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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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 [3-5].

METHODOLOGY

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

CASE SCENARIO: PT TRANSITIONING CARE

"[Transitioning] is a process which must begin years prior to 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, potential complications, important signs and symptoms to watch for as well as insurance, etc..." — Gastroenterologist, California

CHALLENGE OF TRANSITION

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

"...the steps changes as age progresses: At 12 to 13 years of age, after the initiation of transition planning, the transition policy statement 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, the patient's transition readiness is clarified and 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 DISCUSSION TOPICS DURING TRANSITION

What are the most important topics to discuss with the patient as they transition to adult care? (open-ended, N = 558)

Themes

% SAMPLE QUOTE

Independence/self-care

20% "Self-management of the medical condition and monitoring symptoms and making appointments for care are needed at 16 and 17 years of age.

Adherence to therapy

18% "She feels her condition and what her goals may be.

Personal goals

17% "She feels her condition and what her goals may be.

Continuity of care

15% "The culture of adult care differs from that of pediatric - she knows how to reach new doctor, establish care, etc.

Long-term plans (family, personal, family)

15% "What her long-term goals are, ask her if she is family planning and having that discussion as needed and support in continuing care.

Nutrition and diet

11% "Establishing parameters for healthy weight, nutrition and support for ongoing parental nutrition.

REFERENCES


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RESPONDENT DEMOGRAPHICS

METHODOLOGY

Using a literature review, anonymous focus groups, and the input of an SBS expert panel, a survey instrument was developed to understand current practice patterns and perceptions by specialty, as well as the impact of clinician expertise on transition practices. Statistical and qualitative analyses were conducted to understand practice variations among SBS healthcare providers (HCPs).

The web-based survey was randomly distributed to US practicing gastroenterologists (GIs), pediatricians (Peds), surgeons, GI nurses (RNs), patient advocates for short bowel syndrome (PB), and registered dietitians in December 2019 and January 2020. 

Survey and qualitative analyses were conducted to understand surgical resection [1,2]. Evidence suggests that SBS care varies widely among providers [3-5]. SBS healthcare providers (HCPs). 


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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 management) may be overrepresented due to the respondent demographics (pediatric gastroenterologists).

Psychosocial elements may be given attention by other members of the interprofessional team (social work, psychology).

Some ideas include: Pediatric-adult bridge programs or chronic disease passports/checklists.