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Getting ready for transition to adult care: Tool validation and multi-informant strategy using the Transition Readiness Assessment Questionnaire in pediatrics

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Abstract

Background: Transitioning from pediatric to adult healthcare can be challenging and lead to severe consequences if done suboptimally. The Transition Readiness Assessment Questionnaire (TRAQ) was developed to assess adolescent and young adult (AYA) patients' transition readiness. In this study, we aimed to (1) document the psychometric properties of the French-language version of the TRAQ (TRAQ-FR), (2) assess agreements and discrepancies between AYA patients' and their primary caregivers' TRAQ-FR scores, and (3) identify transition readiness contributors.

Methods: French-speaking AYA patients ($n = 175$) and primary caregivers ($n = 168$) were recruited from five clinics in a tertiary Canadian hospital and asked to complete the TRAQ-FR, the Pediatric Quality of Life Inventory™ 4.0 (PedsQL™ 4.0), and a sociodemographic questionnaire. The validity of the TRAQ-FR was assessed using confirmatory factor analyses (CFA). Agreements and discrepancies were evaluated using intraclass correlation coefficients and paired-sample t tests. Contributors of transition readiness were identified using regression analyses.

Results: The five-factor model of the TRAQ was supported, with the TRAQ-FR global scale showing good internal consistency for both AYA patients' and primary caregivers' scores ($\alpha = .85-.87$). AYA patients and primary caregivers showed good absolute agreement on the TRAQ-FR global scale with AYA patients scoring higher than primary caregivers ($ICC = .80$; $d = .25$). AYA patients' age and sex were found to be contributors of transition readiness.

Conclusions: The TRAQ-FR was found to have good psychometric properties when completed by both AYA patients and primary caregivers. Additional research is needed to explore the predictive validity and clinical use of the TRAQ-FR.

KEYWORDS

adolescent, patient transfer, proxy measure, psychometrics, quality of life, young adult

1 | INTRODUCTION

Despite recent infectious outbreaks, chronic conditions have been the leading cause of death around the world (World Health Organization., 2019). Due to recent technological and medical breakthroughs, 90% of adolescents and young adults (AYA) suffering from a chronic condition are expected to survive into adulthood and go through the process of transition (Blum, 1995; Wood et al., 2014). Transition refers to “a multi-faceted active process that attends to the medical, psychological, and educational/vocational needs of [AYA] as they move from the child-focused to the adult-focused health care system” (Blum et al., 1993, p. 573). Because a suboptimal transition is associated with higher rates of acute complications and early mortality (Nandakumar et al., 2018), an optimal transition is warranted.

Measuring AYA transition readiness is useful to identify necessary transition-related skills and orient future interventions. To this end, a number of assessment instruments have been developed. According to a recent systematic review, the Transition Readiness Assessment Questionnaire (TRAQ) was the best instrument to measure transition readiness to date (Parfeniuk et al., 2020). The TRAQ is a disease-neutral, self-administered questionnaire, and its final version consists of 20 items divided into five subscales (Wood et al., 2014). The TRAQ has shown high reliability and good validity (Sawicki et al., 2009; Wood et al., 2014). The transition of chronically ill AYA being a worldwide issue, it is important to translate and culturally adapt the TRAQ to make it available for use amongst non-English speakers. To date, the TRAQ has been translated into Spanish (De Cunto et al., 2017; González et al., 2017) and Portuguese (Anelli et al., 2019). Both versions had high reliability for the global scale and lower reliability for the five subscales (Anelli et al., 2019; González et al., 2017). Both versions also showed good criterion validity.

The transition readiness of AYA has been found to be influenced by their sex (González et al., 2017; Wood et al., 2014) and age (Anelli et al., 2019; González et al., 2017; Wood et al., 2014). There are reasons to believe that it may also be influenced by their quality of life. AYA suffering from a more complex condition are likely to experience worse health than their healthy peers (Varni et al., 2001) and rely more heavily on their parents (Blum et al., 1993) and healthcare providers (Nandakumar et al., 2018), potentially undermining their emerging autonomy, which is necessary for a successful transition (Blum et al., 1993; Sawicki et al., 2009; Wood et al., 2014).

To our knowledge, no French-language version of the Transition Readiness Assessment Questionnaire (TRAQ-FR) has yet been developed and validated. Furthermore, the TRAQ has only been administered to AYA but never to primary caregivers. Using a multi-informant approach would have the added benefits of obtaining a more complete picture of AYA transition readiness (De Los Reyes et al., 2015). The aims of the current study are to (1) document the psychometric properties of the TRAQ-FR, (2) assess agreement

Key messages

- In a group of 343 participants recruited from 5 follow-up clinics in a tertiary pediatric hospital, the French version of the Transition Readiness Assessment Questionnaire (TRAQ-FR) showed good construct validity;
- The global scale of the TRAQ-FR was found reliable in both samples of AYA and primary caregivers;
- Primary caregivers' and AYA patients' transition readiness ratings were similar, supporting the validity of the proxy-version of the TRAQ-FR;
- On average, AYA rated their transition readiness slightly higher than their primary caregivers did;
- Being a girl and older than 15 years of age contributed to higher transition readiness, suggesting that younger and male AYA are more vulnerable subgroups.

between AYA patients' and primary caregivers' perceptions of AYA transition readiness, and (3) identify potential contributors of transition readiness.

2 | METHODS

2.1 | Participants

Inclusion criteria for AYA were (1) being between 14 and 20 years old, (2) having a diagnosis of chronic illness and being followed at least once a year at either the hematology-oncology, diabetes, cystic fibrosis, epilepsy, or nephrology clinic of a tertiary pediatric hospital, and (3) speaking and reading French. Primary caregivers who usually accompany patients to medical follow-ups were also invited to participate given that they generally play an active role in AYAs' care and preparation towards transition.

2.2 | Procedure

The study protocol was approved by the local research ethics committee (#2016-1220). Participants were recruited from October 2016 to January 2018. Eligible participants were told about the study either over the phone or in person by a research assistant or healthcare professional. AYA and primary caregivers who agreed to participate gave their written informed consent and consecutively received an identification number as they were recruited at the outpatient clinics. AYA and primary caregivers were asked to complete the questionnaires separately and to answer them based on their perceptions of AYA patients' current situation. They were given the option to complete them at the clinic or at home. The latter received a stamped self-addressed envelope.

2.3 | Measures

2.3.1 | Sociodemographic and medical questionnaire

AYA sociodemographic and medical information was collected from AYA and primary caregivers. The information collected was the following: age (≤ 15 years old, > 15 years old), sex (male, female), ethnicity (Black, Caucasian, Hispanic, Middle Easterner, North African), education level (high school, college), chronic condition (cancer, cystic fibrosis, diabetes, epilepsy, kidney disease), age at diagnosis (ages ≤ 5 , 6–10, 11–15, ≥ 16), perceived health compared with that of others (not good, somewhat good, good, very good, excellent), perceived health compared with that of the previous year (worse, slightly worse, similar, slightly better, better), frequency of medical follow-ups (once every 1–3 months, 3–6 months, 6–12 months, 12+ months), level of perceived control over the condition (not good, somewhat good, good, very good, excellent), and complications (yes, no). Primary caregivers were also asked to identify the nature of their relationship (father, mother, other).

2.3.2 | French version of the Transition Readiness Assessment Questionnaire

The TRAQ was translated into French by the Mapi Research Trust, a non-profit research organization offering linguistic validation for patient-reported outcomes following a standardized procedure involving forward translation, reconciliation, backward translation, and pilot testing for comprehension (Mapi Research Trust, 2019). The final version was reviewed by a panel of 6 young cancer patients as part of the translation process. Furthermore, the TRAQ-FR was reviewed by Canadian, Belgian, and French members of the research team to ensure comprehension of the items (Data S1, S2, and S3). The TRAQ-FR is composed of 19 items divided into five subscales: Managing Medication (four items); Appointment Keeping (six items); Tracking Health Issues (four items); Talking with Providers (two items); and Managing Daily Activities (three items; Wood et al., 2014). The item “Do you apply for health insurance if you lose your current coverage” was removed as it did not culturally apply to several French-speaking communities worldwide. Each item is rated on a 5-point Likert scale ranging from “No, I don't know how” to “Yes, I always do this when I need to,” with higher scores indicating higher transition readiness.

2.3.3 | Pediatric Quality of Life Inventory™ Version 4.0

The Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL™ 4.0) is a widely used instrument intended for the assessment of health-related quality of life in a pediatric population (Varni et al., 2001, 2007). In this study, the validated French versions of self-reports for

AYA (either the version for ages 13–18 or 18–25) and of adult proxy-reports for primary caregivers were used (Tessier et al., 2008). Scores were reverse coded and transformed into percentages (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), with higher scores indicating better quality of life (Varni et al., 2001, 2007). In this study, the PedsQL™ 4.0 scale showed good internal consistency (Kline, 1993; Table S1).

2.4 | Statistical analysis

2.4.1 | Construct validity

Confirmatory factor analyses (CFAs) were performed to assess the construct validity of the TRAQ-FR separately for AYA and primary caregivers. The CFAs were conducted to determine whether the factorial structure of the TRAQ-FR replicates that of the original scale. Evaluation of goodness-of-fit was determined using the normalized chi-squared ($\chi^2/d.f.$), comparative fit index (CFI), Tucker–Lewis index (TLI), root mean square error approximation (RMSEA), and standardized root mean square residual (SRMR). A model has a good fit when $\chi^2/d.f. < 2$, CFI and TLI $\geq .95$, RMSEA $\leq .06$, and SRMR $\leq .08$ (Hu & Bentler, 1999). CFI and TLI values $>.90$ are acceptable (Lai & Green, 2016).

2.4.2 | Internal consistency

The internal consistency of the TRAQ-FR was examined by calculating Cronbach's alpha (α) separately for AYA patients' and primary caregivers' global and subscale scores. An $\alpha \geq .70$ is considered acceptable (Kline, 1993).

2.4.3 | Agreement between AYA and primary caregivers

Intraclass correlation coefficients (ICCs) and paired-samples *t* tests were performed to determine agreements and differences within AYA-primary caregiver dyads. Based on a 95% confidence interval, ICCs $<.50$ suggest poor agreement, $.50$ – $.75$ moderate agreement, $.75$ – $.90$ good agreement, and $>.90$ excellent agreement (Koo & Li, 2016). A confidence interval of 95% was used to determine the statistical significance of mean differences between AYA patients' and primary caregivers' scores on the TRAQ-FR (Field, 2013). The effect size of mean differences was calculated using Cohen's *d* with a $d < .20$, $.20$ – $.50$, $.50$ – $.80$, and $>.80$ representing minimal, small, medium, and large effects, respectively (Cohen, 1988).

2.4.4 | Contributors of transition readiness

Pearson's correlation coefficient and analyses of variance (ANOVAs) were used to evaluate the criterion validity of the

TRAQ-FR. Subsequently, multivariate regression analyses using the stepwise method were performed to identify the variables most predictive of AYA transition readiness in each group of informants. Variables with the smallest partial correlation were removed progressively to identify the best model of contributors. The variables entered in these analyses were AYA patients' age, sex, ethnicity, education level, chronic condition, age at diagnosis, perceived health compared with that of others', perceived health compared with that of the previous year, frequency of medical follow-ups, level of perceived control over the condition, complications, and PedsQL™ 4.0 global score. The significance threshold was set at .05 (Field, 2013).

The statistical software R (version 1.1.643) and the Statistical Package for the Social Sciences (SPSS, version 25) were used.

3 | RESULTS

3.1 | Sample characteristics

The final sample of the study consisted of 343 participants (175 AYA; 168 primary caregivers) with a participation rate of 62% (Figure 1). However, there were only 138 matched AYA-primary caregiver dyads. Sociodemographic and medical data are presented in Table 1. As

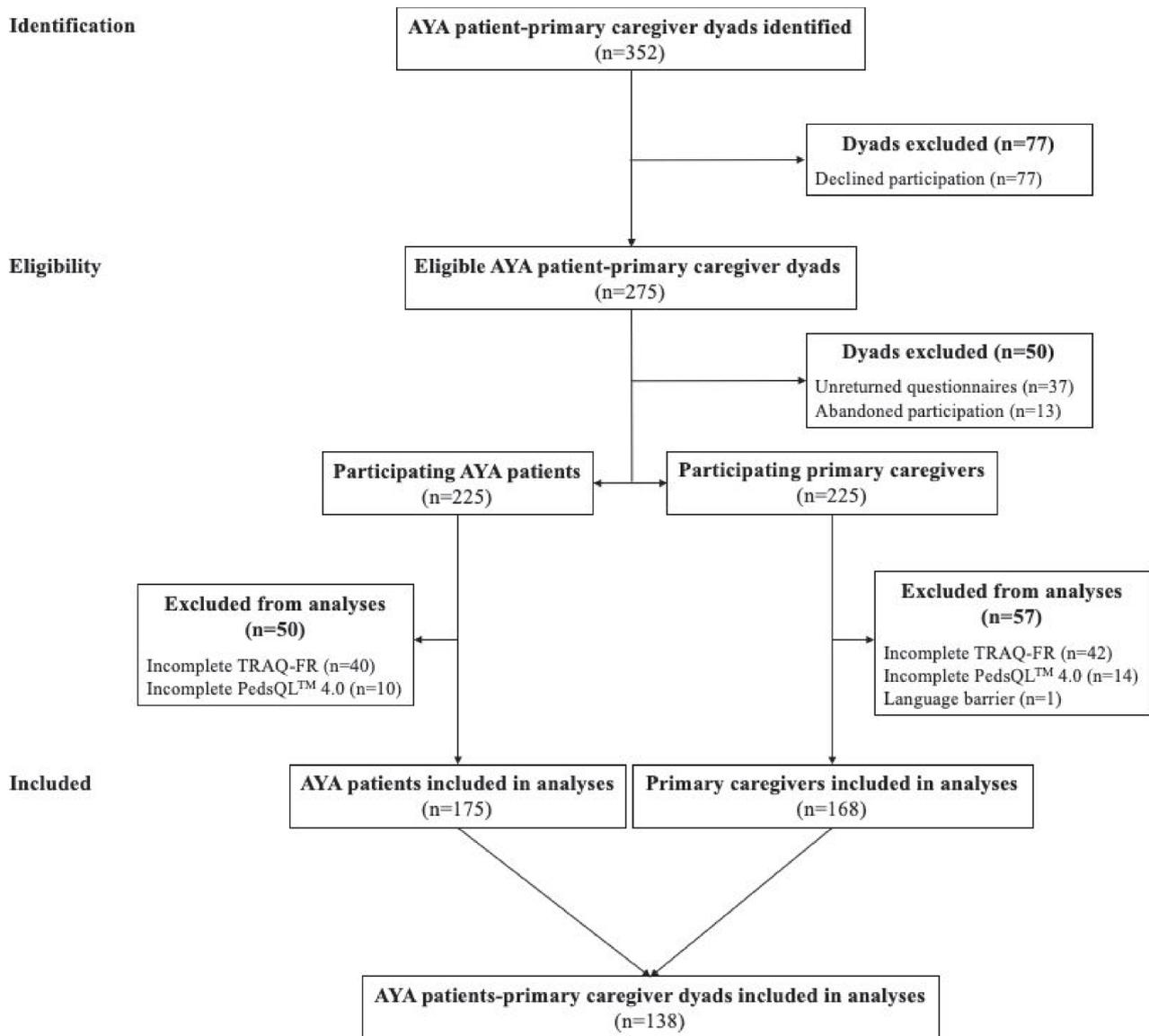


FIGURE 1 Flow of participants. Note: AYA = adolescent and young adult; n = number of individuals; PedsQL™ 4.0 = Pediatric Quality of Life Inventory™ version 4.0; TRAQ-FR = French version of the Transition Readiness Assessment Questionnaire

missing values correspond to incomplete surveys, we decided not to impute them (Table S2).

3.2 | Construct validity

For both informants' TRAQ-FR scores, the indices $\chi^2/d.f.$, RMSEA, and SRMR showed good fit (Hu & Bentler, 1999), whereas the CFI and TLI showed acceptable fit (Lai & Green, 2016) to the original scale (Table 2). This finding supports the five-subscale model of the TRAQ.

3.3 | Internal consistency

The global scale and the "Appointment Keeping" subscale showed good reliability in both AYA ($\alpha = .85$ and $\alpha = .81$, respectively) and primary caregivers ($\alpha = .87$ and $\alpha = .83$, respectively). In primary

caregivers, the subscale of "Tracking Health Issues" also showed an acceptable internal consistency coefficient ($\alpha = .85$; Kline, 1993). The other subscales had low reliability (Table S1).

3.4 | Agreement between AYA and primary caregivers

Within dyads, the TRAQ-FR showed good agreement on its global scale (ICC = .801), moderate agreement on the subscales "Managing Medications" (ICC = .695), "Appointment Keeping" (ICC = .733), "Tracking Health Issues" (ICC = .745), and "Managing Daily Activities" (ICC = .745), and poor agreement on the subscale "Talking With Providers" (ICC = .335; Koo & Li, 2016). AYA reported significantly higher transition readiness scores than their primary caregivers on the global scale and two subscales of the TRAQ-FR, but the differences were small (Cohen, 1988; Table 3).

TABLE 1 Participants' sociodemographic and clinical information

	n (%)	Mean \pm SD	Range
AYA (n = 175)			
Sex			
Female	73 (41.7)		
Male	102 (58.3)		
Age groups			
≤ 15 years old	76 (43.4)	14.61 \pm 0.518	14–15
>15 years old	99 (56.6)	16.90 \pm 1.01	16–20
Ethnicity			
Caucasian	162 (92.6)		
North African	5 (2.9)		
Hispanic	4 (2.3)		
Black	2 (1.1)		
Other	2 (1.1)		
Education			
High school level	137 (78.3)		
College level	33 (18.9)		
Clinics			
Hematology-oncology	71 (40.6)		
Diabetes	35 (20.0)		
Cystic fibrosis	30 (17.1)		
Epilepsy	25 (14.3)		
Nephrology	14 (8.0)		
Primary caregivers (n = 168)			
Nature of the relationship with AYA patients			
Mother	134 (79.8)		
Father	33 (19.6)		
Other ^a	1 (0.6)		

Note: AYA = adolescent and young adult; n = number of respondents; SD = standard deviation.

^aOne of the primary caregivers was an AYA patient's grandfather.

	Indices				
	$\chi^2/d.f.$	CFI	TLI	RMSEA	SRMR
AYA patients' TRAQ-FR scores ($n = 175$)	1.37	.94	.92	.05	.07
Primary caregivers' TRAQ-FR scores ($n = 168$)	1.56	.93	.92	.06	.07

TABLE 2 Confirmatory factor analysis indices of the TRAQ-FR

Note: AYA = adolescent and young adult; CFI = Comparative Fit Index; n = number of respondents; RMSEA = root mean square error approximation; SRMR = standardized root mean square residual; TLI = Tucker–Lewis Index; TRAQ-FR = French version of the Transition Readiness Assessment Questionnaire; $\chi^2/d.f.$ = model chi-square.

TABLE 3 Absolute agreement and mean differences between AYA patients' and their primary caregivers' scores on the five subscales and global scale of the TRAQ-FR in 138 dyads

Measures	AYA mean (SD)	Caregivers mean (SD)	ICC	Cohen's d	Paired t test	95% CI of difference	
						Lower	Upper
Managing medications	2.63 (0.979)	2.35 (0.889)	0.695***	0.30	3.76***	0.134	0.431
Appointment keeping	1.68 (1.085)	1.35 (0.942)	0.733***	0.32	4.20***	0.171	0.474
Tracking health issues	1.59 (1.093)	1.48 (0.927)	0.745***	0.11	1.52	−0.036	0.271
Talking with providers	3.53 (0.758)	3.51 (0.625)	0.335**	0.03	0.24	−0.130	0.166
Managing daily activities	3.06 (0.819)	3.01 (0.808)	0.745***	0.06	0.81	−0.073	0.174
Overall TRAQ-FR	2.50 (0.666)	2.34 (0.602)	0.801***	0.25	3.71***	0.074	0.243

Note: AYA = adolescent and young adult; CI = confidence interval; ICC = intraclass correlation coefficients; SD = standard deviation; TRAQ-FR = French version of the Transition Readiness Assessment Questionnaire.

** $p < .01$.

*** $p < .001$.

3.5 | Contributors of transition readiness

Bivariate associations between AYA patients' TRAQ-FR scores and potential contributors showed that a higher transition readiness was associated with being further in one's studies ($r = .31, p < .001$), older ($r = .27, p < .001$), and female ($r = -.22, p < .01$). Other associations were not statistically significant (Table S3). In AYA patients' multivariate model, a unique significant contribution was found for older age ($B = .18, \beta = .40, p < .001$) and being female ($B = -.36, \beta = -.28, p < .001$), predicting 21% of their transition readiness scores (Table S4). In primary caregivers' multivariate model, a unique significant contribution was found for female ($B = -.29, \beta = -.23, p = .014$) and older ($B = .25, \beta = .20, p = .032$) AYA, predicting 8% of their transition readiness scores (Table S5).

4 | DISCUSSION

This study was the first to explore the psychometric properties of a French-language adaptation of the TRAQ in a sample of 343 participants, to assess agreement in 138 AYA-primary caregiver dyads, and identify transition readiness contributors in 175 AYA and 168 primary caregivers.

The factorial structure of the TRAQ-FR is consistent with the original version when completed by AYA and primary caregivers (Wood et al., 2014). This finding implies that the items of the TRAQ-

FR can be divided into five distinct subscales and that a global score may be computed. These results differ from those of the Portuguese version of the TRAQ in which the subscale "Talking With Providers" was removed from the model (Anelli et al., 2019). The internal consistency of the TRAQ-FR global scale ($\alpha = .85-.87$) is also consistent with previous research, with coefficients ranging from .78–.94 in the literature for the global scale (Anelli et al., 2019; González et al., 2017; Wood et al., 2014). The majority of the TRAQ-FR subscales did not show acceptable reliability, but this is often found in scales with few items (median = 4), with fewer items leading to a lower α (Streiner, 2003). Other analyses to ascertain the TRAQ-FR subscales' reliability should be explored. The good response rate and the results suggest that the questionnaire was feasible, accepted, and understood. One implication of these findings is that the English and French versions of the TRAQ could be used concurrently and equally in English–French bilingual settings such as in Canada.

AYA and primary caregivers showed good agreement on the TRAQ-FR global scale and moderate agreement on most TRAQ-FR subscales (Koo & Li, 2016). The level of agreement in dyads' assessment of AYA transition readiness may be due to the nature of their relationship and to the ecological aspect of the TRAQ-FR items. Because most primary caregivers were AYA patients' parents and the skills described in the instrument can be observed and performed in their everyday life, primary caregivers were likely to know whether or not their child performed the specific behaviors described in the items. However, poor agreement was found on the Talking With

Providers subscale, which may be explained by the fact that primary caregivers were less likely to observe the specific behaviors described in these items at the moment they occurred. This is coherent with a recent systematic review showing that parent-child agreement is enhanced when measured with instruments assessing observable actions rather than feelings (Poulain et al., 2020). The results also underline the necessity to assess transition readiness in both populations as perceptions may vary across subscales (e.g., subscale "Talking with Providers").

As in prior studies on the TRAQ, the criterion validity of the TRAQ-FR was tested by exploring bivariate associations. Significant relationships were found based on AYA patients' age and sex but not on their ethnicity, which is consistent with previous research on transition readiness (Anelli et al., 2019; González et al., 2017; Wood et al., 2014). Additionally, AYA who were further in their studies reported higher transition readiness scores. This may be because AYA at higher levels of education tend to be more conscientious, that is, likely to plan in advance and be goal directed (Mike et al., 2015), to respond to the increased cognitive demands of post-high school education, which may increase their transition readiness.

This study was also the first to attempt identifying contributors of AYA patients' and primary caregivers' perceptions of AYA transition readiness. Interestingly, even though the analyses were conducted separately, the best contributors were AYA patients' age and sex across informants. Higher transition readiness scores were reported for older and female AYA. Older age may contribute to higher transition readiness because it is likely that health care professionals have addressed the topic of transition more often with older than with younger AYA patients, the process of transition starting at age 14 and transition occurring around age 18. It may also be due to change in daily life and the gradual maturation of the prefrontal cortex of the developing brain. This brain area is essential for executive functions that are responsible for planning, organizing, and skills related to a successful transition (Steinberg, 2005). Similarly, being female may lead to higher transition readiness as brain maturation begins earlier in women (Ellison & Nelson, 2009). This potential sexual dimorphism in brain morphology may result in female AYA acquiring the skills related to a successful transition earlier than male patients.

The present study has limitations. First, only 76.2% of participants were included in the analyses as 23.8% of participants had missing data on either the TRAQ-FR or PedsQL™ 4.0. This may result in a selection bias, including more AYA with higher functioning and a better profile in terms of autonomy or social participation, which influence their transition readiness. For ethical reasons, data from individuals who refused to participate in the study were not collected, preventing us from estimating this selection bias. Second, due to clinical constraints, an unequal number of participants was recruited from the five participating clinics. However, the sample represents the experiences of a wide variety of individuals suffering from different chronic conditions. Finally, causal interpretations should be made cautiously as this is a cross-sectional study.

Future studies could use alternative approaches to explore validity such as the item response theory, as documented in a recent

validation study of another transition readiness questionnaire (Mellerio et al., 2019). Furthermore, future research could explore the predictive value of the TRAQ-FR to determine whether higher scores predict a more successful transition. Additionally, future use of the TRAQ-FR in clinical practice could have the added benefits of initiating conversations within AYA-professional dyads or AYA-caregiver-professional triads about the transition process. This could strengthen partnerships between families and the healthcare team, potentially fostering AYA self-management and consequently facilitating their transition (Fu et al., 2018).

To conclude, in a sample of 343 participants, the TRAQ-FR global scale was found to have good psychometric properties when completed by AYA and primary caregivers. AYA and primary caregivers showed good agreement on the TRAQ-FR global scale with small mean differences. Finally, for both AYA and primary caregivers, the contributors of transition readiness were older age and being female. Additional research is needed to explore the predictive value of the TRAQ-FR and to evaluate its clinical utility.

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CONFLICT OF INTERESTS

The authors declare no conflict of interest, perceived or real.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

AUTHOR CONTRIBUTION

Pascale Chapados co-designed the study and wrote the first drafts of the article. Jennifer Aramideh coordinated data collection across the participating clinical departments and critically revised several drafts of the manuscript. Kristopher Lamore analyzed and interpreted data (CFA) while on a post-doctoral fellowship and wrote parts of the manuscript, and critically revised drafts of the manuscript. Émilie Dumont collected, coded, and cleaned data and critically revised several drafts of the manuscript. Tziona Lugasi co-designed the study, helped interpret data and write portions of the article, and critically revised several drafts of the manuscript. Marie-José Clermont participated actively in data collection in the nephrology clinic, helped interpret data, and critically revised several drafts of the manuscript. Sophie Laberge

participated actively in data collection in the pneumology clinic, helped interpret data, and critically revised several drafts of the manuscript. Rachel Scott participated actively in data collection in the endocrinology clinic, helped interpret data, and critically revised several drafts of the manuscript. Caroline Laverdière participated actively in data collection in the hematology-oncology clinic (long-term follow-up clinic), helped interpret data, and critically revised several drafts of the manuscript. Serge Sultan designed the study, supervised data acquisition, analysis, and interpretation, drafted several parts of the manuscript, and critically revised all versions of the manuscript.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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