educational activities, such as online or local meetings. Instead, innovative activities beyond continuing medical education meetings and workshops might be needed.³⁷ Educational programming that may be useful to HCPs includes peer-to-peer networks, engaging patient journey videos, education spanning multiple specialties, and clinical tools such as clinical guideline development and dissemination. As this study suggests, clinical guidelines need updates to address issues commonly encountered by HCPs treating patients with SBS, such as the need for initiation or modification of parenteral support, optimization of medical therapy, or engagement or transition to a dedicated multidisciplinary team specializing in IF. Until further research resolves basic evidence gaps, clinical practice will continue to be based on anecdotal evidence, which has the potential to contribute to variations in care.

The strengths of this study include that respondents belong to a large and nationwide sample and that the survey was developed in conjunction with an expert gastroenterologist. The case vignettes provided a valid and comprehensive method to

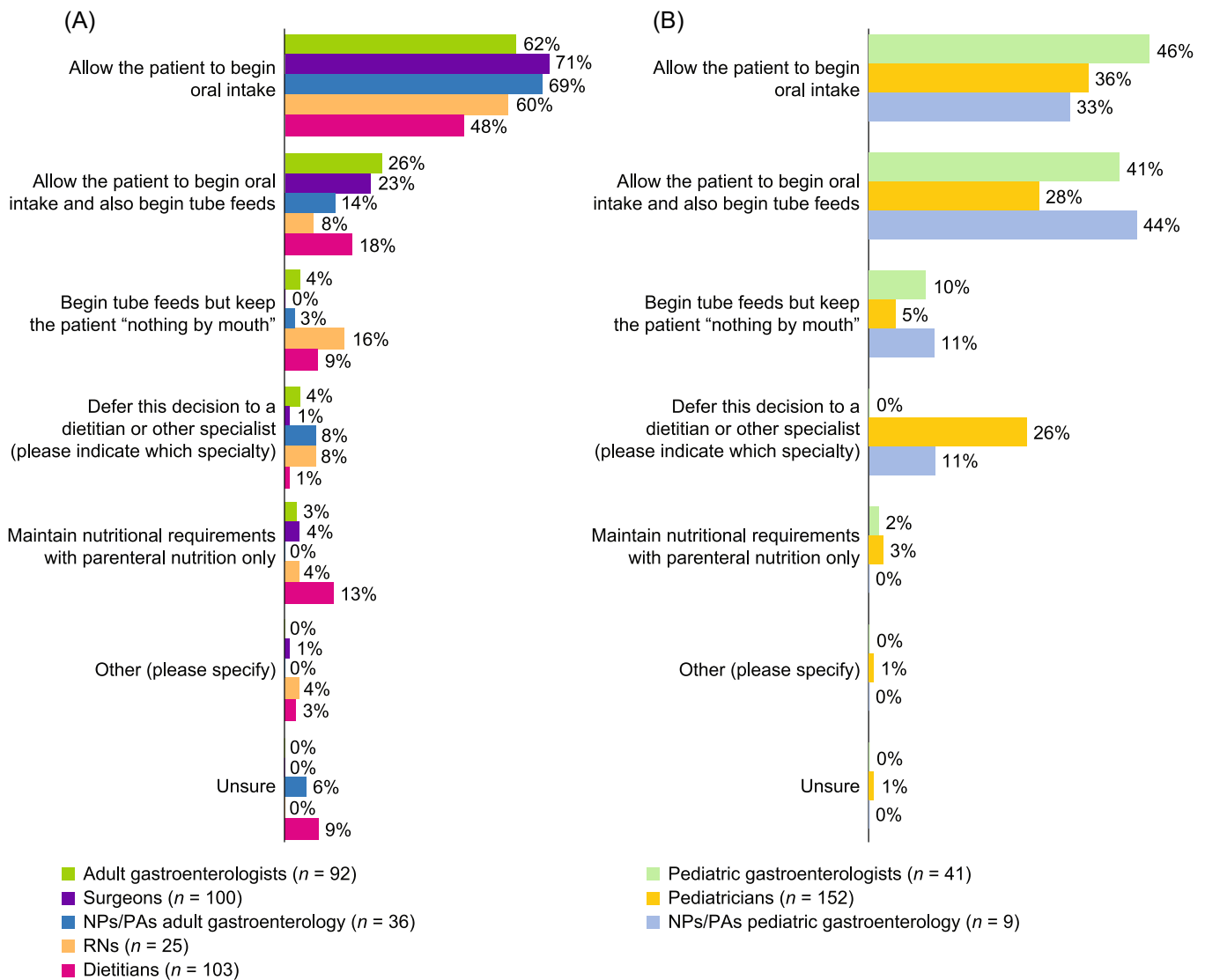


FIGURE 2 Prescriber recommendations for short-bowel syndrome case 2. NP, nurse practitioner; NPO, nothing per mouth; PA, physician assistant; RN, registered nurse.

measure processes of care in actual clinical practice.^{31,32,38,39} A limitation of this study is that clinical practice patterns may differ from the survey results. A further potential study limitation is its generalizability, given that the survey was performed immediately before the coronavirus disease 2019 (COVID-19) pandemic. The authors acknowledge a host of challenges that medical education needed to address during the COVID-19 pandemic, including economic repercussions; impact of equity, diversity, and inclusion; impact on mental health; virtual programming; challenges with testing; dissemination of misinformation; and social media.⁴⁰ However, the authors believe that despite the myriad of ways life has changed owing to the COVID-19 pandemic, it is unlikely that SBS-IF educational gaps were affected. As such, these study findings remain relevant for proposing future SBS-IF educational programming.

CONCLUSIONS

The study identified knowledge gaps and disparities in practice among US HCPs involved in treating patients with SBS-IF. Future educational interventions should seek to improve awareness and understanding of SBS-IF among healthcare providers to facilitate timely and accurate diagnosis, and to standardize the management of SBS-IF by using evidence-based guidelines to ensure optimal care for all patients.

AUTHOR CONTRIBUTIONS

Emily Belcher, David Mercer, Bram P. Raphael, Gregory D. Salinas, Sylvie Stacy, and Kelly A. Tappenden equally contributed to the conception and design of the research; Emily Belcher, David Mercer, Bram P. Raphael, Gregory D. Salinas, Sylvie Stacy, and Kelly A.

Tappenden contributed to the acquisition and analysis of the data; and Emily Belcher, David Mercer, Bram P. Raphael, Gregory D. Salinas, Sylvie Stacy, and Kelly A. Tappenden contributed to the interpretation of the data. All authors critically revised the manuscript, agree to be fully accountable for ensuring the integrity and accuracy of the work, and read and approved the final manuscript.

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CONFLICTS OF INTEREST

Emily Belcher, Gregory D. Salinas, and Sylvie Stacy are employees of CE Outcomes, LLC. Bram P. Raphael is an employee of Takeda Pharmaceuticals, Inc, Lexington, MA, USA, and has stock in the company. David Mercer has no conflict of interest to declare. Kelly A. Tappenden has received consulting fees from Takeda Pharmaceuticals.

DATA AVAILABILITY STATEMENT

The datasets, including the redacted study protocol, redacted statistical analysis plan, and individual participants data supporting the results reported in this article, will be made available within 3 months from initial request to researchers who provide a methodologically sound proposal. The data will be provided after deidentification, in compliance with applicable privacy laws, data protection, and requirements for consent and anonymization.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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