

# Transition readiness assessment in adolescents and young adults with chronic intestinal failure on home parenteral nutrition: A descriptive cross-sectional study

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## Abstract

**Background and Aims:** Life expectancy for patients with chronic intestinal failure (CIF) receiving home parenteral nutrition (HPN) has improved over the past decades. Consequently, more children on HPN grow into adulthood. Until now, no assessment of transition readiness of these patients exists. Aim is to assess readiness of adolescents receiving HPN.

**Methods:** This is an international, prospective, cross-sectional multicenter study in collaboration with members of the Intestinal Failure working group—European Reference Network for Rare Inherited and Congenital (Digestive and Gastrointestinal) Anomalies and the Network of Intestinal Failure and Intestinal Transplant in Europe—European Society for Pediatric Gastroenterology Hepatology and

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Nutrition conducted between April and November 2023. A validated Transition Readiness Assessment Questionnaire was used to measure patient- and parent-reported transition readiness in adolescents on HPN.

**Results:** A total of 57 participants aged 16 to 24 years were included across eight countries. Patient-reported outcomes show a lack of readiness for transition among the total cohort with 65% scoring below the threshold. Younger patients (aged 16–18 years), male patients, and those in pediatric settings reported significant lower readiness. Parent-reported scores were higher compared with the patient-reported outcomes, reaching the threshold for transition readiness.

**Conclusion:** The transition readiness of adolescents with CIF receiving HPN presents is proven to be low. This study underscores the necessity for the use of a standardized transition protocol. Emphasizing the importance of successful transition in this vulnerable patient group will enhance the outcomes and independence of adolescents during their transition into the adult healthcare system.

#### KEYWORDS

children, home parenteral nutrition, intestinal failure, transition

## INTRODUCTION

Chronic intestinal failure (CIF) in children is a rare, complex disease caused by various underlying morbidities including short bowel syndrome, gastrointestinal motility disorders and congenital or acquired enteropathies.<sup>1</sup> The primary therapy for CIF is home parenteral nutrition (HPN) administered through a central venous catheter. HPN is needed to correct or prevent nutrition deficiencies when adequate enteral nutrition is not possible.<sup>2</sup>

The life expectancy of patients with CIF has improved over the last decades as a result of the increased availability and quality of HPN and improved processes in the management of catheters. These improvements have resulted in a decrease in complications and disease-specific mortality with overall survival rates now varying between 84% and 97%.<sup>3–7</sup> Consequently, a higher number of patients reach adulthood, which leads to an increase in focus to transitional care.

There has been a growing interest in the transition process in CIF, defined as the purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult healthcare systems.<sup>8</sup> Recently, the first international transition protocol for CIF and HPN has been published, created by European expert teams in intestinal failure.<sup>9</sup> This protocol will serve as practical guidance for CIF team members providing a more structured, optimal transition process when used as a checklist to track the transition process of patients. Implementation of this protocol is highly needed, followed by assessment of its efficacy in enhancing transition readiness. Transition might be a potentially dangerous process for adolescents with complex chronic diseases with respect to medication and treatment adherence, neglect or ignorance of alarm symptoms, disengagement from services and

risk-taking behavior that endangers their health.<sup>10–12</sup> Although the survival rate of patients with CIF receiving HPN has improved, this disease remains associated with various, life-threatening complications that require intensive management by all key stakeholders, especially during transition.<sup>6,13</sup>

A study performed in HPN expertise centers reported that adolescents frequently have psychological problems and confusion around catheter care and administration of HPN during transition.<sup>14</sup> In addition, children with CIF may endure abnormal development, such as stunting growth, delayed cognitive maturity, and learning challenges, resulting into delayed development of autonomy.<sup>15–17</sup>

Despite the importance of involvement of patients and parents in the transition process, limited data of their experience exist. Understanding their current circumstances through transition-readiness assessments is valuable to understand the state of readiness of these patients and necessary to develop and implement protocols for transition. Currently, no assessment of transition readiness of patients with CIF exist. The aim of this study was to evaluate transition readiness of patients with CIF receiving HPN who soon will be transferred or already have been transferred to adult care using validated and reliable Transition Readiness Assessment Questionnaires (version 6.0).<sup>18</sup>

## MATERIALS AND METHODS

### Study procedures and participants

This study was performed between April 2023 until November 2023 and led by the Pediatric Intestinal Failure and Home Parenteral Nutrition team of the Emma Children's Hospital at Amsterdam

University Medical Centers in Amsterdam, the Netherlands. We performed an international, prospective, cross-sectional, multicenter study of patients with CIF receiving HPN in order to assess transition readiness using the Transition Readiness Assessment Questionnaire (TRAQ) (version 6.0).<sup>18</sup> This is a skill-focused, self-report tool for assessing the developmental stage of transition readiness in youth with chronic medical conditions, including patients with CIF receiving HPN. We collaborated with members of the Intestinal Failure working group—European Reference Network for Rare Inherited and Congenital (digestive and gastrointestinal) Anomalies (IF working group-ERNICA) and the Network of Intestinal Failure and Intestinal Transplant in Europe—European Society for Paediatric Gastroenterology Hepatology and Nutrition (NITE-ESPGHAN). Healthcare professionals from a total of 48 intestinal failure expertise centers located in Europe were asked to include participants through email. The TRAQ (published in English) was translated by healthcare professionals in their own language and distributed among patients with CIF receiving HPN and their parents through email, post or during outpatient visits.

Inclusion criteria were patients diagnosed with CIF receiving HPN aged between 16 and 24 years who were receiving care in the pediatric or adult services of an IF expertise center. Exclusion criteria were the inability to complete the TRAQ because of subjective cognitive impairment or significant developmental delays assessed by their treating physician.

In order to collect parent-reported outcomes of transition readiness of their child, parents were also asked to participate and complete the TRAQ tool.

Data on age, sex, underlying disease and healthcare setting (pediatric vs adult) at the time of the readiness assessment were collected. Patients treated by a pediatric physician and pediatric HPN team are defined as belonging to the pediatric healthcare setting. Patients treated by an adult physician and adult HPN team are defined as belonging to the adult healthcare setting.

## Transtheoretical model: TRAQ

TRAQ 6.0 is a validated patient-reported assessment tool and emerged as the current best-validated measure of transition readiness in chronically ill adolescents aged  $\geq 16$  years.<sup>18</sup> This 20-item

questionnaire includes four domains: (1) managing medications; (2) keeping appointment; (3) tracking health issues; and (4) talking with providers. Each item was recorded and analyzed on a 5-point scale basis. Each item was scored 1 to 5, with 1 being assigned to “No, I do not know how” and a score of 5 assigned for “Yes, I always do this when I need to.” Two types of scores emerge from the TRAQ: an overall total score and a subscale score for each of the four domains (see Supporting Information: File S1 for the TRAQ tool).

The TRAQ is designed to represent the five stages of change of the Transtheoretical Model as proposed by Prochaska and DiClemente: (1) precontemplation; (2) contemplation; (3) preparation; (4) action; and (5) maintenance.<sup>19,20</sup> The 5-point scale of the TRAQ corresponds to these five stages (see Table 1).<sup>21</sup>

## Outcomes

The primary outcome was the patient-reported total TRAQ score and domain subscores of patients with CIF receiving HPN in order to assess transition readiness. Secondary outcomes included the percentage of patients in the total cohort who were ready for transition and the association of sex, age, and healthcare setting (pediatric vs adult) with transition readiness in patients. In addition, parent-reported outcomes of total TRAQ score and domain subscores of their child were assessed in order to assess whether differences between perceptions regarding transition exist between patients and their parents.

High transition readiness was defined as a total TRAQ score  $\geq 4$  and TRAQ domain subscore  $\geq 4.75$ , corresponding with the “action” and “maintenance” stage of behavioral change. Low transition readiness was defined as a total TRAQ score  $< 4$  and TRAQ domain subscore  $< 4.75$ .<sup>22</sup> These cutoff scores were selected based on previous literature and the Transtheoretical Model, in which these scores align within the action and maintenance stages, in which an individual actively engage in behavior change and demonstrate self-management skills (see Table 1).

## Statistical Analysis

Patient characteristics including age and sex, underlying disease, and healthcare setting (pediatric vs adult) were

**TABLE 1** Transtheoretical model and TRAQ by Prochaska.<sup>19</sup>

5 stages of changes	Definition of stages	TRAQ response	TRAQ score
Precontemplation	Having no intention to change	No, I do not know how	1
Contemplation	Thinking about change	No, but I want to learn	2
Preparation	Becoming determined to change	No, but I am learning to do this	3
Action	Actively modifying behavior and/or environment	Yes, I have started doing this	4
Maintenance	Maintaining new behaviors	Yes, I always do this when I need to	5

analyzed using appropriate descriptive statistics, depending on normality. The mean total score and the mean subscale score for each of the four domains of the questionnaire were calculated. The Student *t* test or one-way analysis of variance were used to compare mean TRAQ (sub)scores by sex, age group (16–18 years, 19–21 years, and 22–24 years) and healthcare setting. Statistical significance testing was performed with the use of a two-sided alpha level of 0.05 and was defined as a *P* value of <0.05.

## Ethical considerations

This study was approved by the Medical Ethics Review Committee of the Amsterdam University Medical Centers.

## RESULTS

### Participants

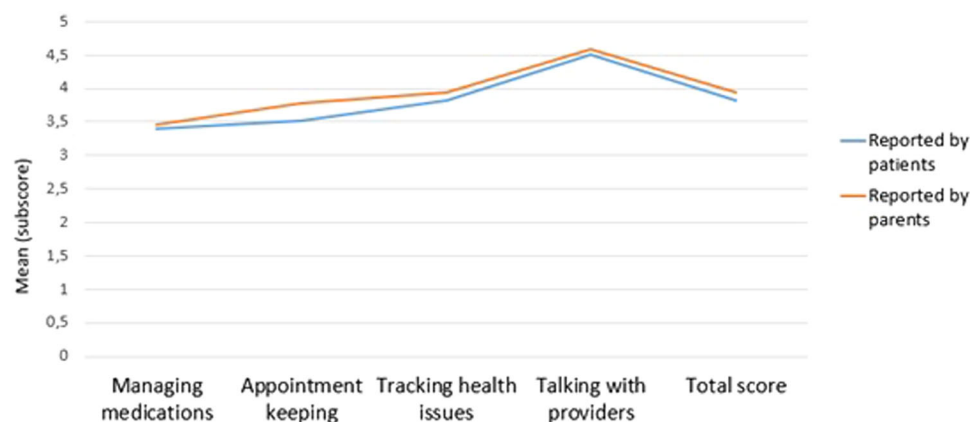
A total of 57 patients and 49 parents from 13 centers in 8 countries were included (Belgium, France, Germany, Israel, Italy, the Netherlands, Portugal, Spain; see Table 2). A total of 37 out of 57 patients (65%) scored below the threshold for readiness in the total score.

### Patient-reported vs parent-reported TRAQ (sub) scores in total cohort

The mean patient- and parent-reported TRAQ (sub)scores are summarized in Figure 1. Patient-reported (*n* = 57) mean subscores for the

**TABLE 2** Patient characteristics.

	Total cohort ( <i>n</i> = 57)	Pediatric healthcare ( <i>n</i> = 25)	Adult healthcare ( <i>n</i> = 32)	<i>P</i> value
Age, mean (SD), years	20 (2.5)	18 (1.9)	21 (1.8)	0.633
Sex, male, <i>n</i> (%)	30 (53)	15 (60)	15 (47)	0.325
Underlying disease, <i>n</i> (%)				0.724
Short bowel syndrome	23 (40)	8 (32)	14 (43)	
Motility disorder	19 (33)	9 (36)	9 (28)	
Congenital enteropathy	9 (16)	5 (20)	5 (16)	
Other	6 (11)	3 (12)	4 (13)	
Healthcare setting, <i>n</i> (%)				
Pediatric	25 (44)			
Adult	32 (56)			
Threshold of transition readiness reached				<0.001
Yes	37 (65)	3 (12)	23 (72)	
No	20 (35)	22 (88)	9 (28)	



**FIGURE 1** Patient-reported vs parent-reported TRAQ (sub)scores in total cohort.

domains were as follows: managing medications,  $3.4 \pm 1.2$ ; appointment keeping,  $3.5 \pm 1.3$ ; tracking health issues,  $3.8 \pm 0.9$ ; and talking with providers,  $4.5 \pm 0.7$ . The total score was mean  $3.8 \pm 0.9$ . Scores for all domains and the total score were below the cutoff value of 4.75 and 4.0 for transition readiness, respectively.

Parent-reported ( $n = 47$ ) mean subscores for the domains were as follows: managing medications,  $3.5 \pm 1.1$ ; appointment keeping,  $3.8 \pm 1.4$ ; tracking health issues,  $3.9 \pm 0.9$ ; and talking with providers,  $4.6 \pm 0.6$ . The total score was mean  $4.0 \pm 0.8$ . Scores for all domains were below the cutoff value of 4.75, and the total score reached the cutoff value of 4.0.

### TRAQ (sub)scores based on age, sex, and healthcare setting reported by patients

The patient-reported TRAQ total- and subscale scores based on age, sex, and healthcare setting are shown in Table 3. Patients aged 16–18 years ( $n = 17$ ) scored significantly lower within the domains managing medications (mean:  $2.4 \pm 1.0$ ), appointment keeping (mean:  $2.4 \pm 1.1$ ), tracking health issues (mean:  $3.0 \pm 0.8$ ), and total score (mean:  $3.1 \pm 0.7$ ) compared with patients aged between 19–21 ( $n = 23$ ) and 22–24 years ( $n = 17$ ;  $P < 0.05$ ). Male patients ( $n = 30$ ) scored significantly lower within the domain managing medications (mean  $3.0 \pm 1.2$ ) and total score (mean  $3.6 \pm 0.8$ ) compared with female patients ( $n = 27$ ;  $P < 0.05$ ). Patients receiving care in the pediatric healthcare setting ( $n = 25$ ) scored significantly lower in the domains managing medications (mean:  $2.6 \pm 1.1$ ), appointment keeping (mean:  $2.5 \pm 1.2$ ), tracking health issues (mean:  $3.1 \pm 0.8$ ), and total score (mean:  $3.2 \pm 0.8$ ) compared with patients in the adult healthcare setting ( $n = 32$ ;  $P < 0.05$ ). See Figure 2 for

the significant differences between subgroups based on age, sex, and healthcare setting. None of the subgroups scored above the cut of value for high transition for each domain. Patients aged between 22–24 years, women, and patients in the adult healthcare setting scored above the cutoff value for high transition readiness for total score.

### TRAQ (sub)scores based on age, sex, and healthcare setting reported by parents

The parent-reported TRAQ total and subscale scores based on age, sex, and healthcare setting are shown in Table 4. Patients aged 16–18 years ( $n = 16$ ) scored significantly lower within the domain appointment keeping (mean:  $3.2 \pm 1.7$ ) compared with patients aged between 19–21 ( $n = 18$ ) and 22–24 years ( $n = 15$ ;  $P < 0.05$ ). No other significant differences in domains and total score were found. None of the subgroups scored above the cutoff value for transition readiness in each domain. Patients aged between 19–24 years, women, and patients in adult healthcare setting scored above the cutoff value for high transition readiness for total score (see Figure 3).

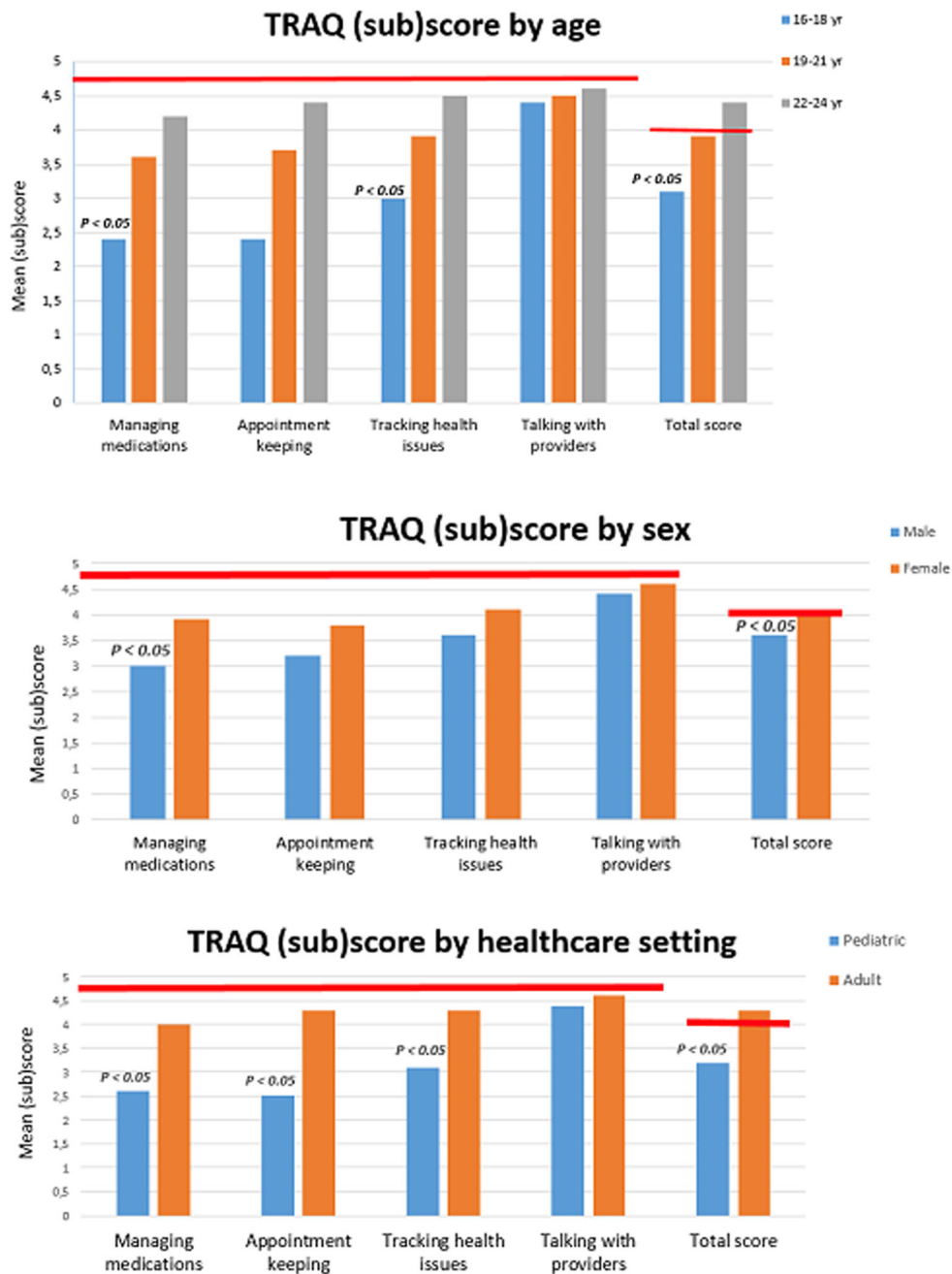
## DISCUSSION

This is the first study to assess transition readiness in adolescents and young adults with chronic intestinal failure (CIF) receiving home parenteral nutrition (HPN) before and after transition to adult healthcare and the perception of their parents regarding their child's readiness through validated TRAQ tools. In this study,

**TABLE 3** Patient-reported TRAQ (sub)scores by age, sex and healthcare setting.

	Managing medications, mean (SD)		Appointment keeping, mean (SD)		Tracking health issues, mean (SD)		Talking with providers, mean (SD)		Total score, mean (SD)	
		<i>P</i> value		<i>P</i> value		<i>P</i> value		<i>P</i> value		<i>P</i> value
Age in yr (N)		<0.001*		<0.001*		<0.001*		0.651		<0.001
16–18 (17)	2.4 (1.0) <sup>†</sup>		2.4 (1.1) <sup>†</sup>		3.0 (0.8) <sup>†</sup>		4.4 (0.9) <sup>†</sup>		3.1 (0.7) <sup>†</sup>	
19–21 (23)	3.6 (1.2)		3.7 (1.3)		3.9 (0.8)		4.5 (0.7)		3.9 (0.8)	
22–24 (17)	4.2 (0.8)		4.4 (0.9)		4.5 (0.6)		4.6 (0.4)		4.4 (0.5)	
Sex (N)		0.007*		0.96		0.068		0.258		0.024
Male (30)	3.0 (1.2)		3.2 (1.3)		3.6 (0.9)		4.4 (0.8)		3.6 (0.8)	
Female (27)	3.9 (1.1)		3.8 (1.4)		4.1 (0.90)		4.6 (0.7)		4.1 (0.9)	
Healthcare setting (N)		<0.001*		<0.001*		<0.001*		0.344		<0.001
Pediatric (25)	2.6 (1.1)		2.5 (1.2)		3.1 (0.8)		4.4 (0.9)		3.2 (0.8)	
Adult (32)	4.0 (0.9)		4.3 (0.9)		4.3 (0.6)		4.6 (0.5)		4.3 (0.6)	

Note: All effect sizes were medium to large with a Cohen D between 0.5 and 1.4 (unpaired *t* test) and eta squared >0.14 (ANOVA). \*, †: Statistically significant.



**FIGURE 2** Patient-reported scores based on age, sex and healthcare setting. Threshold for transition readiness depicted in red ( $\geq 4.75$  for domains;  $\geq 4$  for total score).

we categorized patients into three age groups (16–18 years, 19–21 years, and 22–24 years) to assess transition readiness at different stages of the process. These divisions align with the typical age range for transitioning from pediatric to adult care, allowing for a nuanced analysis of readiness and adaptation post-transfer. Our findings clearly show low transition readiness of patients with CIF receiving HPN. Significant differences with respect to sex, age, and healthcare setting were found in total TRAQ scores and subscores in domains managing medication, appointment keeping and the tracking of health issues. Younger patients (aged 16–18 years), men, and those in pediatric settings

reported lower readiness. Surprisingly, parents scored the overall transition readiness of their children higher than the children themselves.

### Transition readiness in HPN according to the transtheoretical model

The Transtheoretical Model of behavior change provides a comprehensive theoretical framework for understanding the stages through which an individual progresses to change behavior (Prochaska and

**TABLE 4** Parent-reported TRAQ (sub)scores by age, sex and healthcare setting.

	Managing medications, mean (SD)	P value	Appointment keeping, mean (SD)	P value	Tracking health issues, mean (SD)	P value	Talking with providers, mean (SD)	P value	Total score, mean (SD)	P value
Age in yr (N)		0.193		0.049*		0.139		0.961		0.114
16–18 (16)	3.1 (1.3)		3.2 (1.7) <sup>†</sup>		3.7 (1.1)		4.6 (0.7)		3.6 (1.1)	
19–21 (18)	3.6 (1.0)		3.8 (1.2)		3.9 (0.8)		4.6 (0.5)		4.0 (0.7)	
22–24 (15)	3.7 (0.9)		4.4 (1.1)		4.3 (0.7)		4.6 (0.6)		4.3 (0.6)	
Sex (N)		0.419		0.868		0.557		0.258		0.624
Male (29)	3.3 (1.1)		3.8 (1.4)		3.9 (0.9)		4.5 (0.7)		3.9 (0.9)	
Female (20)	3.6 (1.1)		3.8 (1.4)		4.0 (0.9)		4.6 (0.5)		4.0 (0.8)	
Healthcare setting (N)		0.444		0.086		0.158		0.671		0.224
Pediatric (23)	3.3 (1.2)		3.4 (1.6)		3.8 (1.0)		4.6 (0.6)		3.8 (0.9)	
Adult (26)	3.6 (1.1)		4.1 (1.2)		4.1 (0.8)		4.5 (0.6)		4.1 (0.7)	

Note: All effect sizes of significant differences were medium to large with a Cohen D between 0.5 and 1.4 (unpaired *t* test) and eta squared between 0.06 and 0.14 (ANOVA). \*, †: Statistically significant.

DiClemente, 1983).<sup>23</sup> In our cohort, participants aged younger than 22 years scored lower for subscores in all domains and the total score than the threshold for readiness as proposed by Rosen et al.<sup>22,24</sup> Most HPN patients <22 years of age were in the “preparation” stage, indicating an awareness and some action towards independent management but not yet full competence.<sup>25</sup> This stage is critical in behavioral change because it is the precursor to “action,” where actual behavior change occurs. In order to advance these adolescents to the “action” and “maintenance” stages, targeted interventions that enhance self-efficacy are essential. Examples of interventions that may help are explaining the skills needed for HPN and catheter care to the patients, showing how to take care of the management, how to make appointments, and how to recognize symptoms of serious complications.

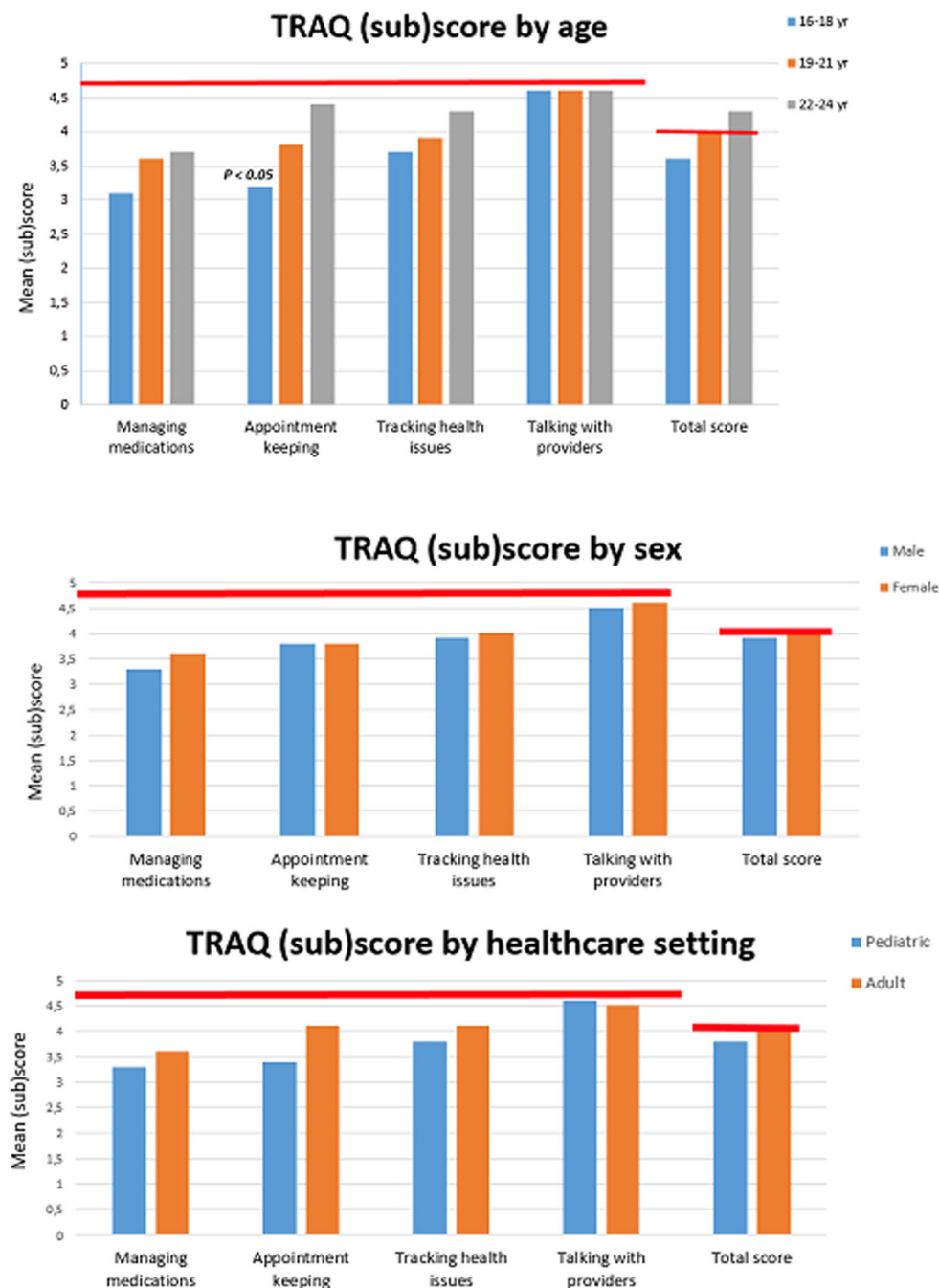
### CIF and HPN vs inflammatory bowel disease

Higher scores for transition readiness through TRAQ were found within another gastrointestinal chronic disease, such as inflammatory bowel disease (IBD), compared with CIF patients receiving HPN. A study in 655 IBD patients, 12–21 years of age, reported that all domains had mean scores of  $\geq 4$  among 21-year-olds, whereas in our cohort, only “talking with providers” scored  $> 4$  among patients aged 21 years.<sup>26</sup> Two other study in patients with IBD reported also higher mean TRAQ scores for patients aged 14.5–20 years including a total mean score of 3.9, vs 3.8 in our cohort, despite the younger age of the cohort compared with ours.<sup>27,28</sup> Our cohort with a higher mean age (20 years) showed lower transition readiness. This might be explained by the unique challenges patients with HPN face related to technical aspects of daily HPN and catheter care, which may further complicate their transition process. They need to master skills such as the creation of a sterile field to prevent infections, daily (dis)

connection of the parenteral nutrition, administration of medications intravenously through the catheter, and locking of the catheter with catheter lock solution.

### Patient vs parent-reported outcomes

A surprising finding of this study was the discrepancy between patient- and parent-reported outcomes, with parents generally rating their children's readiness higher than the adolescents did themselves. The tendency for parents to overestimate their children's health behavior as shown in our results has been shown before in other studies comparing child- and parent-reported outcomes in the general population and is likely a consequence of parents using their own viewpoint and knowledge as a basis from which to think about the emotional or cognitive state of their child.<sup>29</sup> This means that the more proficient parents rated themselves in the care of HPN, the more optimism they attributed to their child. Another explanation for this optimism can be that this is a consequence of social desirability bias and being unaware of their children's capability.<sup>30</sup> In CIF, where parent involvement in the transition process is critical because of the complexity of HPN, this discrepancy between child- and parent-perception highlights the need for objective assessments and education to ensure that both parents and adolescents have realistic expectations of the adolescent's readiness. Parents can be key facilitators of their child's healthcare transition, supporting them to become experts in their own condition and care. To do so, they require clarification on their role and support from service providers.<sup>31</sup> This emphasizes that the process of transition in chronic diseases involve multiple stakeholders including the patient, adult, and pediatric care providers and parents.<sup>32</sup>



**FIGURE 3** Parent-reported scores based on age, sex and healthcare setting. Threshold for transition readiness depicted in red ( $\geq 4.75$  for domains;  $\geq 4$  for total score).

### Strengths and limitations

An important strength of this study is that this is the first transition readiness assessment in adolescents and young adults with CIF receiving HPN. Through international collaboration, a large sample size with participants throughout Europe was created, which is paramount for showing the current transition readiness of these patients. One important limitation of the current study is the lack of information regarding family background, education, socioeconomic status or migration background, which might have affected transition

readiness, although this was not proven to be significantly associated in previous studies in adolescents and young adults with chronic diseases (eg sickle cell anemia, rheumatic-, endocrine- or gastrointestinal conditions).<sup>33,34</sup> Furthermore, no detailed clinical data were collected on HPN care such as age at initiation of HPN, duration of HPN, and HPN dependence level, all of which could potentially influence transition readiness. This limitation was primarily due to practical constraint associated with legal regulation concerning data collection across various countries. Another limitation is that the questionnaires are translated by each physician in their

own language. The original English version is reported to be validated and reliable; however, it was chosen to use nonvalidated translated versions because of practical issues. The quality of translation may have varied across languages, potentially influencing responses. However, the TRAQ questionnaire consists of 20 straightforward and practical sentences that assess basic self-management skills. Although translations were conducted by medical professionals rather than trained linguists, the simplicity of the questionnaire minimizes the likelihood of significant translation inconsistencies affecting comprehension. In addition, the generality of the TRAQ tool is also an important limitation. Although this tool facilitates comparison with other underlying diseases, it lacks an important aspect of HPN, including catheter care, the managing of parenteral nutrition, and the recognition of life-threatening complications. Therefore, in the future, HPN-specific questionnaires should be created and validated in various languages to assess readiness concerning HPN and catheter care. It might be helpful to apply a HPN-specific transition readiness tool as standard clinical practice during follow-up to recognize needs and offer help when necessary. Although no overall score has been established that serves as a cutoff for readiness to transition, a higher score corresponds to greater transition readiness. We used the thresholds of 4.0 for overall score and 4.75 for subscore as proposed by Rosen et al.<sup>22</sup> The effectiveness of this cutoff value in predicting long-term healthcare outcomes remains unvalidated. To ensure these values are efficient and clinically meaningful thresholds, future longitudinal studies should evaluate its association with key health outcomes, including weaning and complication rates, emergency department visits, hospitalizations, and mortality.

## Implications for future

The low transition readiness in this group highlights the needs for better support of patients receiving HPN when leaving pediatric services. Findings from this study suggest several gaps to improve transition outcomes for CIF patients. Healthcare providers should consider implementing a recently published standardized transition protocol that includes assessment of the developmental stages of adolescents, followed by a tailored stepwise transition procedure.<sup>9</sup> After implementation of this protocol, regular assessments using tools such as TRAQ can help track readiness progression and tailor interventions to individual needs. Moreover, engaging both patients and their parents in the transition process is crucial to include their perceptions and expectations, which can facilitate a better process.

## CONCLUSION

The transition readiness of adolescents and young adults with CIF receiving HPN presents challenges considering the technical knowledge required for HPN and catheter management, and medical knowledge needed to recognize life-threatening complications. Our

study underscores the necessity of the use of a standardized transition protocol. Regular assessments of the transition readiness will contribute to assess the efficacy and optimization of the international CIF-transition protocol throughout time. In addition, specialized transition programs that address both essential technical and medical competencies for CIF and HPN management are needed. Emphasizing the importance of transition in this vulnerable patient group will enhance the outcomes and independence of adolescents during their transition into the adult healthcare system.

## AUTHOR CONTRIBUTIONS

Aysenur Demirok contributed to conceptualization, methodology, formal analysis, investigation, data curation, writing of the original draft, and visualization; Marc A. Benninga contributed to conceptualization, review and editing, and supervision; Antonella Diamanti, Myriam El Khatib, Anat Guz, Johannes Hilberath, Cécile Lambe, Lorenzo Norsa, Loris Pironi, and Alida A. Sanchez contributed to investigation; Mireille J. Serlie contributed to conceptualization, review and editing, and supervision; and Merit M. Tabbers contributed to conceptualization, methodology, formal analysis, investigation, review and editing, and supervision.

## CONFLICT OF INTEREST STATEMENT

None declared.

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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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