Université de Montréal

Getting ready for transition to adult care: tool validation and multi-informant strategy

using the Transition Readiness Assessment Questionnaire (TRAQ) in pediatrics

par

Pascale Chapados

Département de psychologie

Faculté des arts et des sciences

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Résumé

Introduction : La transition des soins pédiatriques aux soins pour adultes peut être difficile. Si elle est réalisée de façon sous-optimale, cela peut entraîner de graves conséquences. Afin de mesurer la préparation à la transition de patients adolescents et jeunes adultes (AJA), le *Transition Readiness Assessment Questionnaire* (TRAQ) a été développé. Les objectifs de l'étude sont de 1) documenter les propriétés psychométriques de la version française du TRAQ (TRAQ-FR), 2) évaluer le degré d'accord sur le TRAQ-FR entre les AJA et leurs aidants naturels et 3) identifier les prédicteurs de la préparation à la transition.

Méthodologie : Des AJA francophones (n=175) et leurs aidants naturels (n=168) ont été recrutés dans cinq cliniques d'un hôpital tertiaire canadien et ont complété le TRAQ-FR, le *Pediatric Quality of Life Inventory Version 4.0* (PedsQL^{TM} 4.0) et un questionnaire sociodémographique. La validité du TRAQ-FR a été déterminée en réalisant des analyses factorielles confirmatoires. Les accords et différences ont été mesurés en calculant des corrélations intra-classe et des tests-*t* pour échantillons appariés. Des prédicteurs de la préparation à la transition ont été identifiés par des régressions multivariées.

Résultats : Le modèle à cinq facteurs du TRAQ est soutenu par les données et l'échelle globale du TRAQ-FR montre une bonne cohérence interne pour les scores des AJA et des aidants naturels (α=.85-.87). Le degré d'accord absolu sur l'échelle globale du TRAQ-FR est bon entre les informants (ICC=.80; d=.25), les AJA rapportant un score plus élevé que leurs aidants naturels. L'âge et le sexe des AJA sont des prédicteurs de la préparation à la transition.

Conclusion : Le TRAQ-FR a de bonnes propriétés psychométriques lorsqu'il est complété par les AJA et leurs aidants naturels. Des études futures devraient explorer la validité prédictive et l'utilisation clinique du TRAQ-FR.

Mots-clés : Pédiatrie; Psychométrie; Étude de validation; Adolescent; Jeune adulte; Aidant naturel;

Transition; Maladie chronique; Mesures de substitution; Qualité de vie

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 intra-class 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 (α=.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.

Key words: Pediatrics; Psychometrics; Validation study; Adolescent; Young Adult; Primary caregiver; Patient Transfer; Chronic illness; Proxy measures; Quality of Life

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ANOVA – Analysis of variance

AYA – adolescent and young adult

CFA – Confirmatory factor analysis

CFI – Comparative fit index

e.g. – exempli gratia

i.e. – id est

ICC – Intra-class correlation coefficient

RMSEA – Root mean square error approximation

SD – Standard deviation

SJUHC – Sainte-Justine University Health Centre

SPSS – Statistical Package for the Social Sciences

SRMR – Standardized root mean square residual

TLI – Tucker-Lewis index

TRAQ – Transition Readiness Assessment Questionnaire

TRAQ-FR – French version of the Transition Readiness Assessment Questionnaire

Liste des abréviations

α – Cronbach's alpha coefficient

B – Unstandardized regression coefficient

β – Standardized regression coefficient

d – Cohen's *d*

F – F-value

M – Mean

n – number of respondents

p – p-value

PedsQL^{TM} 4.0 – Pediatric Quality of Life Inventory^{TM} version 4.0

R^2 – R-squared value

t – t-value

$X^2/d.f.$ – Normalized chi-squared

Dédicace

À mes parents que j'aime tant, Hermel Chapados et Suzanne Corneau.

Article

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

Pascale Chapados[1], Jennifer Aramideh[1,2], Kristopher Lamore[1,2], Émilie Dumont[1,2], Tziona Lugasi[2], Caroline Laverdière[3], Marie-José Clermont[3], Sophie Laberge[3], Rachel Scott[3], Serge Sultan[1,2,3]

[1] Department of Psychology, Université de Montréal, Montreal, Quebec, Canada

[2] Sainte-Justine University Health Centre, Montreal, Quebec, Canada

[3] Department of Psychiatrics, University of Montreal, Quebec, Canada

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Corresponding author: Pascale Chapados, email: pascale.chapados@umontreal.ca

Abstract

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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^{TM} 4.0 (PedsQL^{TM} 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 intra-class 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 (α=.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.

Key words: Psychometrics; Adolescent; Young Adult; Patient Transfer; Proxy Measure; Quality of Life

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 "the purposeful, planned movement of [AYA] with chronic physical and medical conditions from child-centered to adult-oriented health-care systems" (Blum et al., 1993, p. 570). Since 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, being informed by theory, used longitudinally, easy to administer, and short to fill out (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, Seid, & Kurtin, 2001) and rely more heavily on their parents (Blum et al., 1993) and pediatricians (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 TRAQ (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 between AYA patients' and primary caregivers' perceptions of AYA transition readiness, and 3) identify potential contributors of transition readiness.

Methods

Participants

Inclusion criteria for AYA were 1) being between 14-20 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 the Sainte-Justine University Health Centre (SJUHC), and 3) speaking and reading French. The five clinics included in this study were selected because they had previously expressed the need to better understand their patients' transition readiness. The primary caregiver who usually accompanies the patient to medical follow-ups was

also invited to participate. The sample size was calculated following the recommendation by Jöreskog and Sörbom (1996), which suggests that the minimum sample size requirement is (p+1)(p+2)/2, where p is the number of variables. In this study, the minimum recommended sample size is 210.

Procedure

The study protocol was approved by the SJUHC's Research Ethics Committee (#2016-1220). Participants were recruited from October 2016 to January 2018. The study was described to eligible participants 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 to the research team 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.

Measures

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 to that of others (not good, somewhat good, good, very good, excellent), perceived health compared to 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).

French version of the Transition Readiness Assessment Questionnaire (TRAQ-FR). 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. The TRAQ-FR is composed of 19 items divided into five subscales: Managing Medication (4 items); Appointment Keeping (6 items); Tracking Health Issues (4 items); Talking with Providers (2 items); and Managing Daily Activities (3 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 five-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.

Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL™ 4.0). The PedsQL™ 4.0 is a widely used instrument intended for the assessment of health-related quality of life in a pediatric population (Varni, Limbers, & Burwinkle, 2007; Varni, Seid, & Kurtin, 2001). 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, Vuillemin, Lemelle, & Briançon, 2008). Both versions of the PedsQL™ 4.0 include a total of 23 items and each item is rated on a

five-point Likert scale, ranging from "0=Never a problem" to "4=Almost always a problem". 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, Limbers, & Burwinkle, 2007; Varni, Seid, & Kurtin, 2001). In this study, the PedsQL™ 4.0 scale showed good internal consistency (Kline, 1993; **Table S1**).

Statistical analyses

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 (χ^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 χ^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).

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. As a rule of thumb, an α $\geq$.70 is considered acceptable in the scientific literature (Kline, 1993).

Agreement between AYA and primary caregivers. Intra-class 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).

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 to that of others', perceived health compared to that of the previous year, frequency of medical follow-ups, level of perceived control over the condition, complications, and PedsQL^{TM} 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.

Results

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**). Sociodemographic and medical data are presented in **Table 1**. As missing values correspond to incomplete surveys, we decided not to impute them (**Table S2**).

Figure 1. Flow chart representing the recruitment process of the study
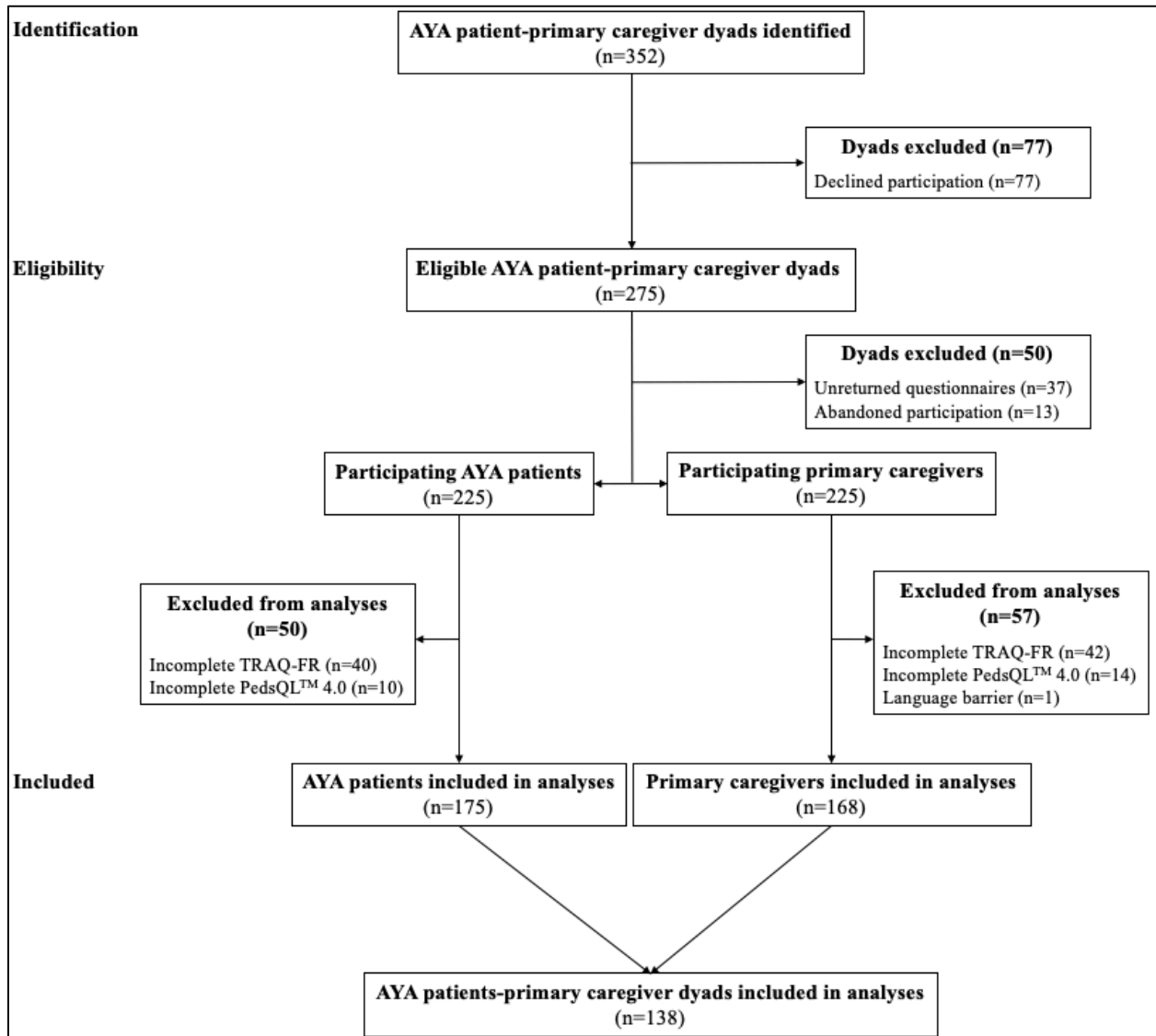
Note. AYA=Adolescent and young adult; n=Number of individuals; PedsQL^{TM} 4.0=Pediatric Quality of Life Inventory^{TM} version 4.0; TRAQ-FR= French version of the Transition Readiness Assessment Questionnaire.

Table 1. Participants' sociodemographic and clinical information

AYA (n=175)	n (%)	Mean ± SD	Range
Sex			
Female	73 (41.7)		
Male	102 (58.3)		
Age groups			
≤ 15 years old	76 (43.4)	14.61 ± .518	14 – 15
> 15 years old	99 (56.6)	16.90 ± 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.
[a] One of the primary caregivers was an AYA patient's grandfather.

Construct validity

For both informants' TRAQ-FR scores, the indices χ^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. The factor loadings are >.40 except for two items (Q3=.106; Q10=.387; **Table S3**).

Table 2. Confirmatory factor analysis indices of the TRAQ-FR

	Indices				
	χ^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

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; χ^2/d.f.=Model Chi-Square.

Internal consistency

The global scale and the "Appointment Keeping" subscale showed good reliability in both AYA (α=.85 and α=.81 respectively) and primary caregivers (α=.87 and α=.83 respectively). In primary caregivers, the subscale of "Tracking Health Issues" also showed an acceptable internal consistency coefficient (α=.85; Kline, 1993). The other subscales had low reliability (**Table S1**).

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 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=Intra-class correlation coefficients; SD=Standard deviation; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire.
**p<.01.
***p<.001.

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 S4**). In AYA patients' multivariate model, a unique significant contribution was found for older age (B=.18, *ß*=.40, p<.001) and being female (B=-.36, *ß*=-.28, p<.001), predicting 21% of their transition readiness scores (**Table S5**). In primary caregivers' multivariate model, a unique significant contribution was found for female (B=-.29, *ß*=-.23, p=.014) and older (B=.25, *ß*=.20, p=.032) AYA, predicting 8% of their transition readiness scores (**Table S6**).

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 (α=.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. Since 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. 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 (Upton, Lawford, & Eiser, 2008). 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, i.e., likely to plan in advance and be goal-

directed (Mike, Harris, Roberts, & Jackson, 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 since healthcare professionals may have addressed the topic of transition more often with older than with younger AYA patients. It may also be due to change in daily life and the gradual maturation of the prefrontal cortex of the developing brain. The prefrontal cortex 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^{TM} 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, the sample consisted of fewer female than male AYA patients and over three-fourth of primary caregivers were AYAs' mothers. Additionally, due to clinical constraints, an unequal number of participants was recruited from the five participating clinics. Future studies could include equal sample sizes and study gender interactions in AYA-primary caregiver dyads. 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; however, we cannot conclude that a causal relationship exists on the basis of the current data.

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). Moreover, alternative statistical models could be used, such as polychoric correlations and weighted least squares means and variance adjusted methods (Beauducel & Herzberg, 2006). Furthermore, future research could explore the predictive value of the TRAQ-FR to determine whether higher scores predict a more successful transition. Additional research could also examine the convergent and discriminant validity of the TRAQ-FR. 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, McNichol, Marczewski, & José Closs, 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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Supplementary material

Table S1. Cronbach's alpha coefficients of the five subscales and global scale of the TRAQ-FR and of the four subscales and global scale of the PedsQL™ 4.0

| | | Cronbach's alpha | |
	Number of items	AYA (n=175)	Primary caregivers (n=168)
TRAQ-FR			
Managing Medications	4	.62	.61
Appointment Keeping	6	.81	.83
Tracking Health Issues	4	.62	.70
Talking With Providers	2	.42	.62
Managing Daily Activities	3	.50	.66
TRAQ-FR global scale	19	.85	.87
PedsQL™ 4.0			
Physical Health	8	.75	.83
Emotional Functioning	5	.76	.85
Social Functioning	5	.86	.86
School Functioning	5	.64	.77
PedsQL™ 4.0 global scale	23	.89	.91

Note. AYA=Adolescent and young adult; n=Number of respondents; PedsQL™ 4.0= Pediatric Quality of Life Inventory™ version 4.0; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire.

Table S2. Raw number of responses for each item of the TRAQ-FR in a sample of AYA (n=225) and primary caregivers (n=225) and percentage of missing data

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to	Total
Q1.	42 (19.7%)	44 (20.6%)	30 (14.1%)	34 (16.0%)	63 (29.6%)	213 (94.7%)
	52 (23.7%)	*60 (27.4%)*	*31 (14.2%)*	*40 (18.3%)*	*36 (16.4%)*	*219 (97.3%)*
Q2.	47 (21.9%)	42 (19.5%)	11 (5.1%)	31 (14.4%)	84 (39.1%)	215 (95.6%)
	43 (19.9%)	*45 (20.8%)*	*21 (9.8%)*	*54 (25.0%)*	*53 (24.5%)*	*216 (96.0%)*
Q3.	3 (1.4%)	0 (0.0%)	11 (5.1%)	40 (18.4%)	163 (75.1%)	217 (96.4%)
	7 (3.2%)	*7 (3.2%)*	*13 (6.0%)*	*36 (16.5%)*	*155 (71.1%)*	*218 (96.9%)*
Q4.	35 (16.4%)	31 (14.6%)	25 (11.7%)	27 (12.7%)	95 (44.6%)	213 (94.7%)
	53 (25.2%)	*41 (19.5%)*	*29 (13.8%)*	*43 (20.5%)*	*44 (21.0%)*	*210 (93.3%)*
Q5.	71 (33.2%)	57 (26.6%)	35 (16.3%)	22 (10.3%)	29 (13.6%)	214 (95.1%)
	78 (35.6%)	*75 (34.2%)*	*30 (13.7%)*	*19 (8.7%)*	*17 (7.8%)*	*219 (97.3%)*
Q6.	73 (34.0%)	55 (25.6%)	31 (14.4%)	16 (7.4%)	40 (18.6%)	215 (95.6%)
	81 (36.7%)	*77 (34.8%)*	*29 (13.1%)*	*16 (7.3%)*	*18 (8.1%)*	*221 (98.2%)*
Q7.	62 (29.0%)	29 (13.6%)	23 (10.7%)	26 (12.1%)	74 (34.6%)	214 (95.1%)
	81 (37.3%)	*49 (22.6%)*	*26 (12.0%)*	*28 (12.9%)*	*33 (15.2%)*	*217 (96.4%)*
Q8.	77 (36.2%)	55 (25.8%)	29 (13.6%)	22 (10.3%)	30 (14.1%)	213 (94.7%)
	84 (39.1%)	*72 (33.5%)*	*22 (10.2%)*	*20 (9.3%)*	*17 (7.9%)*	*215 (95.6%)*
Q9.	80 (37.2%)	48 (22.3%)	28 (13.0%)	17 (7.9%)	42 (19.6%)	215 (95.6%)
	88 (40.9%)	*43 (20.0%)*	*27 (12.6%)*	*21 (9.8%)*	*36 (16.7%)*	*215 (95.6%)*
Q10.	44 (20.3%)	23 (10.6%)	22 (10.1%)	46 (21.2%)	82 (37.8%)	217 (96.4%)
	46 (21.0%)	*30 (13.7%)*	*33 (15.1%)*	*69 (31.5%)*	*41 (18.7%)*	*219 (97.3%)*
Q11.	50 (23.3%)	24 (11.1%)	9 (4.2%)	51 (23.7%)	81 (37.7%)	215 (95.6%)
	32 (14.5%)	*51 (23.1%)*	*22 (9.9%)*	*74 (33.5%)*	*42 (19.0%)*	*221 (98.2%)*
Q12.	71 (32.9%)	31 (14.4%)	29 (13.4%)	35 (16.2%)	50 (23.1%)	216 (96.0%)
	53 (24.3%)	*66 (30.3%)*	*34 (15.6%)*	*40 (18.3%)*	*25 (11.5%)*	*218 (96.9%)*
Q13.	95 (44.6%)	31 (14.6%)	25 (11.7%)	30 (14.1%)	32 (15.0%)	213 (94.7%)
	50 (22.9%)	*71 (32.6%)*	*35 (16.1%)*	*41 (18.8%)*	*21 (9.6%)*	*218 (96.9%)*
Q14.	149 (74.1%)	10 (5.0%)	4 (2.0%)	11 (5.5%)	27 (13.4%)	201 (89.3%)
	145 (72.9%)	*20 (10.1%)*	*6 (3.0%)*	*18 (9.0%)*	*10 (5.0%)*	*199 (88.4%)*
Q15.	19 (8.9%)	10 (4.7%)	12 (5.6%)	50 (23.3%)	123 (57.5%)	214 (95.1%)
	7 (3.2%)	*18 (8.2%)*	*12 (5.5%)*	*72 (32.9%)*	*110 (50.2%)*	*219 (97.3%)*
Q16.	1 (0.5%)	1 (0.4%)	3 (1.4%)	24 (11.1%)	187 (86.6%)	216 (96.0%)
	3 (1.4%)	*3 (1.4%)*	*3 (1.4%)*	*40 (18.3%)*	*169 (77.5%)*	*218 (96.9%)*
Q17.	19 (8.7%)	18 (8.3%)	36 (16.5%)	67 (30.7%)	78 (35.8%)	218 (96.9%)
	16 (7.2%)	*20 (9.0%)*	*34 (15.4%)*	*87 (39.4%)*	*64 (29.0%)*	*221 (98.2%)*
Q18.	10 (4.6%)	7 (3.2%)	37 (17.0%)	69 (31.6%)	95 (43.6%)	218 (96.9%)
	12 (5.4%)	*20 (9.0%)*	*28 (12.6%)*	*72 (32.5%)*	*90 (40.5%)*	*222 (98.7%)*
Q19.	9 (4.2%)	4 (1.8%)	7 (3.2%)	44 (20.4%)	152 (70.4%)	216 (96.0%)
	6 (2.7%)	*7 (3.1%)*	*12 (5.5%)*	*82 (37.3%)*	*113 (51.4%)*	*220 (97.8%)*

Note. AYA=Adolescent and young adult; n=Number of participants; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire. In regular font are the responses from AYA. In italic font are the responses from primary caregivers. Items were renumbered as a result of the removal of Q9 from the original version. Consequently, Q9 in the translated version corresponds to Q10 of the original version, Q10 to Q11, and so on.
Q1. Do you fill a prescription if you need to?
Q2. Do you know what to do if you are having a bad reaction to your medications?
Q3. Do you take medications correctly and on your own?
Q4. Do you reorder medications before they run out?

Q5. Do you call the doctor's office to make an appointment?

Q6. Do you follow-up on any referral for tests, check-ups or labs?

Q7. Do you arrange for your ride to medical appointments?

Q8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?

Q9. Do you know what your health insurance covers?

Q10. Do you manage your money & budget household expenses (For example: use checking/debit card)?

Q11. Do you fill out the medical history form, including a list of your allergies?

Q12. Do you keep a calendar or list of medical and other appointments?

Q13. Do you make a list of questions before the doctor's visit?

Q14. Do you get financial help with school or work?

Q15. Do you tell the doctor or nurse what you are feeling?

Q16. Do you answer questions that are asked by the doctor, nurse, or clinic staff?

Q17. Do you help plan or prepare meals/food?

Q18. Do you keep home/room clean or clean-up after meals?

Q19. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?

Table S3. Factor loadings of the TRAQ-FR subscales

Factor loadings	
Managing Medications	
Q1	.839
Q2	.505
Q3	.106
Q4	.628
Appointment Keeping	
Q5	.861
Q6	.801
Q7	.658
Q8	.757
Q9	.443
Q10	.387
Tracking Health Issues	
Q11	.636
Q12	.588
Q13	.510
Q14	.412
Talking With Providers	
Q15	.523
Q16	.746
Managing Daily Activities	
Q17	.574
Q18	.492
Q19	.457

Note. TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire. Items were renumbered as a result of the removal of Q9 from the original version. Consequently, Q9 in the translated version corresponds to Q10 of the original version, Q10 to Q11, and so on.
Q1. Do you fill a prescription if you need to?
Q2. Do you know what to do if you are having a bad reaction to your medications?
Q3. Do you take medications correctly and on your own?
Q4. Do you reorder medications before they run out?
Q5. Do you call the doctor's office to make an appointment?
Q6. Do you follow-up on any referral for tests, check-ups or labs?
Q7. Do you arrange for your ride to medical appointments?
Q8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?
Q9. Do you know what your health insurance covers?
Q10. Do you manage your money & budget household expenses (For example: use checking/debit card)?
Q11. Do you fill out the medical history form, including a list of your allergies?
Q12. Do you keep a calendar or list of medical and other appointments?
Q13. Do you make a list of questions before the doctor's visit?
Q14. Do you get financial help with school or work?

Q15. Do you tell the doctor or nurse what you are feeling?
Q16. Do you answer questions that are asked by the doctor, nurse, or clinic staff?
Q17. Do you help plan or prepare meals/food?
Q18. Do you keep home/room clean or clean-up after meals?
Q19. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?

Table S4. Relations between AYA patients' scores on the global scale of the TRAQ-FR and their sociodemographic and clinical data (n=175)

Sociodemographic and medical data	Overall TRAQ-FR		
	M	*SD*	*F*
Age			14.00***
≤15 years old (n=76)	2.30	0.61	
>15 years old (n=99)	2.66	0.64	
Sex			8.56**
Female (n=73)	2.67	0.69	
Male (n=102)	2.38	0.59	
Ethnicity			0.46
Caucasian (n=162)	2.50	0.66	
North African (n=5)	2.38	0.48	
Hispanic (n=4)	2.88	0.45	
Black (n=2)	2.30	0.80	
Middle Easterner (n=2)	2.35	0.75	
Education level (n=170)			18.22***
High school (n=137)	2.41	0.62	
College (n=33)	2.92	0.59	
Chronic condition			1.24
Cancer (n=71)	2.63	0.61	
Diabetes (n=35)	2.47	0.67	
Cystic Fibrosis (n=30)	2.39	0.73	
Epilepsy (n=25)	2.39	0.73	
Kidney disease (n=14)	2.37	0.38	
Age at diagnosis			2.05
≤ 5 years old (n=86)	2.40	0.64	
6-10 years old (n=32)	2.57	0.70	
11-15 years old (n=46)	2.63	0.61	
≥ 16 years old (n=9)	2.78	0.57	
Perceived health compared to that of others (n=172)			2.13
Not good (n=10)	2.67	0.53	
Somewhat good (n=17)	2.29	0.61	
Good (n=65)	2.38	0.62	
Very good (n=59)	2.66	0.71	
Excellent (n=21)	2.47	0.59	
Current health compared to the previous year (n=173)			1.03
Worse (n=1)	2.88	.	
Slightly worse (n=9)	2.54	0.81	
Similar (n=93)	2.45	0.63	
Slightly better (n=48)	2.46	0.68	
Better (n=22)	2.74	0.60	
Frequency of medical follow-ups – once every… (n=172)			1.85
1-3 months (n=29)	2.46	0.44	

3-6 months (n=67)	2.52	0.74	
6-12 months (n=46)	2.35	0.65	
12+ months (n=30)	2.70	0.59	
Perception of control over the condition (n=171)			2.60
Not good (n=5)	2.61	0.39	
Somewhat good (n=25)	2.25	0.64	
Good (n=52)	2.42	0.71	
Very good (n=89)	2.62	0.61	
Complications (n=171)			1.37
Yes (n=128)	2.48	0.63	
No (n=43)	2.62	0.69	

Note. AYA=Adolescent and young adult; d.f.=Degrees of freedom; F=F-value; M=Mean; n=Number of respondents; SD=Standard deviation; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire.

**$p<.01$.

***$p<.001$.

Table S5. Contributors of AYA transition readiness as measured by the TRAQ-FR global scale

	R^2	R^2 Adjusted	B	β	t	CI 95% Lower	CI 95% Upper
Model	.21***	.20***					
AYA patients' age			.19	.41	5.99***	.13	.25
AYA patients' sex			-.32	-.25	-3.64***	-.50	-.15

Note. This model was generated using the stepwise method, including p-values under .05 and excluding p-values over .10. The variables included in the model are AYA patients' age and AYA patients' sex. The variable of AYA patients' age was coded as follows: 0=13-15 years old; 1=Over 15 years old. The variable of AYA patients' sex was coded as follows: 0=Female; 1=Male. The variables excluded from the model are AYA patients' ethnicity, chronic illness, age at the time of diagnosis, perceived health compared to that of others', perceived health compared to that of the previous year, frequency of medical follow-ups, level of perceived control over the chronic condition, presence or absence of complications, and quality of life as measured by the global scale of the PedsQL™ 4.0 on the global scale of the TRAQ-FR. AYA=Adolescent and young adult; B=Unstandardized regression coefficient; β=Standardized regression coefficient; CI=Confidence interval; PedsQL™ 4.0=Pediatric Quality of Life Inventory™ version 4.0; R^2=R-squared value; t=t-value; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire.
***p<.001.

Table S6. Contributors of primary caregivers' perception of AYA transition readiness as measured by the TRAQ-FR global scale

	R^2	R^2 Adjusted	B	β	t	CI 95% Lower	CI 95% Upper
Model	.08*	.06*					
AYA patients' sex			-.29	-.23	-2.50*	-.51	-.06
AYA patients' age			.25	.20	2.18*	.02	.48

Note. Note. This model was generated using the stepwise method, including p-values under .05 and excluding p-values over .10. The variables included in the model are AYA patients' age and AYA patients' sex. The variable of AYA patients' sex was coded as follows: 0=Female; 1=Male. The variable of AYA patients' age was coded as follows: 0=13-15 years old; 1=Over 15 years old. The variables excluded from the model are AYA patients' ethnicity, chronic illness, age at the time of diagnosis, perceived health compared to that of others', perceived health compared to that of the previous year, frequency of medical follow-ups, level of perceived control over the chronic condition, presence or absence of complications, and quality of life as measured by the global scale of the PedsQL™ 4.0 on the global scale of the TRAQ-FR. AYA=Adolescent and young adult; B=Unstandardized regression coefficient; β=Standardized regression coefficient; CI=Confidence interval; PedsQL™ 4.0=Pediatric Quality of Life Inventory™ version 4.0; R^2=R-squared value; *t*=t-value; TRAQ-FR=French version of the Transition Readiness Assessment Questionnaire; *p<.05.