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POSITION PAPER

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Pediatric to adult transition care in neurogastroenterology and motility: A position paper from the American Neurogastroenterology and Motility Society and European Society of Neurogastroenterology and Motility

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Abstract

Transition services—programs that support adolescents and young adults (AYAs) as they move from a child-centered to a more autonomous, adult-orientated healthcare system—have been associated with improved short- and long-term healthcare outcomes. Unfortunately, there is a paucity of evidence exploring transition services within the neurogastroenterology and motility (NGM) field. The overall aim of this article, endorsed by the American Neurogastroenterology and Motility Society and European Society of Neurogastroenterology and Motility, is to promote a discussion about the role of transition services for patients with NGM disorders. The AYAs addressed herein are those who have: (a) a ROME positive disorder of gut–brain interaction (DGBI), (b) a primary or secondary motility disorder (including those with motility disorders that have been surgically managed), or (c) an artificial feeding requirement (parenteral or enteral tube feeding) to manage malnutrition secondary to categories (a) or (b). The issues explored in this position paper include the specific physical and psychological healthcare needs of patients with NGM disorders; key healthcare professionals who should form part of a secondary care NGM transition service; the triadic relationship between healthcare professionals, caregivers, and patients; approaches to selecting patients who may benefit most from transition care; methods to assess transition readiness; and strategies with which to facilitate transfer of care between

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healthcare professionals. Key areas for future research are also addressed, including the construction of NGM-specific transition readiness questionnaires, tools to assess post-transfer healthcare outcomes, and educational programs to train healthcare professionals about transition care in NGM.

KEYWORDS
disorder of gut–brain interaction, neurogastroenterology, pediatrics, transition clinic

1 | INTRODUCTION

Transition services are well-recognized in the 21st century healthcare model and represent a bridge between pediatric and adult healthcare settings. The overall aim of a transition service is to support adolescents and young adults (AYAs) with chronic health conditions, as well as their caregivers, as they gradually move from a child-centered to a more autonomous, adult-orientated medical system.[1] Unlike "transfer of care" which is an event that occurs at a single point in time, transition is a multistep process which caters for the medical, psychological, developmental, and vocational needs of AYAs to ensure that patients are better able to independently manage their healthcare needs (Figure 1). Appropriately executed transition services in gastroenterology can increase medication adherence, reduce inpatient admissions, and allow AYAs to achieve their estimated maximum growth potential.[2]

Policy documents from professional bodies highlight the importance of transition care, yet it is undertaken poorly in many instances.[1,3] Until a publication from the British Society of Gastroenterology Adolescent and Young People's Committee in 2017,[4] no national or international professional body had published consensus guidelines for healthcare professionals coordinating transition care for AYAs with chronic digestive disease, although attempts were made to a promote a discussion in the field. For instance, in 2003, the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition published non-consensus-based recommendations for transition care for AYAs with inflammatory bowel disease (IBD).[5] In Europe, in 2015, a similar non-consensus-based approach was undertaken by four Italian Societies of Gastroenterology who published recommendations for transition care for AYAs with IBD, celiac disease, and chronic liver disease.[6] At the time of publication, the British Society of Gastroenterology Adolescent and Young People's Committee acknowledged the relative dearth of data addressing transition care in neurogastroenterology and motility (NGM) compared to IBD and hepatology,[4,7–10] which to our knowledge has remained largely unchanged. This is particularly concerning since data suggest that health related quality of life among patients with NGM disorders, such as irritable bowel syndrome, fecal incontinence, and/or functional constipation, is at least as impaired as those who have IBD.[11,12]

Although stakeholders interested in developing NGM transition services may leverage data from IBD or hepatology subspecialties, there are highly specific considerations when managing patients with NGM disorders. Indeed, many NGM disorders, particularly those characterized by visceral hypersensitivity, are multifactorial and do not have an apparent structural or biochemical cause of symptoms that can be identified using routine medical testing, which may delegitimize the patient experience. Therefore, healthcare professionals managing NGM disorders, particularly disorders of gut-brain interaction (DGBI), should be more willing to readily engage with the biopsychosocial model of care.[13] The biopsychosocial framework dictates close collaboration between patients, caregivers, and healthcare professionals to thoroughly understand the reciprocal interaction between biological, psychological, and social factors, rather than focus exclusively on monocausal etiopathogenic processes.

The overall aim of this article, endorsed by the American Neurogastroenterology and Motility Society and European Society of Neurogastroenterology and Motility, is to promote a discussion

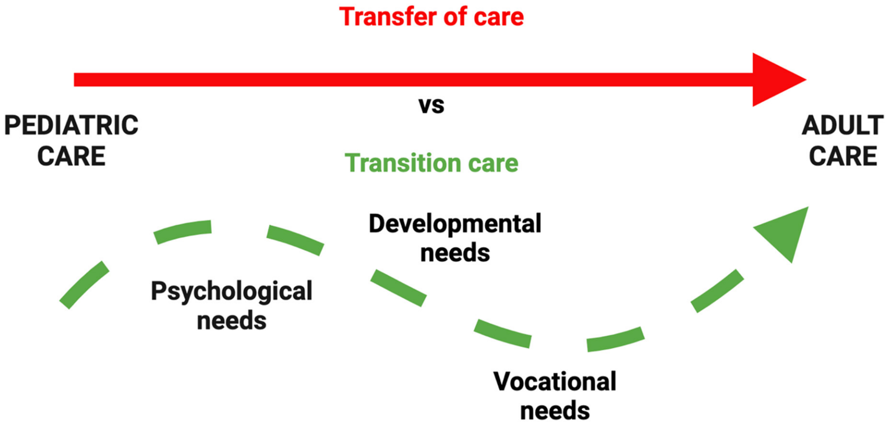

FIGURE 1 A comparison of transfer of care versus transition care. Transfer of care is an event which occurs at a single point in time when an adult team takes over responsibility of a patient's care. On the other hand, transition care is a gradual process which takes place over several years and caters for the psychological, developmental, and vocational needs of adolescents and young adults.

about the role of transition services for patients with NGM disorders. The manuscript's co-authorship draws on the experience of a variety of healthcare professionals: pediatric neurogastroenterologists, adult neurogastroenterologists, pediatric- and adult gastrointestinal surgeons, psychiatrists, psychologists, and dietitians. In our commitment to patient and public involvement, a person with experience of transition care (SJ) was consulted and contributed to the content of this review.

TABLE 1 Disorders of gut–brain interaction recognized by the ROME Foundation, and a selection of primary/secondary motility disorders of the gastrointestinal tract in children and adolescents.

ROME disorders of gut–brain interaction in children and adolescents	H1. Functional nausea and vomiting disorders
	H1a. Cyclic vomiting syndrome
	H1b. Functional nausea and vomiting syndrome
	H1c. Rumination syndrome
	H1d. Aerophagia
	H2. Functional abdominal pain disorders
	H2a. Functional dyspepsia
	H2b. Irritable bowel syndrome
	H2c. Abdominal migraine
	H2d. Functional abdominal pain—not otherwise specified
	H3. Functional defecation disorders
	H3a. Functional constipation
	H3b. Nonretentive fecal incontinence
Examples of primary motility disorders	1. Achalasia
	2. Esophageal atresia and tracheo-esophageal fistula
	3. Disorders of gastric emptying (gastroparesis)
	4. Pediatric intestinal pseudo-obstruction
	5. Hirschsprung's disease
Examples of secondary motility disorders	1. Diabetes mellitus
	2. Connective tissue disorders
	3. Cerebral palsy
	4. Medication-induced (e.g. opioids and antipsychotics)

2 | METHODOLOGY

For this narrative review, a medical librarian (EA, see acknowledgements) in the Mayo Clinic Libraries (Rochester, Minnesota, USA) performed a comprehensive search of the MEDLINE, EMBASE, and Scopus databases. Full details of this search are enclosed in the supplementary material (S1). For the first phase, the MEDLINE database was searched for pediatric-adult transition services in the context of general gastroenterology (that is, not specific to NGM). For the second phase, MEDLINE, EMBASE, and Scopus databases were searched specifically for pediatric-adult transition services in the context of NGM. In this search, records with “transition* AND neurogastroenterol*” in the title, abstract, keyword, and keyword heading were identified. Following title and abstract screening, six potentially relevant articles were identified and two were retained in the MEDLINE database, and 16 potentially relevant articles were found in the EMBASE database, with seven retained. The Scopus database had no unique references. In total, five unique (non-duplicate) articles or conference abstracts were retrieved which referred specifically to NGM transition care.[14–18]

2.1 | Which patients to select?

Ultimately, any patient in pediatric care who is likely to require ongoing multidisciplinary team input from adult services should be eligible for transition care. The three broad categories of patients who require transition care in NGM are those who have (a) a ROME positive DGBI, (b) a primary or secondary motility disorder, or (c) an artificial feeding requirement (parenteral or enteral tube feeding) to manage malnutrition secondary to factors (a) or (b). A proportion of patients will have all three of these factors (Table 1). An NGM transition service should be adequately resourced to manage the interrelationship between altered motility, nutritional intake, visceral hypersensitivity, surgical complications, and psychosocial factors. Three clinical cases which illustrate the overlap between these issues are outlined in Table 2.

2.1.1 | ROME positive DGBI

DGBI, previously referred to as functional gastrointestinal disorders, relate to recurrent and chronic gastrointestinal symptoms secondary to a combination of visceral hypersensitivity, gastrointestinal dysmotility, altered mucosal and immune function, microbiota dysbiosis, and abnormal central nervous system processing.[1] The ROME Foundation recognizes 13 different DGBI in children and adolescents (Table 1), which can be diagnosed by clinicians on symptoms alone if, after appropriate medical evaluation, symptoms cannot be attributed to another medical condition.[19] The proportion of children and adolescents who have been shown to meet the symptom-based criteria for ROME II, III or IV DGBI ranges from 9.9% to 29%, and can reach as high as 87% in clinical samples.[20]

At least 60% of pediatric patients, at least those with abdominal pain, will “outgrow” their DGBI and not experience symptoms in adulthood.[21,22] Predicting the subgroup of AYAs who will most likely experience long-term DGBI symptoms and, therefore, require care into adulthood is a key challenge faced by a transition team. Pediatric patients who will most likely require ongoing care are generally those who have “complex” DGBI, a term previously used to describe those with a cluster of extra-intestinal co-morbidities, such as migraine, chronic fatigue syndrome, fibromyalgia, autonomic dysfunction, and

TABLE 2 Examples of three patient cases that may benefit from a neurogastroenterology and motility transition service. The selection of cases illustrates the overlap between aberrant motility, nutritional intake, visceral hypersensitivity, and psychosocial factors.

Case 1 A 15-year-old male patient with poorly controlled type-1 diabetes (HbA1c 86 mmol/L) and a background of Hirschsprung's disease was managed by a pediatric neurogastroenterology service for recurrent constipation following a previous transanal Soave's endorectal pull through surgical procedure. In addition to constipation, the patient had a fear of fecal incontinence, was preoccupied about the precise location of feces within the gastrointestinal tract, and had an overly restrictive diet. Clinical symptoms and pH impedance testing were consistent with a diagnosis of reflux hypersensitivity. Given the patient's complex medical history with requirements for long-term follow-up, he was identified as a candidate for adult neurogastroenterology input and was recruited onto the transition pathway.
Case 2 A 14-year-old female patient with a background of hypermobile Ehlers-Danlos syndrome, postural tachycardia syndrome, fibromyalgia, and mast cell activation syndrome was initially seen in a pediatric gastroenterology practice for post-prandial fullness and epigastric pain. Gastric emptying tests were normal and foregut symptoms were thought to be secondary to visceral hypersensitivity. Over a period of two years, the patient developed objective features of malnutrition and, following a psychiatric evaluation, she was diagnosed with DSM-5® avoidant-restrictive food intake disorder. Following a multidisciplinary meeting, an enteral tube feeding approach was pursued, and the patient was transitioned to the adult neurogastroenterology service for management of artificial feeding and gastrointestinal symptoms that were refractory to conventional medical therapy.
Case 3 A 17-year-old female patient with a history of chronic urinary tract infections and adenomyosis was referred to a pediatric surgery department to explore surgical options for intractable constipation, accompanied by chronic pain in the umbilical region. Her symptoms significantly impacted psychosocial functioning and quality of life. The patient was diagnosed with treatment-resistant, slow transit constipation and a multidisciplinary team decided that she was eligible for an antegrade continence enema (ACE). Management of the chronic umbilical abdominal pain was overseen by a chronic pain team who offered her transcutaneous electrical nerve stimulation, which the patient responded favorably towards. Although the ACE prevented constipation, a local cutaneous inflammatory reaction caused intolerable pain, so it was removed. Problems with defecation reoccurred following removal of the ACE, so she was advised to perform transanal irrigation. Unfortunately, transanal irrigation was ineffective and the ACE was reinserted following a risk–benefit assessment by a multidisciplinary team. Given the complexity of her symptoms and their profound negative impact on psychosocial functioning, she was transitioned to an adult neurogastroenterology team for ongoing care and consideration of treatments approved for use in adults.

connective tissue disorders (e.g. hypermobile Ehlers-Danlos syndrome).[23] Among those who have persistent DGBI, it is likely that the majority of care in adulthood would be delivered in primary care, whilst gastroenterologists would manage those with moderate-to-severe symptoms, and neurogastroenterologists would manage those who have “complex DGBI” who are refractory to traditional treatment strategies.[24,25]

Psychological co-morbidities and extra-intestinal somatic symptoms, defined as physical symptoms that affect multiple organ symptoms which cannot be explained using routine medical testing,[26] have been convincingly shown to predict the persistence of DGBI into adulthood.[21,27] Therefore, patients with a greater number and/or severity of these complaints may be more likely to require long-term care and benefit from transition care into adult practice. Indeed, one study demonstrated that those with increased risk for persistent abdominal pain, measured over the course of five years, were not characterized by the highest pain severity at baseline, but rather by higher levels of anxiety and depressive symptoms, lower perceived self-worth, and a greater number of negative life events.[28] Interestingly, somatic symptom severity, defined using the Children's Somatization Inventory,[29] has been reported to mediate the relationship between anxiety/depression and pediatric DGBI, which suggests that somatic symptoms are an important treatment target to improve psychopathology and abdominal pain in pediatric DGBI.[26]

2.1.2 | Primary and secondary motility disorders

Primary motility disorders arise as a direct consequence of alterations in the neuromuscular architecture of the gastrointestinal tract[30] and may affect the esophagus (e.g. achalasia), stomach (e.g. gastroparesis), small intestine (e.g. pediatric intestinal pseudo-obstruction), and colon (e.g. Hirschsprung's disease). Secondary dysmotility disorders arise because of systemic disease, such as diabetes mellitus, connective tissue disease, or a neurological disorder that affects gastrointestinal sensorimotor function. In some of these motility disorders, patients are subjected to repeated invasive surgical and/or endoscopic interventions which require long-term follow-up in adult practice to guide continued care of adjuncts (e.g. anterograde continence enema catheters) and monitor complications.[31,32] For conciseness, a complete overview of the various presentations and sequelae of gastrointestinal motility disorders in AYAs, as well as their long-term management, is not provided in this article since this has been addressed elsewhere.[30]

2.1.3 | Artificial feeding

A proportion of patients within an NGM transition service will receive artificial feeding secondary to a DGBI or primary/secondary motility disorder. Artificial feeding is an evidence-based approach to treat AYAs in whom oral intake alone is unable to sustain their macro- and micronutrient requirements,[33] which may be delivered enterally, parenterally, or via a combination of both routes. Patients who receive home enteral tube feeding,[34] as well as their caregivers,[35] have several unique physical, psychological, and social needs that should be carefully managed by a transition team.

Patients' physical needs may relate to tube-related complications (e.g. tube dislodgement, blockage, or leakage) or feed-related issues (e.g. volume intolerance, excessive weight loss/gain, vomiting, hypoglycemia, aspiration pneumonia, or altered bowel movements). Psychological issues commonly relate to problems with body image or sleep disturbance.[36] Both physical and psychological issues may be compounded by the various limitations imposed upon a patient's social life as a result of artificial feeding,[36–38] since patients may find it challenging to leave their home.[34] Given the complications associated with enteral tube feeding,[39] a transition team may wish to periodically revisit whether a patient can be weaned from an enteral tube feeding regimen to oral feeding, but this should occur only when clinically indicated.[40]

A subgroup of patients within an NGM transition service will have small intestinal motility disorders (e.g. pediatric intestinal pseudo-obstruction), which represent rare causes of chronic intestinal failure requiring long-term parenteral feeding. Data addressing transition care for AYAs receiving artificial feeding, including recommendations tailored to this patient subgroup, have been published elsewhere, although not exclusively within the context of NGM disorders.[41–43]

2.2 | Which healthcare professionals should form part of the transition service?

The list of healthcare professionals that should form an NGM transition service is extensive and must be tailored to local resources and patients' needs. For instance, the healthcare professionals required to manage the three patients described in Table 2 will differ largely because the AYAs have different underlying diagnoses and associated sequelae. The nuances of specific cases aside, the authors reached a consensus that the following healthcare professionals should ideally form the foundation of a secondary care NGM transition service (Figure 2): a transition coordinator, an adolescent psychologist/psychiatrist (ideally both as they have different clinical skills), a dietitian, a pediatric neurogastroenterologist, an adult neurogastroenterologist, an adult gastrointestinal surgeon (with a subspecialty interest in NGM), a pediatric gastrointestinal surgeon (with a subspecialty interest in NGM), and nurse specialist (whose role will depend on the condition being addressed e.g. a stoma or nutrition nurse). A primary care physician is crucial for continuity of care in the community, but they are not included in the above list as they operate outside of secondary care.

2.3 | A transition coordinator

The presence of a coordinator, usually a nurse, nurse practitioner or other allied healthcare professional, has been proposed as the single most important factor to the development of an effective transition service.[44] In addition to improving communication between patients, caregivers, and providers, transition coordinators may have the critical time needed to work with patients on skills related to self-management and self-advocacy. The value of transition coordinators has been demonstrated in the adolescent IBD population.[45] Indeed, patients who had their transition overseen by a coordinator demonstrated significantly higher scores in transition readiness and self-management skills compared to those without this support.[45] Moreover, compared to patients who did not work with a coordinator, the presence of a coordinator meant it was more likely for IBD patients to maintain clinical remission.[45]

2.4 | Mental health professionals

Based on non-peer reviewed data from a tertiary care UK NGM transition service (University College London and Great Ormond Street Hospitals), 56.5% of AYAs had a psychiatric diagnosis, and psychological interventions were found to be necessary in 69% of patients.[15] Similarly, in the USA, co-morbid psychiatric conditions were present in 90% of patients consulted in a tertiary care transition service.[14] The high prevalence of comorbid psychiatric diagnoses in the NGM transition setting, as well as the importance of brain-gut behavior therapies in the management of NGM disorders more broadly,[46,47] underscores the importance of integrating of psychologists and psychiatrists in the transition team.

Mental health professionals not only help AYAs conceptualize their symptoms through the biopsychosocial model, but also help patients navigate the psychosocial factors associated with

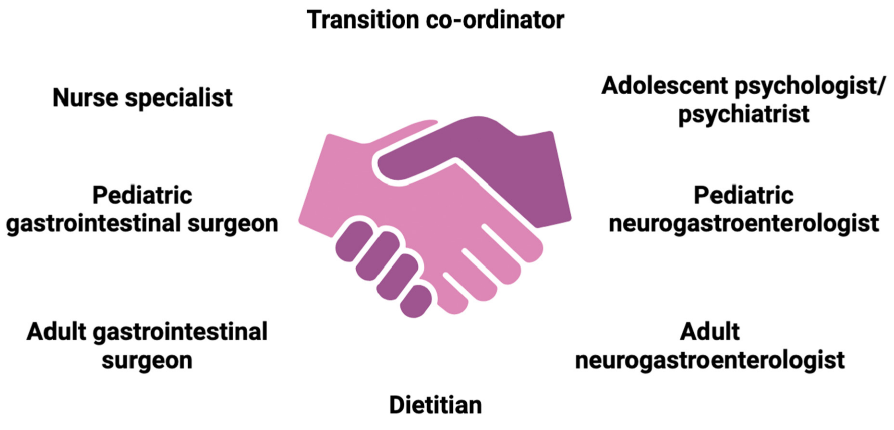

FIGURE 2 Key healthcare professionals who should ideally form the foundation of a secondary care neurogastroenterology and motility transition service.

adolescence, including the strive for greater autonomy, educational/employment goals, psychosocial health, sexuality, and reproduction.

Moreover, mental health professionals who specialize in psychogastroenterology—a field dedicated to applying effective psychological techniques to gastrointestinal problems—help address the cognitive, emotional, and behavioral factors associated with NGM disorders.[46] Unfortunately, there is ever increasing pressure on adolescent mental health services,[48] so identifying suitably qualified mental health professionals, let alone those who are adept in psychogastroenterology focused treatment, may be challenging. Reassuringly, based on non-peer-reviewed data from a tertiary care NGM transition service, a psychiatric diagnosis has not been shown to result in a suboptimal transition outcome,[49] defined as a return to pediatric care or an emergency room visit for a gastrointestinal-related complaint during the transition period.

2.5 | Dietitians

Diet plays an important role in the development and progression of NGM disorders,[50] so it is perhaps not surprising that dietetic interventions were necessary in 76% of AYAs in a UK tertiary care NGM transition service.[51] Among other roles, dietitians help patients achieve adequate nutrient intake, identify "fear foods", and provide guidance on safe refeeding after a period of dietary restriction. The work of dietitians is often closely intertwined with those of other healthcare professionals. For instance, given the association between neurodiversity (e.g., attention deficit hyperactivity disorder/autism spectrum disorder) and DGBI, as well as feeding problems related to food selectivity, food refusal, and poor oral intake,[52] dietitians may collaborate with psychologists to offer a dual psychological-dietetic management approach. Additionally, patients with DGBI have been shown to experience a variety of DSM-5® eating disorders, including avoidant-restrictive food intake disorder,[53] which may also benefit from a dual treatment approach.[50] Ideally, dietitians within the multidisciplinary team should be trained in NGM disorders, since the management of these conditions requires expertise that is not always addressed within the broad-based, general training curriculum. However, in many cases, a suitably qualified allied healthcare professional cannot be identified, so a transition team should ensure that professionals receive the training they need to deliver optimal outcomes for this patient population.

2.6 | Pediatric and adult neurogastroenterologists

Pediatric and adult neurogastroenterologists who are well-versed in the classification, diagnostic methods, treatment, and natural history of NGM disorders are important components of a transition service. AYAs with NGM disorders are often subjected to lengthy courses of repeated, inconclusive investigations and, as is purported to occur in the model of perceived uncertainty in illness,[54] inconclusive investigations can trigger diagnostic uncertainty, which can lead patients to misinterpret symptoms.[55] Diagnostic doubt would be significantly reduced by the presence of neurogastroenterologists at the 'front door' who are comfortable using a positive diagnostic approach to diagnosing DGBI[56] and who can safely manage primary/secondary motility disorders. However, we recognize the difficulties in identifying knowledgeable and enthusiastic neurogastroenterologists who would be interested in being "transition gatekeepers." Indeed, surveys disseminated to gastroenterology trainees in North America[57] and Europe[58] suggest that they lack awareness around how to manage DGBI and often hold dismissive attitudes towards those who have such conditions. These results indicate that the future workforce of consultant/attending gastroenterologists may not have the optimal skillset nor empathetic attitudes to manage NGM disorders and develop such services. Reassuringly, stakeholders who have developed the NGM curriculum for physician trainees across North America and Europe have integrated transition care into the postgraduate pediatric[16] and adult[18] curricula. However, ensuring that trainees assimilate the NGM curriculum in spirit, not only letter, may require education and training initiatives that combat stigma.[59,60]

2.7 | Pediatric and adult gastrointestinal surgeons

Pediatric and adult gastrointestinal surgeons (with subspecialty interests in NGM) should be involved in the care of patients who have congenital gastrointestinal anomalies, those who have previously undergone a surgical procedure, and/or in cases where surgery is likely to be required in future. The extent of involvement of gastrointestinal surgeons is institution and situation dependent, since many issues may potentially be managed by a gastroenterologist with crucial oversight provided by a surgical team. Where a stoma has been created, it is not unusual for much of the care to be coordinated by a stoma nurse who liaises directly with gastrointestinal surgeons if complications arise that require correction.

Diverting enterostomies may be necessary to manage upper and/or lower gastrointestinal motility disorders, including congenital conditions (e.g. anorectal malformation or Hirschsprung's disease), intractable functional constipation, and pediatric intestinal pseudo-obstruction.[31,61] In one study comparing post-operative healthcare outcomes following enterostomy in pediatric patients with ($n=62$) and without ($n=128$) a motility disorder, significantly more patients with motility disorders experienced troublesome passage of stools, abdominal pain, and ileus.[32] In addition to the higher post-operative complication rate, children with motility diagnoses had a significantly higher proportion of high-grade complications versus those who had not (61.8% vs. 31.0% $p=0.002$). Two postulates have been proposed to explain this relatively higher complication rate. Firstly, many motility disorders are pan-enteric in nature, so localized surgery to one region may not necessarily eliminate symptoms caused by widespread dysmotility.[62,63] Secondly, patients in whom an enterostomy is created to manage symptoms related to a DGBI may have ongoing visceral hypersensitivity, owing to a dysregulated brain-gut axis,[64] which may contribute to the greater frequency or severity of post-operative abdominal pain reported among those with NGM disorders versus those without.[32] Overall, the remarkably high enterostomy-related complication rate reported in this study, particularly among those with an underlying motility disorder, underscores the need for this subgroup of patients to be closely monitored during transition.

2.8 | How to assess transition readiness?

The age at which adolescence commences and the transition point into adulthood can be interpreted through various biological, cultural, religious, and legal lenses and will vary between different patients. The advent of unprecedented social forces, including digital media, delays in the completion of education, marriage, and parenthood, were proposed in The Lancet as reasons to support a shift in the definition of adolescence from 10–19 years to 10–24 years.[65] Indeed, self-management skills are thought to be mastered after the age of 18–20 years for AYAs with IBD and other chronic disorders.[66,67]

Often, for practical reasons, such as AYAs entering the college system in the USA, age 18 years is typically used to delineate between pediatric and adult care in clinical practice, and individuals aged between 16 and 19 years are transitioned to adult services for management of ongoing healthcare requirements.[68] An argument could be made that the transition process should begin as early as 11–12 years of age, since this may lead to improved knowledge, skills, and the confidence required to negotiate adult healthcare.[69,70] This supports the recommendation made by the anorectal malformation working group to commence transition at 12–13 years of age.[71] However, adult gastroenterology training programs, at least in the USA, do not require trainees to be familiar with the care of patients below the age of 18 years, so adult gastroenterologists may not always have the appropriate training or resources to manage disorders that are more frequently encountered in the pediatric setting. As such, it is not unheard of for some patients to remain with their pediatric providers well into adulthood due a lack of adult healthcare providers in their geographical region.

A comprehensive assessment of transition readiness, which should be independent of an arbitrary age, ought to begin at the time a pediatric team decides that adult care may be necessary in future. Validated self-administered questionnaires have been developed to assess readiness for transition and can help identify areas for improving patient education and track progress throughout the transition process.[72] One systematic review[72] identified 10 different generic and disease-specific assessment tools, and only one tool—the Transition Readiness Assessment Questionnaire (TRAQ)— demonstrated adequate content validity, construct validity, and internal consistency. The TRAQ, originally published in 2010[73] and refined in 2014,[74] is a disease-neutral patient-report instrument with 29 questions that assess AYAs' disease self-management and healthcare utilization skills before and during transition. Older age and a primary diagnosis of an activity limiting physical condition were shown to be associated with higher scores in the self-management domain, whilst female gender and a primary diagnosis of an activity limiting physical condition were associated with higher scores in self-advocacy.[73] Interestingly, no association between age and different TRAQ scores was identified on the self-advocacy domain, which suggests that health management skills are independent of age.[73]

The “Ready, Steady, Go” program, a generic stepwise framework used widely across the UK National Health Service, helps young people with long-term health conditions transition into adult services.[69] Healthcare providers are permitted to use “Ready Steady Go” material, developed by researchers at University Hospital Southampton NHS Foundation Trust, in their original format purely for non-commercial purposes.[69] Briefly, the “ready” aspect of the program gives young people (from the age of 11 years, if developmentally appropriate) and their caregivers an opportunity to explore knowledge about their health condition and issues related to self-advocacy, daily living, school, leisure activities, and emotions. The “steady” questionnaire, completed around 13–14 years of age, is used to monitor progress on issues identified in the “ready” questionnaire as well as new themes which can be tackled over the next two years. The “Go” questionnaire, completed at approximately 16 years of age, ensures that patients have the correct skills and knowledge to “Go” into adult services, which is followed by the “Hello” questionnaire when the patient enters adult services. Unfortunately, there do not appear to be any validated transition questionnaires for caregivers of patients who lack capacity to make independent decisions related to their healthcare. In such cases, there is often a conversation between caregivers and healthcare providers to develop a transition timeline.

2.9 | Caregivers

There is an argument that the home environment is where transition readiness begins, so caregivers can play an important role in preparing AYAs for transition.[75] Caregivers can face numerous stressors during the transition period, including the termination of their relationship with pediatric healthcare providers, uncertainty about forthcoming adult care, and delays in transition initiation.[76]

It is important for AYAs to eventually become comfortable seeing providers without caregivers and for caregivers to feel comfortable allowing AYAs to consult providers independently, granted this may not always be possible in some patients who have an intellectual disability. Consultations in the absence of caregivers may give patients the opportunity to explore issues which may otherwise be left undisclosed out of embarrassment, including matters related to alcohol, drugs, and sexuality.[77] Consulting a patient independently has been shown to provide a clearer perspective on transition readiness, as evidence suggests that caregivers tend to overestimate their child's skills and knowledge related to transition readiness compared to a patient's self-assessment.[78] In some cases, a caregiver's behavior may perpetuate the disease process. According to the theory of social learning, the way in which caregivers respond to children's abdominal symptoms (reinforcement) and the techniques in which they cope with their own abdominal symptoms (modeling) has been shown to influence abdominal symptom perception in childhood,[79–82] which can also impact the frequency of symptoms, disability days, and healthcare visits made by children when they enter adulthood.[83] Psychosocial interventions that aim to reduce protective responses from caregivers and increase a child's coping skills have been shown to reduce children's gastrointestinal symptom burden compared with controls in randomized controlled settings.[84,85] Given the importance of the patient-caregiver relationship in the evolution of DGBI, experienced psychologists may find it helpful to explore the patient-caregiver relationship to help patients identify thoughts, beliefs, and attitudes that may influence future outcomes. In certain cases, it may be appropriate to invite caregivers into consultations, particularly when patients are not seen to demonstrate adequate self-management and healthcare utilization skills. It should be noted that triadic communication[86] requires a degree of caregiver introspection, and it may be challenging to engage with caregivers who have high expectations and are insensitive to a child's cues.[87] The plight for independence features prominently during adolescence, so healthcare professionals should sensitively explain to patients the rationale for ongoing caregiver input in the management plan.

2.10 | Transfer of information

Poor communication between pediatric and adult care services may lead to incomplete transfer of healthcare information. Across numerous healthcare settings across the world, there is arguably greater scope and flexibility for caregivers to choose a suitable pediatrician for their family's needs than it is for adults to select a clinician. When transition care is necessary, families often expect pediatricians to take the lead and identify a suitable adult practitioner with whom a pediatrician has an established relationship. Transfer of information may be facilitated by direct communication between healthcare providers, but this may become challenging when patients have complex healthcare needs and/or where multiple, often geographically scattered, providers are involved. Where a transition service is not fully formed and a transition coordinator is not present to orchestrate communication, we would encourage the pediatric team to work with the patient and their caregivers to develop a "health passport.

Aside from containing a patient's medical history, a well-constructed "health passport" should contain a compendium of personal, social, and medicolegal data, including but not limited to a patient's living environment, education/employment goals, consent/mental capacity, and best interest decision-making. Colver et al.[88] attempted to study the efficacy of health passports in the transition phase in a National Institute of Health Research study, however, their analysis was limited by a small sample size ($n=13$). Although insufficient quantitative data were generated from which to formulate robust conclusions, strikingly, none of the 13 participants said that they completed the health passport alone and although the majority said that they thought passports were "useful," only half of them took them to health care appointments. In other settings, participants used this document occasionally and its perceived utility was limited.[89]

Priority areas for developing a health passport in the NGM setting include a more thorough understanding of the essential components of this document, the individuals who would benefit most from their use, as well as strategies to improve patient engagement with the tool.

2.11 | Post-transfer assessment

The importance of performing a post-transfer assessment was recognized as early as 1993 by Blum et al.[1] who reported that "outcome measures should include rate of completion of referrals, functional outcomes, sense of well-being, and patient satisfaction." Later, in 2015,[90] a consensus paper reported eight key indicators to assess successful transition, which was developed by 30 experts in adolescent health using the Delphi process (Table 3). Differences in healthcare outcomes between different patient groups with different NGM diagnoses are inevitable, so one key consideration for future research is the development of standardized methods to collect disease- and non-disease specific outcomes based on the "normal" evolution of a distinct NGM diagnosis.[91] Aside from identifying what specific measures should be measured and how groups can go about doing this, research should also evaluate the time points at which outcomes are best evaluated. Consistency in

TABLE 3 Eight indicators for successful transition reached by an international consensus group, published by Suris and Akre.[90]

1. Patient not lost to follow-up
2. Attending scheduled visits in adult care
3. Patient building a trusting relationship with adult provider
4. Continuing attention for self-management
5. Patient's first visit in adult care no later than 3–6 months after transfer
6. Number of emergency room visits for regular care in the past year (avoidable if routine medical care had been occurring)
7. Patient and family satisfaction with transfer of care
8. Maintain/improvement of standard for disease control evaluation (such as durable medical equipment and formula prescriptions in the case of a patient who receives parenteral or enteral tube feeding)

Note: Regarding number 6, although not mentioned specifically in the original table, it is likely that successful transition is marked by a *lower* number of emergency room visits for regular care.

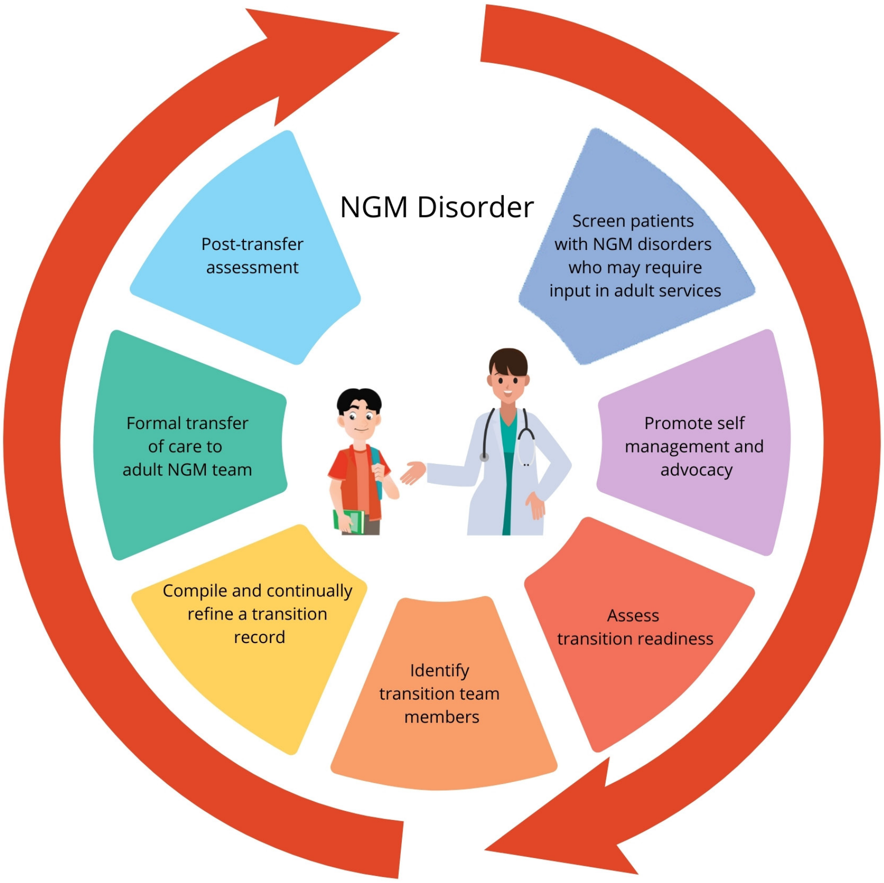

FIGURE 3 A selection of key milestones which should be achieved during the transition process in the neurogastroenterology and motility (NGM) setting by the joint efforts from patients, caregivers, and healthcare professionals.

data collection would help to ensure that different NGM transition models can be more effectively compared with one another. In addition to the suggestions outlined in Table 3, a non-exhaustive list of non-disease specific outcomes which healthcare professionals may consider collecting in routine NGM practice could include educational success, employment status, insurance coverage, quality of life, and mental health status.

3 | CONCLUSION

AYAs with DGBI, those with primary/secondary motility disorders, and those with artificial feeding requirements have unique healthcare needs that require tailor-made transition services to improve short- and long-term healthcare outcomes. The high prevalence of DGBI within the AYA general population and the dearth of data exploring transition clinics within the NGM field suggests that there are significant gaps and unmet needs within current healthcare structures that must be addressed to optimally care for these patients. Key milestones, from "screening" to "post-transfer assessment", are summarized in Figure 3. The multidisciplinary team of healthcare professionals invested in an AYA's journey should be patient-specific, however, the authors propose that an NGM transition service in secondary care should ideally include a transition coordinator, an adolescent psychologist/psychiatrist (ideally both as they have different clinical skills), a dietitian, a pediatric neurogastroenterologist, an adult neurogastroenterologist, an adult gastrointestinal surgeon (with a subspecialty interest in NGM), a pediatric gastrointestinal surgeon (with a subspecialty interest in NGM), and nurse specialist (whose role will depend on the condition being addressed, e.g. a stoma or nutrition nurse). In addition to the patient, it is vitally important to respect the needs of caregivers and develop family support mechanisms where resources permit. Key areas for future research relate to the development of NGM-specific transition readiness questionnaires, robust tools to assess post-transfer healthcare outcomes for patients with NGM disorders, and educational programs to train healthcare professionals about transition care in NGM.

AUTHOR CONTRIBUTIONS

MFB took the lead in writing this manuscript. All other authors contributed equally in the review and editing process. All authors approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

No authors have conflicts of interest to declare in relation to this work.

DATA AVAILABILITY STATEMENT

No additional data available.

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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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