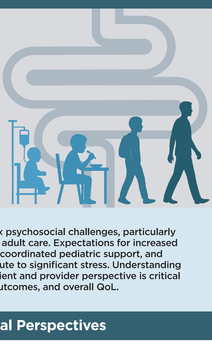
Optimizing Holistic Care for Patients With SBS Transitioning to Adult Care



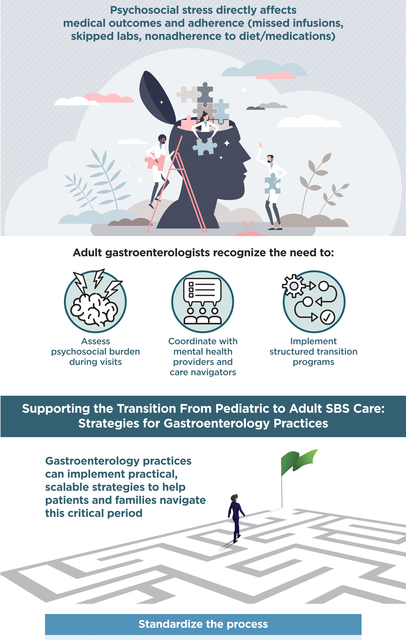
Adults living with SBS face complex psychosocial challenges, particularly during transitions from pediatric to adult care. Expectations for increased self-management, potential loss of coordinated pediatric support, and limited adult HCP expertise contribute to significant stress. Understanding these challenges from both the patient and provider perspective is critical to improving adherence, medical outcomes, and overall QoL.

Psychosocial Perspectives

- **Provider roles in coping and resilience:** Psychologists, therapists, APPs, nurse navigators
- **Transition stressors:** Increased responsibility for self-management, less coordinated care, unfamiliar adult care systems
- **Types of distress experienced by adults with SBS-IF:**
  - Physical restrictions: fatigue, PN schedules, dietary limitations
  - Emotional impact: anxiety, depression, fear of complications
  - Social impact: limitations on social events, travel, intimacy
  - Relationship strain: family, friends, partners
  - Employment challenges: missed work, career progression, disclosure concerns

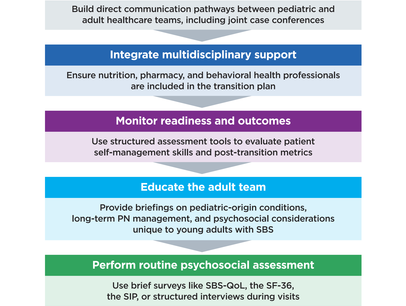


Patient Perspectives



Gastroenterologist Perspectives

Psychosocial stress directly affects medical outcomes and adherence (missed infusions, skipped labs, nonadherence to diet/medications)



Adult gastroenterologists recognize the need to:



Assess psychosocial burden during visits



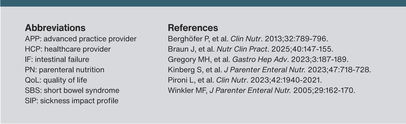
Coordinate with mental health providers and care navigators



Implement structured transition programs

Supporting the Transition From Pediatric to Adult SBS Care: Strategies for Gastroenterology Practices

Gastroenterology practices can implement practical, scalable strategies to help patients and families navigate this critical period



Standardize the process

Develop written transition protocols that outline roles, timelines, and documentation needs

Establish dedicated liaisons

Assign a coordinator or nurse navigator to oversee transfer logistics and ensure follow-up

Enable cross-site collaboration

Build direct communication pathways between pediatric and adult healthcare teams, including joint case conferences

Integrate multidisciplinary support

Ensure nutrition, pharmacy, and behavioral health professionals are included in the transition plan

Monitor readiness and outcomes

Use structured assessment tools to evaluate patient self-management skills and post-transition metrics

Educate the adult team

Provide briefings on pediatric-origin conditions, long-term PN management, and psychosocial considerations unique to young adults with SBS

Perform routine psychosocial assessment

Use brief surveys like SBS-QoL, the SF-36, the SIP, or structured interviews during visits

Key Takeaways



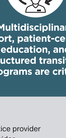
Transitions to adult care are high-risk periods for psychosocial stress in SBS-IF



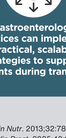
Stress affects adherence, medical outcomes, and QoL



Listening to patient experiences ("walking in their shoes") informs effective care



Multidisciplinary support, patient-centered education, and structured transition programs are critical



Gastroenterology practices can implement practical, scalable strategies to support patients during transition

Abbreviations

APP: advanced practice provider
HCP: healthcare provider
IF: intestinal failure
PN: parenteral nutrition
QoL: quality of life
SBS: short bowel syndrome
SIP: sickness impact profile

References

Berghofer P, et al. *Clin Nutr*. 2013;32:789-796.
Braun J, et al. *Nutr Clin Pract*. 2025;40:147-155.
Gregory MH, et al. *Gastro Hep Adv*. 2023;3:187-189.
Kinberg S, et al. *J Parenter Enteral Nutr*. 2023;47:718-728.
Pironi L, et al. *Clin Nutr*. 2023;42:1940-2021.
Winkler MF, *J Parenter Enteral Nutr*. 2005;29:162-170.