

Educational Needs Related to Transitioning Adolescent Patients with Short Bowel Syndrome from Pediatric to Adult Care: Results of a National Multispecialty Survey

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1 INTRODUCTION

Short bowel syndrome (SBS) is a serious and chronic malabsorptive disorder that results from physical loss and functional deficiency of portions of the intestine, primarily due to surgical resection [1,2]. Evidence suggests that SBS care varies widely among providers during the transition from pediatric to adult care [3,4]. Further, there are documented gaps regarding the lack of psychosocial support, an area that could be exacerbated in the transition process [5,6]. The objective of this study was to investigate current perspectives and future educational needs related to providing SBS transitional care among a variety of SBS healthcare providers (HCPs).

2 METHODOLOGY



Using a literature review, asynchronous focus groups, and the input of an SBS expert, a survey instrument was developed to understand current practice and attitudes related to SBS, including cases to provide context for clinical decision-making in transitioning a patient to adult care. The surveys were field tested with HCPs in each specialty experienced in managing SBS.



The web-based survey was randomly distributed to US-practicing gastroenterologists (GIs), pediatricians (Peds), surgeons, GI nurse practitioners (NPs), physician assistants (PAs), GI nurses (RNs), and registered dietitians (RDs) in December 2019 and January 2020.



Statistical and qualitative analyses were conducted to understand practice patterns and perceptions by specialty, as well as the impact of clinician demographics and experience in managing SBS.

3 RESPONDENT DEMOGRAPHICS

	GIs (n = 133)	Peds (n = 152)	Surgeons (n = 100)	GI NPs / PAs (n = 45)	RNs (n = 25)	Dietitians (n = 103)
Years since most recent degree, mean (SD)	28 (11.8)	28 (10.9)	29 (10.6)	14 (7.9)	23 (10.1)	22 (10.5)
Number unique pts seen/week, mean (SD)	79 (50.8)	90 (56.7)	55 (45.8)	56 (35.0)	45 (33.3)	29 (29.0)
Number of unique ped pts seen/week, mean (SD)	15 (21.5)	81 (42.7)	5 (12.5)	5 (12.6)	14 (25)	5 (7.9)
Number of unique SBS pts managed per month, mean (SD)	6 (9.8)	4 (7.2)	2 (2.1)	8 (15.2)	5 (4.6)	7 (7.2)
Number of SBS pts managed in the last 12 months, mean (SD)	12 (34.6)	2 (6.0)	4 (7.9)	10 (18.4)	11 (15.8)	12 (23.7)
Academic setting	42%	36%	47%	49%	60%	20%
Location						
Urban	53%	43%	50%	60%	52%	34%
Suburban	40%	49%	36%	36%	44%	47%
Rural	7%	9%	14%	4%	4%	19%
Manage SBS						
Currently manage	52%	14%	21%	42%	16%	19%
Managed in past	42%	54%	55%	42%	28%	52%
Never managed SBS	6%	32%	24%	16%	56%	28%

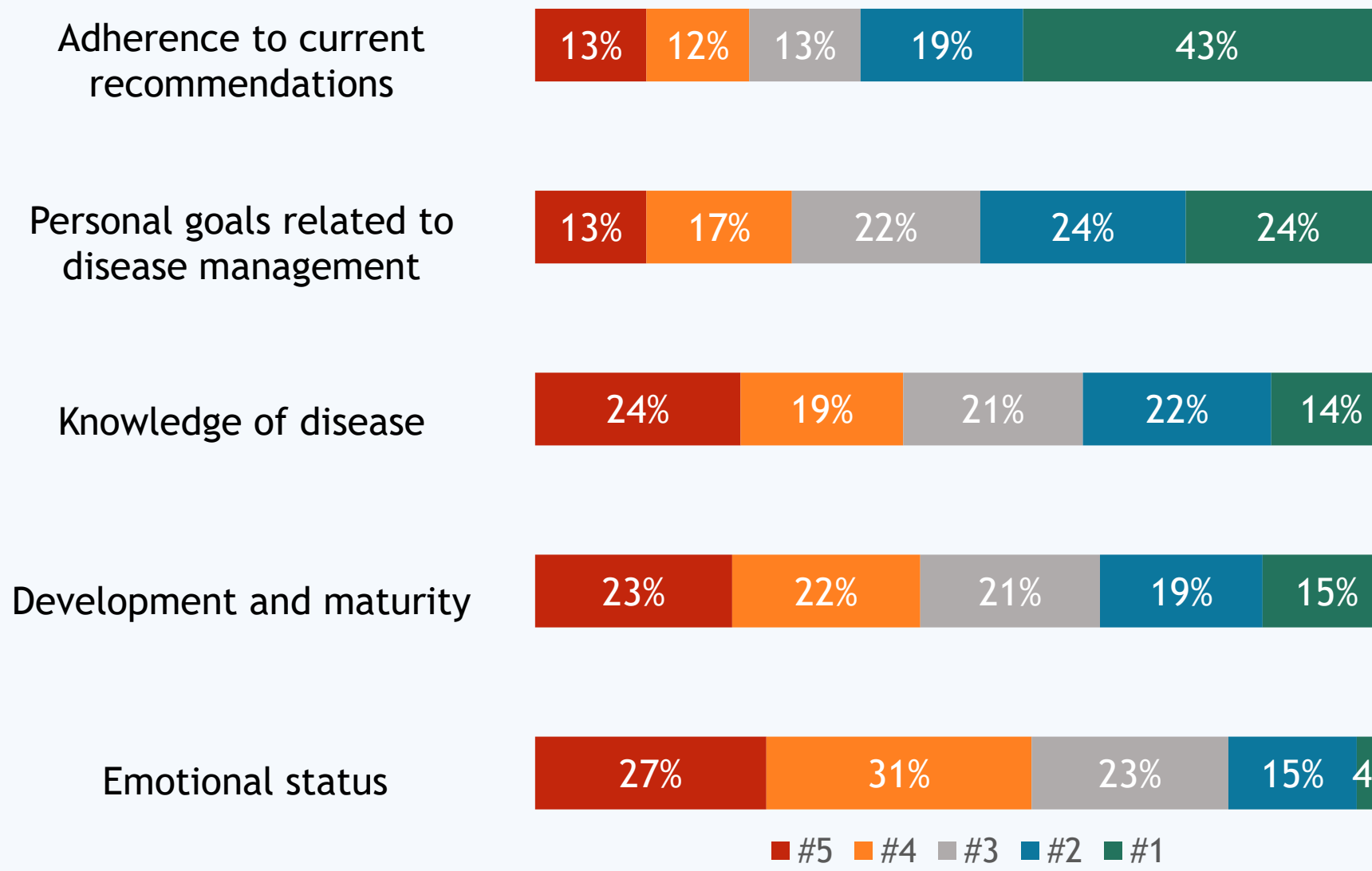
CASE SCENARIO: PT TRANSITIONING CARE

A 20-year-old woman presents to establish care. She developed short bowel syndrome as an infant following surgery for intestinal malrotation. She was not able to be weaned from parenteral nutrition. She takes a GLP-2 analogue. She has received primary and specialty care through a nearby pediatric healthcare system throughout her childhood. Long-term complications have been minimal. She appears well-nourished, and her BMI is 18.5 kg/m².

"[Transitioning] is a process which must begin years prior... and must be individualized to meet the educational and developmental capabilities of the patient and their family. It must involve all disciplines involved in patient care (MD, RN, RD, social work, etc...) It must provide education on underlying disease, medications, TPN, potential complications, important signs or symptoms to watch for as well as insurance, etc..." **Gastroenterologist, California**

4 IMPORTANT FACTORS FOR TRANSITION

Please rank the importance of assessing the following factors at this visit. (Rank from 1 to 5, with 1 being most important and 5 being least important)

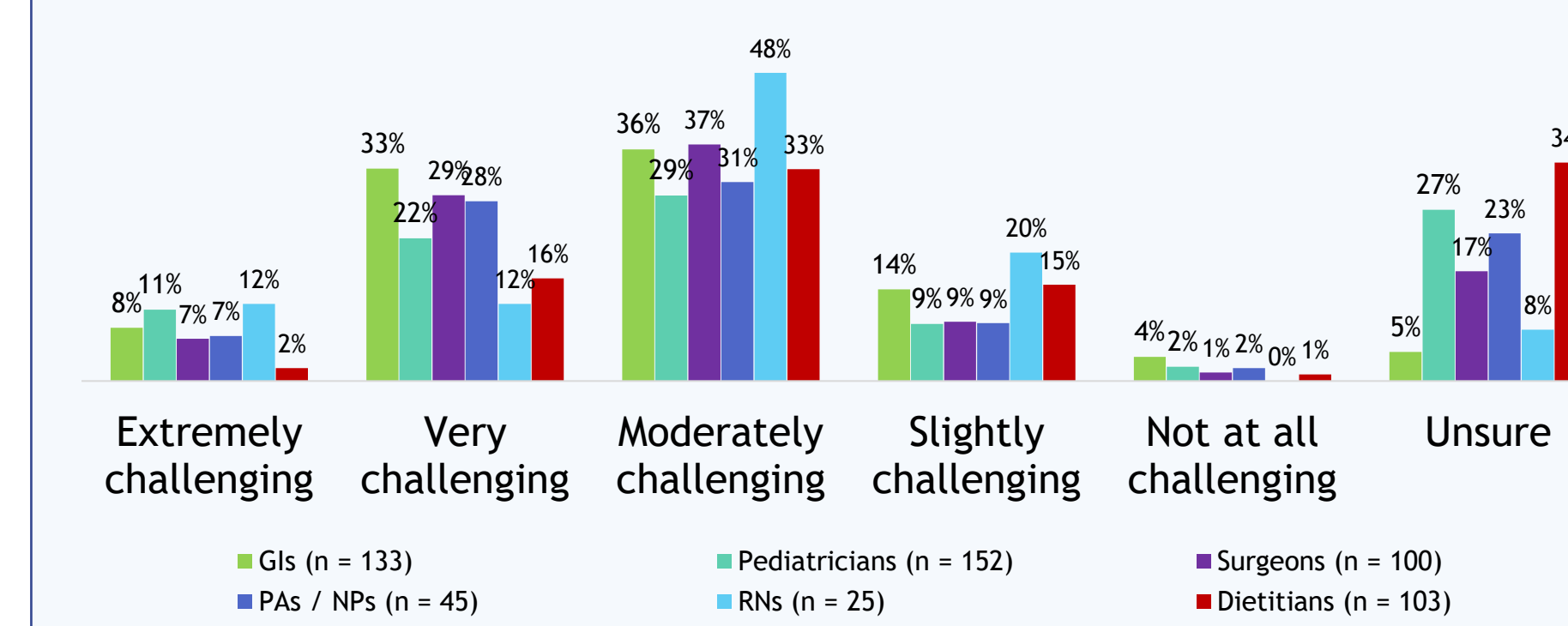


"Patient and family readiness [for transition] is assessed by the following factors: age, support, knowledge of expectations and advocacy for themselves, resources and insurance coverage." **Gastroenterology PA, Texas**

"...the steps changes as age progresses: At 12 to 13 years of age, after the initiation of transition planning, a written transition policy that explicitly states the expectations associated with the care practices and processes should be shared with patients and their families: At 14 to 15 years of age, the patient's transition readiness is assessed, and a transition plan is jointly developed through patient and family interviews: Transition plans should be reviewed on a regular basis and updated as needed at 16 to 17 years of age." **Gastroenterologist, North Carolina**

5 CHALLENGE OF TRANSITION

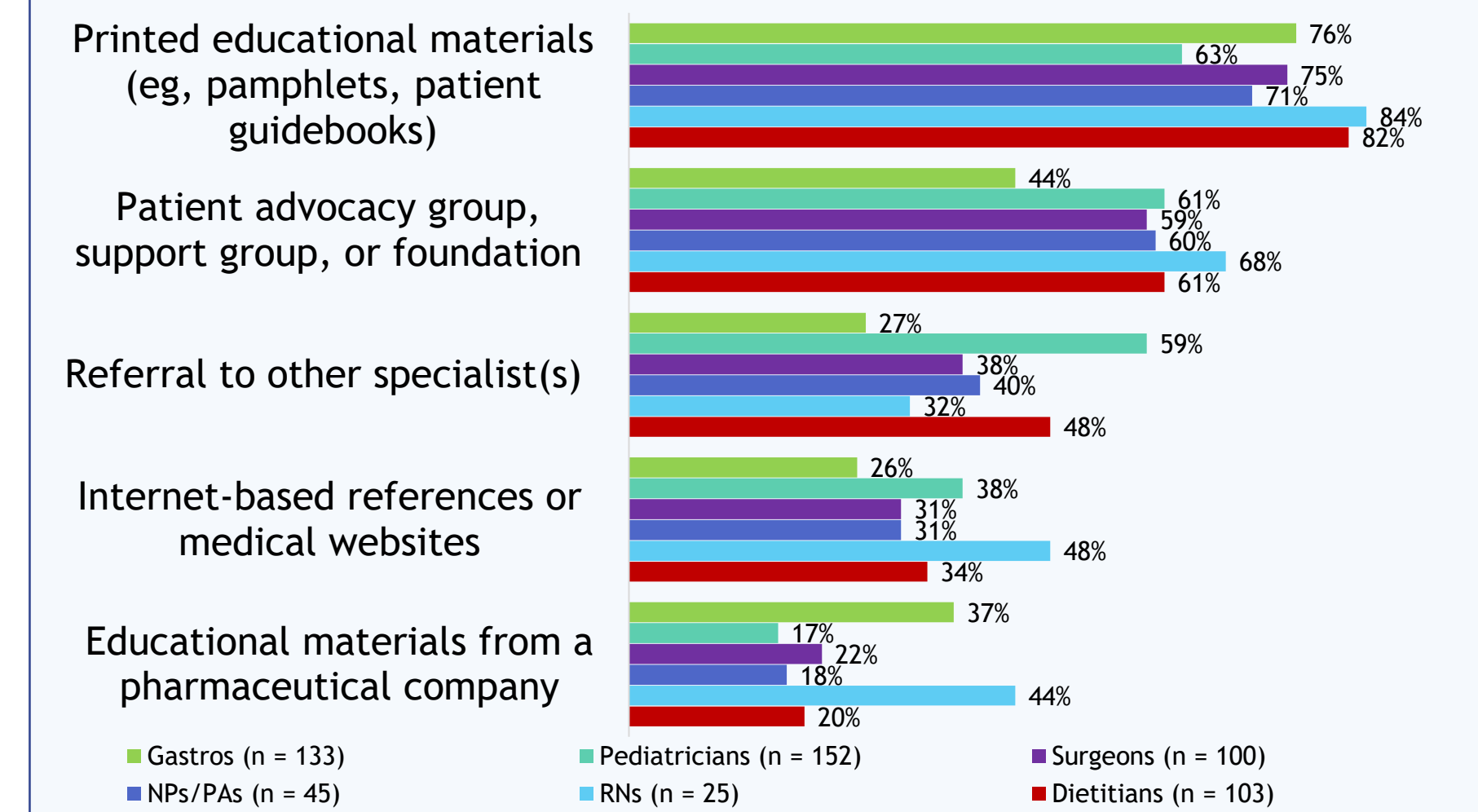
How challenging is transitioning pediatric patients with SBS to adult care?



"[Transition] needs to be a process with good communication AND DOCUMENTATION OF PATIENT VISITS." **Pediatrician, Tennessee**

6 RESOURCES PROVIDED TO PATIENT

What resources would you provide or recommend to the patient to assist with her transitioning to adult care for SBS? (select all that apply)



7 DISCUSSION TOPICS DURING TRANSITION

What are the most important topics to discuss with the patient as she transitions to adult care? [open-ended, N = 558]

THEME	%	EXAMPLE QUOTE
Independence/self-care	20%	"Self management of the medical condition and monitoring symptoms and making appointments for medical follow ups."
Adherence to therapy	18%	"The importance of adherence and consequences of non-adherence."
Personal goals	17%	"How she feels about her condition and what her goals may be."
Knowledge of her condition	15%	"Does she know basic history of her condition, where her central line (last replaced by whom), who supplies TPN and feeding supplies, knowledge of central line dressing changes, what medications is she on?"
Continuity of care	15%	"...the culture of adult care differs from that of pediatrics. Know how to reach new doctor, establish care and continue medicines."
Long-term plans (family, pregnancy)	15%	"What her long-term goals are, ask her if she is family planning and having that discussion as needed and provide education."
Nutrition and diet	11%	"Establishing parameters for healthy weight, nutrition and bowel movements. Support for ongoing parenteral nutrition."

8 CONCLUSIONS

- In a nationally-representative survey, clinicians involved in SBS care report the process of transitioning SBS patients is challenging, involving multiple topics and steps.
- Of note: medical aspects of SBS transition (adherence to current medical recommendations and personal goals related to disease management) may be over-represented in the survey due to the respondent demographics (predominantly physicians). Psychosocial elements may be given attention by other members of the multi-disciplinary team (social work, psychology).
- Given the needs identified here, future SBS transition interventions may be warranted with research to understand patient/provider preference and effectiveness. Some ideas include: Pediatric-adult bridge programs and chronic disease passports/checklists.

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